How can health services contribute effectively and efficiently to facilitating transition of young people with long term conditions from childhood to adulthood? The Transition Research Programme.

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Key words

MeSH terms: Transition to Adult Care; Health Services; Quality of Life; Young Adult; Type 1 Diabetes Mellitus; Cerebral Palsy; Autism Spectrum Disorder
Non-MeSH terms: Young people; Transfer; Wellbeing; Commissioning for Transition; Long term conditions; Developmentally Appropriate Healthcare; Adolescent; Q-sort; Discrete choice experiment; Economics evaluation

Declared competing interests of authors

Vale was a member of the Programme Grants for Applied Health Research Panel 2008-2016; a member of the NIHR Health Technology Assessment Programme CET Panel and Director, NIHR Research Design Service in the North East.
There were no other competing interests.

Disclaimer

This report presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0610-10112). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR or the Department of Health.

Navigation pane

In reading this report and its appendices, we strongly advise opening of the navigation pane in Word or Adobe, so that the structure can be more easily appreciated and for quicker navigation between sections.

Number of words in report (including appendices): 109,503
ABSTRACT
783 words

Background
As young people with long term conditions move from childhood to adulthood, their health may deteriorate, and social participation reduce.

‘Transition’ is the ‘process’ that addresses the medical, psychosocial, and educational needs of young people during this time. ‘Transfer’ is the ‘event’ when medical care moves from child to adult services.

In a typical NHS Trust serving a population of 270,000, about 100 young people with long term conditions requiring secondary care reach age sixteen each year. As transition extends over about seven years, the number in transition at any time is approximately 700.

Objectives
Purpose: To promote the health and wellbeing of young people with long term conditions by generating evidence to enable NHS commissioners and providers to facilitate successful healthcare transition.

Objectives:
1 Work with young people to determine what is important in their transitional healthcare
2 Identify effective and efficient features of transitional healthcare
3 Determine how transitional healthcare should be commissioned and provided

Design, Settings and Participants
Three work packages addressed each objective.

Objective 1. i) A Young People’s Advisory Group met monthly throughout the programme. ii) It explored the usefulness of patient-held health information. iii) A ‘Q-sort’ study examined how young people approached transitional healthcare.

Objective 2. i) We followed for three years 374 young people with type1 diabetes (150 from five sites, England), or autism spectrum disorder (ASD) (118 from four sites, England) or cerebral palsy (CP) (106 from eighteen sites, England, Northern Ireland). We assessed whether nine proposed beneficial features of transition services predicted better outcomes. ii) We interviewed a subset of thirteen young people about their transition. iii) We undertook a ‘Discrete Choice Experiment’ and examined the efficiency of illustrative models of transition.
Objective

3. i) We interviewed staff and observed meetings in three Trusts to identify facilitators and barriers to introducing Developmentally Appropriate Healthcare (DAH). We developed a toolkit to assist introduction of DAH. ii) We undertook literature review, interviews and site-visits to identify facilitators and barriers to commissioning transitional healthcare. iii) We synthesised learning on ‘what’ and ‘how’ to commission, drawing on meetings with commissioners.

Main outcome measures

Participation in life situations, mental wellbeing, satisfaction with services and condition-specific outcomes.

Strengths

Longitudinal study with large sample; representativeness of the conditions chosen; non-participation and attrition appeared unlikely to introduce bias; novelty of the research on commissioning; involvement of a young person’s group.

Limitations

Uncertainty about whether the regions and Trusts in the longitudinal study were representative; however, we recruited from 27 Trusts, widely spread over England and Northern Ireland; the Trusts varied greatly in the number and variety of proposed beneficial features offered.

Quality of delivery of each proposed beneficial feature was not assessed.

Due to the nature of the data, only exploratory rather than strict economic modelling was undertaken.

Results and conclusions

1 Commissioners and providers regarded transition as the responsibility of children’s services. This is inappropriate, given that transition extends to approximately age 24. Our findings indicate an important role for commissioners of adult services to commission transitional healthcare, in addition to the commissioners of child services with whom responsibility for transitional healthcare currently lies.
2 ‘Developmentally Appropriate Healthcare’ is a crucial aspect of transitional healthcare. Our findings indicate the importance of health services being commissioned to ensure providers deliver DAH across all healthcare services, and that this will be facilitated by commitment from senior provider and commissioner leaders, responsibility for implementation resting with the Boards of NHS Trusts.

3 Good practice led by enthusiasts rarely generalised to other specialties or adult services. This indicates the importance of NHS Trusts adopting a Trust-wide approach to implementation of transitional healthcare.

4 Child and adult services were often not joined up. This indicates the importance of adult clinicians, child clinicians and general practitioners planning transition procedures together.

5 Young people adopted four broad interaction styles during transition: ‘laid-back’, ‘anxious’, ‘wanting autonomy’, ‘socially-oriented’. Identifying a young person’s style would help personalise communication with them.

6 Three proposed beneficial features of transition services were significantly associated with better outcomes: ‘Parental involvement, suiting parent and young person’, ‘Promotion of a young person’s confidence in managing their health’ and ‘Meeting the adult team before transfer’.

7 Maximal service up-take would be achieved by services encouraging appropriate parental involvement and young people to make decisions about their care. A service involving ‘Appropriate parental involvement’, and ‘Promotion of confidence in managing one’s health’ may offer good value for money.

**Future work**

How might the Programme’s findings be implemented by commissioners and healthcare providers?

What are the most effective ways for primary healthcare to assist transition, and support young people after transfer?

**Registrations**

UKCRN 12201, 12980, 12731, 15160
Funding details

This report presents independent research funded by the National Institute for Health Research under its Programme Grants for Applied Research scheme (RP-PG-0610-10112).
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- Work package 1.2: Health passport work
- Work package 1.3: Q sort study
- Work package 2.1: Longitudinal study – quantitative data
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We use The World Health Organization’s definition of ‘young person’ as any person between ages 10 and 24; and an ‘adolescent’ as any person between ages 10 and 19.

A ‘long term condition’ is one that cannot currently be cured but can be controlled with the use of medication and/or other therapies. The Chief Medical Officer used this concept in her 2012 report ‘Our children deserve better-prevention pays’. So also did the Department of Health, England in its ‘Outcomes Framework for the NHS’.

In our original submission to NIHR we used the term ‘complex health needs’ to refer to young people with ‘a physical, mental or health impairment that has the potential for a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. However, the term ‘complex health needs’ is used increasingly to describe the relatively small number of young people with very complex needs who require a bespoke package of care constructed for each individual involving multiple agencies, including health, educational and social services. Such young people are usually known by name to Clinical Commissioning Groups and Local Authorities. Shortcomings in co-ordination of care for this group are discussed specifically in the report of the Care Quality Commission ‘From the Pond to the Sea’. The NIHR funded Transition Research Programme was not designed to consider only this very complex group. For this reason, we use the term young people with a ‘long term condition’ instead of ‘complex health needs’ in the title of the Programme and throughout this report to refer to the much larger group of young people who are the focus of the Transition Research Programme.

‘Transition’ is the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-oriented health care systems.

‘Transfer’ is the formal event when medical care of a young person is moved from children’s services to adults’ services.

‘Developmentally Appropriate Healthcare (DAH)’ The concept of DAH is now well accepted in the UK and internationally: NICE, Canada, US, Royal College of Physicians. DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms DAH focuses on the approach of healthcare professionals
to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.

‘Participation’ is defined by the International Classification of Functioning, Disability and Health as involvement in life situations. It is an objective construct, even if self-reported.

‘Mental health and wellbeing’ The World Health Organisation states: Mental health is not just the absence of mental disorder. Mental health is defined as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and can contribute to her or his community. It is a subjective construct.

Participation and mental wellbeing are important components of quality of life and relate well to the concept of ‘person-centred planning’ which is strongly supported in the UK by successive Governments.

We define ‘Proposed beneficial features’ as features of services for transitional healthcare recommended as good practice and for which there is some evidence of benefit, at least in some conditions. At the start of our research we identified nine features and hypothesised that these ‘proposed beneficial features’ would be associated with better outcomes.

- **Age-banded clinic.** An intermediate clinic setting such as a young person’s clinic or a young adult team. In child health services, it would mean that children less than about 12 years would not be at the clinic. In adult services it would mean adults over about 24 years would not be at the clinic.

- **Meet adult team before transfer.** This could be in a joint clinic where senior paediatric and adult clinicians consult together; or the adult clinician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult team.

- **Promotion of health self-efficacy.** The young person is asked ‘Have you received enough help to increase your confidence in managing your condition?’ The clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition.

- **Written transition plan.** This should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated.
Appropriate parent involvement in their child’s care, but with changing responsibilities. Parent and young person are asked separately if they think the level of involvement is appropriate. Involvement concerns what happens in the clinic (parent being present or not and who does the talking) and discussions at home about the young person’s health and how to manage it.

Key worker. This is a single person known to the young person whom they could easily contact or go to if there were any problems of co-ordination or misunderstandings that needed to be resolved. The role could cross into education and social services. Whilst a clinic may have a policy to ‘appoint’ a key worker, the young person may report it is someone else they feel most comfortable with.

Coordinated team. Some young people need to see a team of people. Those with diabetes may need to see doctor, nurse, dietician, and psychologist. Those with cerebral palsy may need to see doctor, physiotherapist, and orthopaedic surgeon. The members of these teams need to work together and communicate well together and demonstrate to the young person that this is happening. Coordination of appointments on the same day demonstrates this.

Holistic life-skills training for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The young person is asked whether they have had any formal life-skill training offered because of their condition. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.

Transition manager for clinical team. The individual who coordinates transition in a clinical team may not be known to the young person. The manager will facilitate good working relationships between adult and child services; ensure that there are appropriate materials available for things such as health education or the transition plan; and will monitor whether the young person has a suitable appointment in adult services and whether the appointment is kept.
### ABBREVIATIONS

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<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
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<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<td>CP</td>
<td>Cerebral Palsy</td>
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<td>CQUIN</td>
<td>Commissioning for Quality and Innovation National Goals</td>
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<td>DAH</td>
<td>Developmentally Appropriate Healthcare</td>
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<td>DCE</td>
<td>Discrete Choice Experiment</td>
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<td>DH</td>
<td>Department of Health, England</td>
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<td>HRQoL</td>
<td>Health Related Quality of Life</td>
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<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<td>NHS</td>
<td>National Health Service</td>
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<td>NIHR</td>
<td>National Institute for Health Research</td>
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<td>NPT</td>
<td>Normalisation Process Theory</td>
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<td>PBF</td>
<td>Proposed Beneficial Feature</td>
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<td>PPI</td>
<td>Patient and Public Involvement</td>
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<td>UP</td>
<td>United Progression - the group name chosen by the members of the Young People’s Advisory Group</td>
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<td>Work Package</td>
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When young people with long term health conditions, such as diabetes or cerebral palsy, move from childhood to adulthood, their health may worsen, and their social participation reduce. ‘Transition’ is the process that addresses the medical, psychosocial and educational needs of young people during this time. ‘Transfer’ is the event when healthcare moves from child to adult services.

Our research included young people, families, healthcare staff, commissioners who buy healthcare, and managers who deliver healthcare. We undertook interviews, administered questionnaires and considered value for money. A young people’s advisory group guided us throughout.

Findings and implications:

- Commissioners and managers thought transitional healthcare was the responsibility of children’s services. This is inappropriate as transition extends well beyond childhood.

- Developmentally Appropriate Healthcare underpins good healthcare for young people, including those in transition. We developed a toolkit to assist its introduction.

- Good practice, led by enthusiasts in one setting, often did not generalise to other specialities or adult services. Organisation-wide approaches are needed to establish better transitional healthcare.

- Shared planning of transition between adult clinicians, child clinicians and general practice is important.

- Young people adopted one of four approaches to transition: ‘laid-back’, ‘anxious’, ‘wanting to be in control’, ‘socially-oriented’ (welcoming involvement of family, friends and healthcare staff). Discussing a young person’s approach would make communication with them more individual.

- Over three years, we collected information from 374 young people with diabetes, cerebral palsy or autism spectrum disorder. Three features of transitional healthcare linked to better health outcomes:
  - appropriate parent involvement. ‘Appropriate’ meant young person and parents were happy with how much and in what way parents were involved
  - young person helped to be confident about managing their health condition
  - young person meeting the adult team before transferring
• Economic analysis found the first two of the above might be good value for money.
SCIENTIFIC SUMMARY
2,476 words

Background
As young people with long term conditions move from child-centred to adult-oriented health services (transition), their health may deteriorate, and their social participation reduce. Chronic illnesses, such as diabetes, may be more difficult to control. Conditions like cerebral palsy give rise to symptoms such as pain or spasticity that interfere with daily living, and for which the health needs may not be met. Few young adults with autism spectrum disorder attain their potential for participation in society.

Despite guidance from Government, the voluntary sector and NICE (February 2016) over the last ten years on how to improve transition, it has been difficult to persuade commissioners and providers of health services to specify arrangements for transitional healthcare because much of the guidance has little evidence to support it.

The number of young people in transition is increasing; many children with long term conditions, who now live into adulthood, might previously have died. In a typical NHS Trust serving a population of 270,000, approximately 100 young people with a long term condition needing secondary care reach age 16 each year. As transition takes place over about seven years, the number in transition at any time in a typical Trust is approximately 700.

Objectives
The overall purpose of the Research Programme was to promote the subjective wellbeing and health of young people with long term conditions by generating evidence to enable NHS commissioners and healthcare providers to facilitate successful transition.

The Programme had three objectives:
1 Work with young people with long term conditions to determine what is important in their transitional healthcare
2 Identify effective and efficient features of transitional healthcare
3 Determine how transitional healthcare should be commissioned and provided

Methods
Three separate work packages (WP) addressed each of the above objectives.
WP 1.1 formed a young people’s advisory group (UP), that met monthly over the five-year Programme.

WP 1.2 explored the usefulness of patient held health information (‘health passports’) in a project co-led by UP.

WP 1.3 explored the importance young people attached to different elements of transitional healthcare by undertaking a Q-sort study.

WP 2.1 assessed whether nine proposed beneficial features of transition services contributed to improved outcomes for young people with type1 diabetes, cerebral palsy or autism spectrum disorder with an associated mental health problem (ASD). We conducted a prospective study of 374 young people, who were visited four times, one year apart, by research assistants. Outcomes covered participation, wellbeing, satisfaction with services and condition-specific measures. Young people with Diabetes were recruited from five NHS Trusts in north, south-west and south-east England and Greater London. Those with ASD, from four NHS Trusts in north and south-west England. Those with cerebral palsy, from one NHS Trust in south-east England and two regional population registers in north England and Northern Ireland (covering seventeen Trusts).

WP 2.2 investigated how young people with long term conditions experienced transition by undertaking in-depth interviews with 13 young people, their families and health professionals.

WP 2.3 examined the relative efficiency of illustrative models of Transition. It involved a Discrete Choice Experiment, estimation of NHS costs, assessment of health-related quality of life, and modelling cost-effectiveness. This used a Markov model that compared a transition service with a proposed beneficial feature to a service containing no such features. The model simulated outcomes for a hypothetical cohort of 14-year-olds over a 10-year time horizon, with discounting at 3.5% per annum.

WP 3.1 identified factors enabling or inhibiting introduction of Developmentally Appropriate Healthcare (DAH) by undertaking an ethnographic study in three NHS Trusts. We then compiled a toolkit to assist introduction of DAH.

WP 3.2 identified factors that enabled or inhibited commissioning for effective transition. It undertook a literature review, in-depth interviews and site-visits.

WP 3.3 synthesised learning from the Programme on ‘what’ and ‘how’ to commission, drawing on meetings with commissioners.
Results

WP 1.1 Involving the UP group
UP was involved in most WPs and a wide range of activities, such as advising the research team, developing video materials, disseminating results to other young person groups and co-leading a workshop at the final conference.

We forged other Patient and Public Involvement links that included shared project work with the Council for Disabled Children, the Association of Young People’s Health and The Health Foundation. Parents, young people and the voluntary sector were represented on the External Advisory Board.

WP 1.2 Health passport work
UP found a lack of conceptual clarity about what a ‘health passport’ was.
In their survey, UP found that many young people thought a health passport was a good idea; but, even if they owned one, they rarely used it.

WP 1.3 Q-sort study
The ‘Q-sort’ study identified four interaction styles that young people adopted when approaching transition: ‘laid back’, ‘anxious’, ‘autonomy-seeking’, ‘socially-oriented’.
Discussing with young people their preferences about transition should help clinicians and young people develop personalised planning.

WP 2.1 Longitudinal study (quantitative)
Services provided very variably the nine proposed beneficial features of service provision. Fewer than half stated they provided an ‘Age-banded clinic’, ‘Written transition plan’, ‘Transition manager for clinical team’, ‘Protocol for promotion of young person’s confidence in managing their health condition (‘health self-efficacy’)’, and ‘Holistic life-skills training’.

There was a striking mismatch between the features that a service said it provided and the features young people reported they had experienced. For example, across the three conditions agreement was 30% for ‘Written transition plan’ and 49% for ‘Key worker’.
Agreement was better at 77% for ‘Appropriate parent involvement’, 77% for ‘Age-banded clinic’ and 80% for ‘Promotion of health self-efficacy’.

The wellbeing scores for each condition group remained similar over time. For those with diabetes or cerebral palsy, average wellbeing was similar to that of the general population; those with ASD reported significantly lower wellbeing. Average satisfaction with services was reasonable at baseline; it remained steady for those with type1 diabetes but worsened for
those with cerebral palsy or ASD. For participation in life activities, there were significant differences between the three conditions with young people with type1 diabetes in a more independent phase than those with cerebral palsy or ASD. All made progress over time.

Average condition specific outcomes worsened over the course of the study for those with type1 diabetes or cerebral palsy. For those with ASD, average condition specific outcomes remained the same between baseline and final visit.

Features of services for transitional healthcare associated with better outcomes were:
‘Appropriate parent involvement’, ‘Promotion of health self-efficacy’ and ‘Meeting the adult team before transfer’.
‘Having a key worker’ was inconsistently associated with better outcomes: Features with no evidence of association with better outcomes were: ‘Transition plan’, ‘Age-banded clinic’, ‘Coordinated team’, ‘Being part of a service with a transition manager for clinical team’ and ‘Having access to holistic life-skills training’.

WP 2.2 Longitudinal study (qualitative)
 Transition and transfer of healthcare were disorientating and disrupting for young people and their families; in part because hard-earned knowledge about how best to navigate the child healthcare system was lost. Health professionals are in a position to help young people and families adjust to and mitigate these disruptions through actions such as: being clear in discussions and documents about processes; explaining how procedures in child and adult healthcare differ; arranging meetings with members of the adult team before transfer.

Although it is important to support young people to become responsible for their healthcare, family members remain important in this process. Such involvement is normal, not dysfunctional. Family members can be helped to modify their roles so there is partnership and sharing of care with their son or daughter.

WP 2.3 Discrete Choice Experiment and Economics analysis
 Preference for current care was strong and even stronger for those who had not transferred to an adult service. Having clinics that welcomed parental involvement was the second most important attribute chosen.

Young people valued clinics in which: information was passed on to the right person; parental involvement was welcomed; staff allowed young people to make decisions about
their care; the same staff were seen at each clinic. Young people valued seeing the same staff at each appointment more than having a keyworker.

In modelling healthcare, we found:
Differences in health-related quality of life between health conditions, as measured by EQ-5D-Y. In those with type 1 diabetes, the median utility score was 0.94 (0 = worst possible health, 1 = best health) and the sum score was 5.2 (lower score = better health), corresponding scores for ASD were 0.76 and 7 and for cerebral palsy 0.70 and 7. There was a trend towards lower scores after transfer.

The median annual NHS cost of appointments, medication and investigations for an individual with type 1 diabetes was £7,003, with cerebral palsy was £2,934 and with ASD was £2,350.

Cost-effectiveness results suggested that provision of ‘holistic life-skills training’; ‘having a key worker’, and ‘promotion of health self-efficacy’ represented better value for money. ‘Having a written transition plan’ and ‘having a transition manager for clinical team’ represented poorer value for money.

Implementing features of transitional healthcare is unlikely to reduce NHS costs over a 10-year time horizon. Therefore, a judgement is needed as to whether the development of a service with for example ‘Appropriate parental involvement’, ‘Promotion of health self-efficacy’ and ‘Meeting the adult team before transfer’ would be worth the cost, given that they may increase engagement with services and prevent deterioration in health in the long term.

WP 3.1 Barriers and facilitators to introduction of Developmentally Appropriate Healthcare (DAH)
Despite different understandings of DAH in the literature and across clinical and managerial staff, we identified common themes which led to a working definition:
‘DAH recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms DAH focuses on the approach of healthcare professionals to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.’
Organisational barriers to introducing DAH were: i) no single group in an NHS Trust was responsible for young people; ii) there was perceived (incorrectly) to be a small number of
young people attending hospital; iii) the mind-set and skill-set of many staff were often not ready; iv) good practices led by enthusiasts in one paediatric specialty rarely generalised to other paediatric specialties or adult services. Organisational solutions to introducing DAH were: i) buy-in and formal support resting at Chief Executive and Board Level; and with senior managers in both child and adult services; ii) planning which engaged from the outset adult and child services; iii) a Trust-wide strategy on and training about DAH.

We developed a toolkit to assist the introduction of DAH available from http://research.ncl.ac.uk/transition/

WP 3.2 Commissioning for transition

Commissioners and providers of adult services regarded transition as the responsibility of commissioners and providers of child services to deal with and improve. This is inappropriate given that transition extends to approximately age 24.

Many commissioners did not regard transition as a priority.

Transition was not usually monitored by commissioners – partly because there were no nationally agreed outcome and quality indicators.

Strengths

A young person’s advisory group was involved throughout the 5 years of the programme.

The sample for the longitudinal study generated the largest study of its kind.

The young people invited to join the longitudinal study were representative of all young people with one of the three chosen conditions; and appeared to remain representative after analysis of non-participation and attrition. In Northern Ireland, there was a small effect of deprivation on attrition of those with cerebral palsy.

Our study did not include young people with learning disability, so results cannot be generalised to this group.

The research into Commissioning for transition is the first work of its kind.

The Trusts varied greatly in the number and variety of the proposed beneficial features they offered. Thus, there was sufficient variety to examine the effects of these features on outcomes, without the analysis being dominated by a combination of features from a few sites.
Limitations

Uncertainty about whether the regions and Trusts in the longitudinal study were representative; however, we recruited from 27 Trusts, widely spread over England and Northern Ireland; the Trusts varied greatly in the number and variety of proposed beneficial features offered.

Quality of delivery of each proposed beneficial feature was not assessed

Due to the nature of the data, the economic modelling had to be exploratory rather than following a strict, formal approach. Therefore, the economic conclusions should be interpreted with caution.

Implications for transitional healthcare

Our results suggest that:

1 there is an important role for commissioners of adult services to commission transitional healthcare, in addition to commissioners of child services with whom responsibility for transitional healthcare currently lies.

2 ‘Developmentally Appropriate Healthcare’ is a crucial aspect of transitional healthcare. Our findings indicate the importance of health services being commissioned to ensure providers deliver DAH across all healthcare services, and that this will be facilitated by commitment from senior provider and commissioner leaders, responsibility for implementation resting with the Boards of NHS Trusts.

3 it is important for NHS Trusts to adopt a Trust-wide approach to implementation of transitional healthcare. Setting up a Transition Steering Committee in an NHS organisation is an effective way to improve service quality.

4 joint planning between adult healthcare providers, child healthcare providers and primary care is likely to improve both transfer of individual young people, and the further adoption of ways of working which improve care for this population.

5 adult and child healthcare providers could explore with a young person how they approach transition, thus personalising their clinical approach. We found young people adopted one of four interaction styles when approaching transition: ‘laid back’, ‘anxious’, ‘seeking autonomy’, ‘socially-oriented’.
6 we found three service features were associated with better outcomes: ‘Appropriate parent involvement’, ‘Promotion of young person’s confidence in managing their health condition’, ‘Ensuring young people and parents meet the adult team before transfer’. These findings provide practical content to be considered in NHS commissioning specifications.

7 maximal service up-take would be achieved by a service which encouraged appropriate parental involvement, emphasised the importance of good communication with young people, and encouraged young people to make decisions about their care. A service involving ‘Appropriate parental involvement’, and ‘Promotion of a young person’s confidence in managing their health condition’ may offer good value for money. A service involving a ‘Transition manager for clinical team’ or ‘Age-banded clinic’ is unlikely to offer value for money.

**Recommendations for research**

1. What are the most effective and efficient ways for the findings of the Programme to be introduced and implemented by health commissioners and healthcare organisations?

2 What are the most effective and efficient ways for primary healthcare services to be involved in improving transition, and in following-up young people after transfer (whether or not they meet criteria for adult services)?

3. What are the most effective and efficient methods to enable young people with long term conditions to successfully manage their own health?
Setting the scene

All young people - defined by the WHO as any person between ages 10 and 24\(^1\) - experience transformations in their lives and their understanding of the world as they grow older. Although it may not be possible for all, young people need to achieve four crucial developmental tasks: i) consolidate their identity, ii) achieve independence from their parents, iii) establish adult relationships outside their families, iv) find a vocation.\(^2\) A fundamental principle is that where young people have a need for health care, such care must be provided in a manner which is appropriate to their stage of development. The term used to describe this principle is Developmentally Appropriate Healthcare (DAH). DAH should underpin all healthcare for young people and in particular for those with a long term condition. However, unfortunately the term has been ill-defined and used inconsistently; in turn this has made it difficult to assess whether it has been implemented in reported studies.\(^3,4\)

Further, a young person with a long term condition has to move from a child to adult services. This process is called ‘Transition’ and is defined as the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-oriented health care systems.\(^5\) ‘Transfer’ is the formal ‘event’ when medical care of a young person is moved from children’s services to adults’ services.

The UK and Australia are the only two high income countries with national guidance on Transition;\(^6\) though academies and speciality groups also make recommendations.\(^7-9\) In the UK much transitional healthcare is sub-optimal and responsibility to improve this lies with commissioners, provider organisations and clinicians. Recent policy and recommendations, setting out the need for improved transitional healthcare, include: advice from the Department of Health in 2006 and 2008;\(^10,11\) recommendation 23 of the 2010 Kennedy Report;\(^12\) the 2015 Care Quality Commission report ‘From the Pond to the Sea’;\(^13\) and NICE Guidance on Transition in 2016.\(^14\)

The number of young people surviving to adulthood is increasing. Many children with long term conditions, who now live into adulthood, might previously have died. In a typical NHS Trust serving a population of 270,000, about 100 young people with chronic illness, complex
physical impairment or neurodevelopmental disorder reach age 16 each year. As transition takes place over about seven years, the number in transition at any time in a typical Trust is approximately 700.

New understanding of adolescent and young adult brain development and its associations with behaviour further reinforce the need for transitional healthcare to be set in a developmental context.

Transition is important because:

- Many young people with a range of long term conditions have poor social outcomes following transition in areas of social participation, employment or further education. For example, young adults with long term conditions, such as cancer, congenital bowel anomalies and renal disease, congenital heart disease, chronic physical disability, and those with chronic illness, have demonstrated delays in autonomy, psychosexual and social development. Further, few young adults with neurodevelopmental disorders such as autism spectrum disorder attained their potential for participation in society.

- Chronic illnesses, such as diabetes or renal disease, are prone to deteriorate during the adolescent years; they need frequent medical monitoring and treatment optimisation. Young people reported finding it difficult to negotiate transition in services for haematology, type 1 diabetes, epilepsy, physical disability, and rheumatology. Conditions such as cerebral palsy give rise to symptoms that interfere with daily living such as pain, spasticity or seizures. Most mental health disorders of adults develop during adolescence just at the time when commissioning and provision of services is most likely to move from child and family-focussed to adult symptom-orientated mental health services. There are disturbing rejection rates after solid organ transplants.

- Some adult services are not routinely provided (for example for adults with Attention Deficit Hyperactivity Disorders or Autism Spectrum Disorder). Other adult services, such as physiotherapy and mental health services, have different and usually narrower entry criteria. Some services which require multidisciplinary co-ordination (such as for those with cerebral palsy) are provided in childhood but are rarely provided in adulthood.

Whilst central government guidance and direction might be expected to lead to improved services for transitional healthcare, it has not done so – there remains a clear need to improve services. In 2017, a National CQUIN (Commissioning for Quality and Innovation
National Goals) was introduced around transitions from children and young people’s mental health services.\textsuperscript{35}

**Developments in healthcare transition during the period of the Research Programme**

Since the start of the Programme in 2012, there have been developments in the field of transition which we have taken account of.

Results of published evaluative studies remain difficult to generalise from because they are usually about an intervention in one clinical setting, for one condition and using a locally designed intervention. The Cochrane Review\textsuperscript{36} on interventions to improve transition confirmed the lack of good evidence. Protocols for more rigorous studies have been published recently.\textsuperscript{37-40} A systematic review\textsuperscript{41} in 2017 reported the limitations of methods used in comparative studies of transition interventions. It found, for example, most were small single condition studies, used un-validated questionnaires, and did not report age of transfer or age and time of questionnaire completion. In designing our research we had anticipated such methodological limitations and addressed them in the methods we used for the longitudinal study (\textit{WPs 2.1, 2.2 and 2.3}).

Two Delphi studies proposed a suite of outcomes\textsuperscript{42} and process measures\textsuperscript{43} for evaluating transition. Our choice of outcomes in the longitudinal study is in line with these international studies.

A synthesis of qualitative studies of young people’s views about transition\textsuperscript{44} confirmed that there is much literature about the issues and difficulties encountered; and supported our decision not to undertake further exploratory work with young people.

As anticipated, arrangements for commissioning NHS services have continued to change during the Research Programme. However, the commissioning focus of our research concerns ‘what’ and ‘how’ to commission. We intended that our findings would be relevant to any commissioning structure, including whether or not commissioning and service provision are brought together in the same organisation.
Aims and objectives of the Research Programme

The overall aim of the Programme was:

To promote the subjective wellbeing and health of young people with long term conditions by generating evidence to enable NHS Commissioners and Trusts to facilitate the successful transition of young people from child to adult health care, thereby improving health and social outcomes.

In order to address this aim, the Programme had three objectives:

Objective 1. To work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional healthcare

Objective 2. To identify the features of transitional healthcare that are effective and efficient

Objective 3. To determine how transitional healthcare should be organised, provided and commissioned

Three separate work packages (WP) addressed each of these objectives. We present a summary of each WP and then bring together the results of all nine strands to inform our conclusions and their implications. As an overview and to aid orientation, the WPs are summarised in Box 1, followed by Figure 1 which shows how the WPs influenced each other.

At the end of the account of each WP we indicate its links to the other WPs and how each WP contributed to the seven main implications of our work.

In Appendix 1 NIHR Programme Development Grant is a summary of work we completed before applying for a Programme Grant.

In Appendix 2 Management are the management arrangements for the Programme and a diagram showing how key groups interacted.
Box 1: Overview of the work packages

Objective 1
WP 1.1
- To form and maintain a Programme Young People’s Advisory Group
- To consult with the Young People’s Advisory Group on all aspects of the Programme

WP 1.2
- To explore the usefulness of a ‘health passport’ through research co-led by the Young People’s Advisory Group

WP 1.3
- To explore the importance young people attach to different components of successful transition

Objective 2
WP 2.1
- To examine whether proposed beneficial features of services predict outcomes for young people with type 1 diabetes, cerebral palsy or autism spectrum disorder with an associated mental health problem
- To determine the resource use and costs of care

WP 2.2
- To investigate the factors that promote or inhibit introduction of the proposed beneficial Features of services

WP 2.3
- To assess the relative efficiency of illustrative models of transition

Objective 3
WP 3.1
- To identify, describe and understand the factors that enable or inhibit the introduction of organisation-wide Developmentally Appropriate Healthcare for young people

WP 3.2
- To identify the structures, processes and relationships between commissioning entities in the NHS and other agencies
- To identify the facilitators of and barriers to commissioning for transitional healthcare
- To identify how transitional healthcare could be better commissioned

WP 3.3
- To synthesise learning from the Research Programme on ‘what’ and ‘how’ to commission
- To learn about the most useful way to provide research based evidence to inform commissioners
Figure 1. How the work packages (WP) influenced each other

WP 1.1 Young person’s working group

WP 1.2 Health passport

WP 1.3 Q-sort

WP 2.1 Longitudinal: quantitative

WP 2.2 Longitudinal: qualitative

WP 2.3 DCE and economic modelling

WP 3.1 Developmentally appropriate healthcare

WP 3.2 Commissioning: data gathering

WP 3.3 Commissioning: synthesis
WP 1.1 Work of UP group

Addressing Objective 1: to work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional healthcare

We ensured that the contributions of the young people were integrated with the Research Programme in meaningful ways for the young people and the research. Funds from the Programme ensured enough staff-time was available to facilitate meaningful involvement of young people throughout the five-year Programme.

The young people called their group United Progression - UP (the term UP is now used throughout this report).

Aims
- To form and maintain UP
- To consult with UP throughout the duration of the Programme

Method

Preliminary work during the development of the grant application

Discussion, between a time-limited young person’s group and co-applicants, concluded that a ‘partnership’ approach to involvement should be the fundamental value. Development of skills and confidence would be required to enable young people to contribute to a research programme. Peer Support Workers (PSW) would be recruited to facilitate the induction and skills’ development of the advisory group.

Development of and recruitment to UP

Three part-time PSWs were appointed. Recruitment to UP was undertaken by the Programme’s PPI lead.

UP members, at the start of the programme, were aged between 15 and 20. They all had experience of accessing a range of healthcare services. Recruitment occurred in a range of ways: via young people’s health services; local schools; local young people’s health action groups. With membership growing steadily in the early months, the group consisted of over 20 members, with active participation fluctuating over time, in line with exams, family events and other commitments. Most meetings had around eight members present. UP had twenty-six members over the five years. By the end of the Programme, eight of the original members
still attended regularly; this was crucial as they brought their five-year insights to the final research outputs.

UP met monthly over the five-year Programme. UP had a hot meal and socialised before meetings began.

UP’s members were involved in advisory, consultative and dissemination roles – not as research participants.

*Maintaining and sustaining the engagement of UP*

Induction for UP members included a description of the project, a meeting with members of the management team, a glossary of research terminology, and attending and presenting at the Programme’s launch.

Each monthly meeting was planned to be enjoyable for UP, and to ensure there was enough guidance and support around tasks UP had agreed to do. Careful planning was needed around communication between UP and the Programme Management Board to ensure fruitful interaction. The PPI lead was the link between UP and the Board. The Board set out timely, structured commissioning briefs for the PPI lead, rather than sending direct requests to UP. The PPI lead ensured tasks were relevant, achievable and that young people had the skills to deliver them.

**Impact on the Programme**

UP provided input to many WPs. For example, UP piloted the Q-sort tool in *WP 1.3*. UP commented on the ‘proposed beneficial features’ that were central to the longitudinal research described in *WP 2.1*; subsequently, two features (‘transfer readiness’ and ‘direct payments’) were dropped as being unclear or not relevant to healthcare transition. UP designed recruitment and retention materials for the longitudinal research of *WP 2.1*. UP responded to the findings of WPs; for example, they made a training DVD on the importance and implementation of Developmentally Appropriate Healthcare for *WP 3.1*.

UP contributed directly to dissemination activities throughout the Programme. They presented at the launch in Newcastle, October 2012; and ran a session at the final dissemination conference in London, October 2017. They wrote blogs for the Programme’s website. UP representatives sat on the interview panels for the research associates and contributed to their induction and sat on the External Advisory Board.

UP advocated for the Programme and offered their skills and expertise to local and national groups. UP helped to develop training materials for doctors in partnership with the Royal College of Paediatrics and Child Health, MindEd and the Association of Young People’s
Health. This generated several videos. UP represented the Transition Programme at the Department of Health’s ‘Takeover Day’ in London, 2015. Finally, UP worked with the Council for Disabled Children to disseminate their experiences and present early results of the Programme to other young people’s groups between autumn 2015 and spring 2017. These meetings also enabled young people involved in research elsewhere to share their experiences with UP. In these meetings, UP disseminated results of the Programme relating to the Q-sort study (WP 1.3), health passport work (WP 1.2) and the concept of Developmentally Appropriate Healthcare (WP 3.1). Meetings took place with: CHAT group North Tyneside; two Croydon groups; Together for Short Lives young person group; St Oswald’s Hospice, Newcastle; Transition2 group in Derby; and the Chatterboxes youth group in Bournemouth. Three facilitator guides (one example in Appendix: 11) were developed for other groups to use, especially voluntary organisations. In Appendix 3 are: the certificate UP designed for participants in the longitudinal study WP 2.1; UP’s PowerPoint presentation for the Programme’s launch; and one of the conference posters prepared by UP.

Key Findings

- UP influenced many of the WPs of the Programme, and was involved in a wide range of dissemination and advocacy activities
- As the members of UP grew in confidence, their contributions became increasingly useful to the Programme. The support and training offered to UP were very important, although they were resource intensive
- Members of UP reported that they enjoyed the challenges, the relationships they formed with other young people and their greater understanding of research

Interrelationships to other parts of Programme

UP influenced many aspects of the Programme through their input to several WPs. The only two WPs they did not influence directly were those (WPs 3.2 and 3.3) on Commissioning for transition.

Further analysis of and discussion of the role of UP is presented in the section of this report on PPI. This section also summarises the internal evaluation of the work UP undertook and points to the paper, nearing acceptance in a peer reviewed journal, which is in Appendix 11.

Though not unique to our Programme, when professionals and managers and commissioners attend meetings where young people contribute and have been closely involved in the work
presented, such young person involvement strengthens the assurance that the audience attaches to the work.

UP thoughts and opinions directly influenced Implication 2 on Developmentally Appropriate Healthcare and the toolkit we developed to assist with introduction of such care across an organisation. By advising on questionnaire content, wording and feasibility, UP directly influenced both what research participants were asked to complete and the key implications of our work, namely: Implication No. 4 concerning joint planning; No. 5 concerning young people’s approaches to transition; No. 6 concerning features associated with better outcomes; and No. 7 concerning features likely to optimise service uptake.
WP 1.2 Health passport

Addressing Objective 1: to work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional healthcare

We determined that engaging UP in a research study co-led by them would help them better understand research processes and generate knowledge important to the Programme. UP chose ‘health passports’ as the focus of their work. These are usually a portable means to record health information.\textsuperscript{45, 46}

Aim

- To explore the usefulness of health passports in a project co-led by UP

Methods

UP examined a range of passports designed to help young people navigate health services and concluded there was no clear definition of what a ‘health passport’ was. As there were many health passports already available, UP decided that it would not be useful to develop another one. However, as no robust analysis of health passport use has been undertaken, UP aimed to examine the use and usefulness of some health passports already used by young people with long term conditions.

UP contacted healthcare professionals from a children’s hospital, a physical disabilities team, an adolescent rheumatology team and a voluntary organisation. UP asked professionals about their experience of health passports and this helped to identify questions and issues to explore with young people such as:

- What kind of passports are used and what are their essential components?
- Who uses health passports and who benefits from them?
- How are they used and how are young people supported to use them?

UP then worked with the Patient Satisfaction Team in the lead Trust to devise a questionnaire to assess the views of young people about health passports. Then the professionals in the above organisations helped UP link to young people who used health passports. However, this proved difficult as ethics and research governance permissions were required; it was impossible to achieve this across several organisations within the available time.
**Analysis**
Young people from one service returned questionnaires (n=13) and, although the response rate was low (20%), interesting findings emerged. None of the 13 participants said they completed the health passport alone; the majority said they thought passports were ‘useful’ but half of them never took them to healthcare appointments. They were considered more useful to health professionals than to young people themselves.

**Strengths and limitations**
This work identified some qualitative findings about health passports. However, the work did not generate, as intended, enough quantitative data from which to draw definitive conclusions. It was difficult to obtain all the research governance permissions in a timely manner to enable UP to approach as many young people as they had intended. The approaches also depended on the willingness and time of local health professionals to approach young people. For other parts of the Programme, all such preliminary contacts and undertakings had been formalised before the Programme started. For this work, co-generated by UP, planning could not begin until UP had worked through its ideas, which was at least a year into the Programme.

Such challenges have been reported before. A Dutch group undertook participatory research with young people with chronic illness\(^47\) and concluded that, although the activity benefited the young people, it was an inefficient and unreliable way to gather research data. Similar benefits to young people were reported in a study in Vancouver.\(^48\)

**Key findings**
- There is a lack of conceptual clarity and no clear definition about what is meant by ‘health passport’.
- The work raises questions about whether a health passport is truly a young person held tool. Who should complete it and when? Do young people really want it to ‘travel’ with them to appointments and between services?
- Even studies by enthusiasts for health passports found difficulties. Participants used their document only occasionally and its perceived utility was modest;\(^49\) only a quarter completed a survey and of those who then agreed to a telephone discussion, only one third had used their passport.\(^45\)
**Interrelation to other parts of the Programme**

This WP contributed directly to the longitudinal study *WP 2.1*. A health passport was discussed as a candidate proposed beneficial feature of transitional healthcare. However, the initial work that UP undertook indicated that ‘health passport’ meant different things to different people; and although considered useful by some professionals, young people appeared to value it much less. We therefore decided not to include health passport as a proposed beneficial feature. This decision was vindicated by the subsequent survey work that UP undertook.

The confidence members of UP gained by carrying out their research and their greater appreciation of research methodology enhanced the quality of all their contributions to the Programme, which were set out in the earlier account of *WP 1.1*. It also increased their self-confidence, and this is discussed in the *PPI section* and the draft paper in *Appendix 11*.

UP presented the health passport work at the Department of Health ‘Takeover Day’ where interest was expressed for taking the passport work forward nationally.

UP presented their work as a poster at several meetings, including the final dissemination meeting at the Kings Fund, London in October 2017. UP’s poster presentation is in *Appendix 4*. 
**WP 1.3 Q-sort study**

Addressing Objective 1: to work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional healthcare

Qualitative research undertaken with young people during and after transition has been systematically reviewed. The first review\(^{50}\) identified four main issues: young people’s feelings and concerns; young people’s recommendations about components of transition services; outcomes after transfer; mode of transfer. The second review\(^ {44}\) examined the point of transfer and identified four themes: facing changes in significant relationships; moving from a familiar to an unknown ward culture; being prepared for transfer; achieving responsibility.

The work of this WP is published\(^ {51}\) with URL in *Appendix 5*.

**Aims**

- To explore the views of young people about transition
- To identify and describe these views using Q-methodology

**Methods**

Q-methodology combines quantitative and qualitative methods to investigate the range of possible views on a subject. It involves the rank ordering (Q-sort) by participants of a set of statements (Q-set) about a topic. Then, a by-person factor analysis of the Q-sorts is used to reveal shared perspectives on the topic. Further detail is in our published paper\(^ {51}\) with URL in *Appendix 5*.

The Q-set of statements relevant to young people in transition was generated using quotations from two reviews of qualitative studies\(^ {44, 50}\) and our own mapping review of service models.\(^ {52}\) These were coded into a set of emergent themes: “planning,” “staff related,” “maturity,” “parent-related,” and “other”; which were then re-categorised into to several sub-themes. One representative statement from each sub-theme was selected. Following consultation with UP, wording was adjusted and each final statement prepared for sorting by participants onto a triangular grid. The statements are set out in Table 1 of the published article\(^ {51}\) with URL in *Appendix 5*. 

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Q-methodology requires individuals in the sample potentially to hold different views. Maximum variation sampling was therefore used, sampling by age, gender, health condition and whether the young person had transferred or not. We sought 45 young people aged 14-22, with a long term condition that would soon require or had recently required them to transfer from child to adult services. Exclusion criteria were those with intellectual disability who could not complete the Q-sort. The number of participants is usually, but not necessarily, smaller than the Q-set.\textsuperscript{53} The aim is to have four or five persons defining each anticipated viewpoint, and there are often two to four, and rarely more than six. Accordingly, breadth and diversity of viewpoints is probably best achieved when a participant group contains between 40 and 60 participants.\textsuperscript{54}

Clinicians from ten child and adult specialties in an NHS Trust with tertiary and secondary care responsibilities invited young people with long term conditions to participate. Q sorts were administered face-to-face by the researcher.

**Analysis**

The degree to which an individual’s Q-sort corresponds to each factor derived from the factor analysis is given by their “factor loading”. This is a correlation coefficient between +1 and -1; the closer to 1 the more similar an individual’s Q-sort is to the factor. Individuals are “exemplars” for a factor if they have a significant factor loading on that factor alone (p≤0.01). We used PQMethod software\textsuperscript{55} with centroid factor analysis followed by varimax rotation.\textsuperscript{56} Outputs include the number of exemplars per factor, eigenvalues and factor variance which provide information on the proportion of variance for the entire study explained by each factor. These are used alongside the postsort qualitative information to determine the “factor solution”: the final number of factors identified.

For each factor an idealized “composite” Q-sort is computed, illustrating how a person with a factor loading of 1 would have laid out their statement cards. Attention is paid to statements which characterize each factor, for example those placed in the +3 and -3 position on the grid, and those statements which distinguish between factors.

We found that a four-factor solution was optimal from a statistical viewpoint and most meaningful in clinical terms:

**Factor 1:** Young people with a ‘laid back’ approach to transition

These young people were not particularly worried about transition. They did not think transition would make much difference to them and expected their new health team to
provide similar care to that they had experienced in child services. They were happy to be
guided by staff on how to manage their condition and wanted continued involvement of their
parents in their care. They also wanted to be well-informed about their condition.

Factor 2: Young people with an anxious approach to transition
For these individuals, transition mattered very much, and it worried them, and they did not
want transfer to happen at a set age, and they wanted a written plan in place for this. They
wanted to be able to say goodbye to their current doctors, thought that the post-transfer
service would provide different care, and that seeing different staff might not help build trust.
They thought their condition was difficult to live with and all areas of their life were affected
by it. They did not know what kinds of support would be available to them in future. They
wanted their parents involved in their care.

Factor 3: Young people with an autonomy-seeking approach to transition
These young people wanted independence and autonomy during transition and were
characterised by their wish for the withdrawal of parental involvement in their care. They
wanted doctors to speak to them, rather than their parents. They wanted doctors to offer
suggestions and choices but allow them to make decisions. They were more developmentally
mature in terms of their responses to statements about leaving home and living
independently. They preferred flexible timings for clinics and wanted to leave the paediatric
environment. They showed that they wanted to meet adult staff before transfer, and then see
the same doctors in order to develop trust.

Factor 4: Young people with a socially-oriented approach to transition
These young people valued social interaction with family, peers and professionals to assist
transition. They thought it important to interact with those involved in their care. They
wanted to meet others in a similar situation and wanted their parents to remain involved in
their care. They were comfortable with other staff being present at consultations and, for
example, did not find it difficult if students were present. They felt attached to doctors
(wanting a chance to say goodbye before transfer) and wanted a particular person at the clinic
to help them plan the practical side of managing their condition.

There is more discussion of these factors in our published paper with URL in Appendix 5.
**Strengths and limitations**
Due to the purposive sampling, claims cannot be made about how many individuals hold each point of view. Nor can inferences be made about sub-group sizes based on gender, age or condition.

We do not know if the four styles are stable over time. The views of some young people might relate to underlying personality characteristics and therefore not change substantially. Alternatively, preferences may change as young people develop or as their health or healthcare change.

**Key findings**
- Reviews of qualitative studies of transition have not revealed how individuals approach the dilemmas they face. Our results add a new dimension.
- Four factors or interaction styles of approaching transition were identified: ‘laid back’, ‘anxious’, ‘autonomy-seeking’ ‘socially-oriented’.
- These four diverse styles show that there is not one view on transition. Thus, a ‘one size fits all’ approach is inappropriate and tailoring care to each to each young person is crucial.

**Interrelation to other parts of the Programme**
The recognition of these four interaction styles for approaching transition is a new finding and yields one of the seven key implications of the Programme – No. 5.

The Q-sort study contributed to the design of the Discrete Choice Experiment (WP 2.3), which identifies aspects of transitional healthcare which young people are more likely to take up. This in turn informed the economic analyses (WP 2.3).
WP 2.1 Longitudinal study (quantitative)
Addressing Objective 2; to identify the features of transitional healthcare that are effective and efficient

Whilst there is some preliminary evidence of the benefit of transition programmes in diabetes care, there has been little research with young people with complex physical impairments. Further, the lack of planned transfer to adult mental health services for young people with neurodevelopmental disorders has been highlighted. Therefore, in order to be as generalisable as possible across long term conditions, a cohort of young people with one of three very different conditions was recruited: individuals with type 1 diabetes as an exemplar of chronic illness; with cerebral palsy (CP) as an exemplar of complex physical impairment; and with autism spectrum disorder (ASD) who continued to access child services for associated mental health problems as an exemplar of neurodevelopmental disorder.

Following examination of published policy documents and research literature, nine proposed beneficial features (PBF) of services were identified and defined for the study. These were age-banded clinic; meet adult team before transfer; promotion of health self-efficacy; written transition plan; appropriate parent involvement; key worker; coordinated team; holistic life-skills training; Transition manager for clinical team. In the Glossary section are the definitions of the features. In Table 2 of the published protocol with URL in Appendix 6 are the details of the policy documents and tabulation of the research literature justifying their inclusion.

The following papers have been published from this work package:
Protocol
Analysis of baseline data
Young people’s experience of the proposed beneficial features
Unmet needs of those with cerebral palsy
Clinical course in diabetes
Longitudinal analysis identifying that only three of the proposed beneficial features are associated with better outcomes
Aims

- To examine whether proposed beneficial features of services are associated with better outcomes for young people with type 1 diabetes, CP or ASD with associated mental health problem

Hypothesis

In combination, and separately for type 1 diabetes, CP and ASD, access to proposed beneficial features during transition from child to adult healthcare predicts better health and social outcomes.

Methods

Sampling frame and site selection

Between June 2012 and October 2013 young people with type 1 diabetes were recruited from children’s services in five UK healthcare provider NHS Trusts which were at different stages of development of transitional healthcare. In the UK, all young people under 15 years of age with Type 1 diabetes mellitus attend secondary hospital care. These five NHS Trusts were from Greater London, north, south-west and south-east England. Young people with ASD with an associated mental health problem were recruited from four NHS Trusts, two of which claimed to have a readily available adult service to which to transfer young people. Similarly, all young people with ASD and an identified mental health problem attend specialised secondary care services. These four NHS Trusts were in north and south-west England.

Young people with CP were recruited from one NHS Trust in south-east England and randomly sampled from two regional population registers, the North of England Collaborative Cerebral Palsy Survey\(^67\) and the Northern Ireland Cerebral Palsy Register,\(^68\) and that covered seventeen NHS Trusts.

We conducted a survey before submission of our application which showed that the Trusts varied greatly in the extent to which they provided PBFs; this was confirmed by the formal survey in all the Trusts described in the previous paragraph undertaken during the study (see three pages on, under the section Proposed Beneficial Features).

All participants were aged 14-18 years 11 months at recruitment and had not transferred to adult services. Participants had no significant learning disability.
Procedures
Young people and their parent(s) were visited on four occasions, one year apart, by a locally-based research assistant at home or clinic.

Information on date approached, date of birth, gender and postcode was collected. Postcodes were used in England to calculate an index of multiple deprivation (IMD)\textsuperscript{69}, and in Northern Ireland to calculate the multiple deprivation measure (MDM).\textsuperscript{70} IMD and MDM are markers of community-level socio-economic status; higher deprivation scores indicate more socio-economic deprivation.

We defined ‘date of transfer’ as the date of the final appointment with a paediatrician or principal child health specialist. This included where the young person saw a paediatrician and adult physician jointly to introduce a member of the adult team. If there was not a letter stating transfer date, the date of turning age 18 was recorded. At study end, the young person’s status was recorded as: still in child services, transferred to adult services, transferred to primary care, or left study.

In order to maximise use of data, we carried out longitudinal analyses on the ‘Final’ visit, defined as visit 4 unless there was a visit 3 that was not followed by a fourth visit - in which case visit 3 was used as the ‘Final’ visit. At the ‘Final’ visit there were 274 young people (73.3\%) with valid follow-up data for analysis (112 with diabetes, 74 with CP and 88 with ASD).

Measures
We captured generic outcome measures about satisfaction with services, participation in life situations and wellbeing.

Parents and young people completed the ‘Mind the Gap’ scale\textsuperscript{71} about their satisfaction with services. Satisfaction is conceptualised as the ‘gap’ between ratings of ‘ideal’ and ‘current’ care; the greater the ‘gap’ score the lower is satisfaction. It yields an overall score and three sub-domain scores.

Young people completed the Rotterdam Transition Profile,\textsuperscript{72} a nine domain questionnaire on participation, defined as involvement in life situations.\textsuperscript{73} On each domain participants select the statement that best describes their current situation. Each statement represents one of three phases of transition: phase 1 childhood/dependence on parents; phase 2 experimenting and orienting to the future; and phase 3 adulthood/independence.
A three-item questionnaire captured the young person’s Independence in Appointments, and had a score range 3 to 15 (15 being the most independent). The psychometric properties of this scale are not established.

At visits 3 and 4, young people completed a frequency of social participation questionnaire, especially developed for adolescents; it has UK general population data available for comparison. Two ‘factors’ are captured: ‘Getting on with people’ and ‘Community recreation’.

Young people completed The Warwick and Edinburgh Mental Wellbeing Scale which is a 14-item questionnaire, developed in the UK and valid in the age range 13-21 years. It has UK general population data for comparisons.

No further psychometric analyses were carried out on the ‘Mind the Gap’ scale and the Rotterdam Transition Profile because they have been validated and used with young people with a variety of long term conditions. However, for the WEMWBS internal consistency was assessed using Cronbach’s alpha with 95 % confidence intervals to check it was an appropriate measure to use in all three groups, particularly the ASD group with associated mental health problems.

In addition, the following condition-specific outcomes and process measures were captured:

*Type 1 diabetes.* Participants were assigned to a ‘satisfactory’ or ‘sub-optimal’ clinical course’ at visits 2, 3 and 4. Following consultation with specialists in adult and paediatric diabetes, participants were deemed to have a satisfactory clinical course if for each year of the study: HbA1c was less than 7% above baseline, no hospital admissions for diabetic ketoacidosis, more than 75% clinic attendance, and 100% attendance for retinal screening, with URL in Appendix 6.

*CP.* An unmet needs questionnaire was developed, based on a model widely used in disability research. The questionnaire was completed separately by young person and parent. Categorical Principal Components Analysis identified two domains: Daily activity healthcare and Medical care, with URL in Appendix 6.

*ASD with associated mental health problem.* Young people completed the self-report Hospital Anxiety and Depression Scale, which has subscales for anxiety and depression. The psychometric properties of this scale have been shown valid for use with young people with ASD.
Proposed beneficial features (PBF)

A summary checklist about the PBFs was discussed by the research assistant with each young person at the first (baseline) visit. Then, at the second, third and fourth home visits, the checklist of PBFs experienced by the young person over each preceding twelve months was completed by the research assistants, in discussion with the young person (and with parents). This was supported by diary information kept by the young person about their consultations. The research assistants also consulted health records to extract information about provision of PBFs; this included whether there was evidence that the clinic had a staff member with the role of transition manager for the clinical team (which was not directly asked to young people). Each PBF was recorded as received (or not) at least once during the year before the visit. The PBFs experienced over the course of the study were also combined to form a ‘trajectory’, deemed optimal or sub-optimal according to whether:

A. in at least one of the three years there was exposure to the feature: ‘Age-banded clinic’; ‘Meet the adult team before transfer’; ‘Written transition plan’; ‘Holistic life-skills training’; ‘Transition manager for clinical team’.

B. in at least two of the three years there was exposure to the feature: ‘Key worker’; ‘Coordinated team’.

C. in each of the three years there was exposure to the feature: ‘Promotion of health self-efficacy’; ‘Young person and/or parent satisfied with level of parent involvement’. Where a visit had been missed, and the trajectory could not be assessed, the trajectory was recorded as missing.

After the first year of the study, a questionnaire was sent to each of the 35 services attended by the young people recruited, to ask whether their service aimed to provide each of the PBFs.

**Analysis**

**Recruitment**

Eight hundred and seventy eight young people were approached and 374 were recruited to the study; 118 with ASD, 106 with cerebral palsy and 150 with diabetes. Further detail and a flow diagram are in Figure 1 of our published paper on baseline characteristics, with URL in Appendix 6. While recruitment rates were reasonably good for the ASD group (50.9 % of those approached) and diabetes group (64.7 %), the rate of recruitment of those with CP was lower (25.6 %). This may be due to the method of recruitment, which was to send letters of invitation, rather than for their clinician to approach young people and their families directly.
As described in our baseline characteristics paper, participants with diabetes or CP were comparable in terms of condition severity to larger population samples. However, those with ASD had more difficulties because we recruited individuals who also had an associated mental health problem.

The target of 150 in each group was achieved for young people with diabetes but not for those with ASD who were in contact with mental health services (n=118) or those with CP (n=106) (Appendix 6 Recruitment graph). For each young person a parent or carer was invited to participate; 369 agreed (367 parents, one grandparent and one foster parent). Thus, data from a parent or carer were available for 98.6 % of the young people.

Participants did not differ significantly from non-participants by age or gender as shown in Table 1 of our published paper on baseline characteristics. Overall, participants had significantly (p < 0.001) lower scores of the Index of Multiple Deprivation (IMD) (i.e. less deprived) than non-participants; however, the difference in overall IMD score on a continuous scale ranging from 0.5 to 87.8, was only 6.1.

Retention

Most of this analysis is reported in our published paper on the longitudinal analysis with URL in Appendix 6, from which the text below is taken. A total of 304 (81.3%) young people remained in the study by visit 2, 259 (69.3%) by visit 3 and 243 (65%) by visit 4 (Appendix 6, Retention). Forty young people became uncontactable (Appendix 6, Retention). Of the 71 who told us they wanted to leave the study, the main reason (n=22) was ‘no longer being interested’. A further 19 had other commitments that came with being older, such as sitting exams, university work, or part-time or full-time jobs. Further, some young people were too mentally unwell to allow visits. This highlights the natural challenges of undertaking longitudinal research during a life stage where so much change is occurring.

274 (73%) had data for ‘final’ visit (defined in Methods as visit 4 unless there was a visit 3 that was not followed by a fourth visit - in which case visit 3 was used). Of these 274 young people, 58% were male and there were 112 with diabetes, 74 with CP and 88 with ASD.

The following text is taken from our published paper, with URL in Appendix 6. The mean time between baseline visit and final visit was 2.9 years (SD 0.4, range 1.8–3.9). There were no significant differences between those remaining in the study and those not remaining with respect to sex (p = 0.6), age (p = 0.6), condition (p = 0.6), diabetes sites (p = 0.4) or ASD sites (p = 0.6) or condition severity (p = 0.7 for diabetes, 0.9 for CP and 0.7 for ASD).
However, in Northern Ireland, those with CP lost to follow-up came from areas with, on average, greater socioeconomic deprivation (p = 0.03) than those remaining in the study. Examining socioeconomic factors based on actual circumstances rather than area of residence, there was a significant reduction in those not retained in the proportion of families with single parents.

To where did young people transfer?
For the 274 participants with a ‘Final’ visit, Table 1 shows whether the young person remained in child services or transferred to adult services or primary care, with breakdown by condition.

Table 1: Service attended by young people at ‘Final’ visit

<table>
<thead>
<tr>
<th>Status</th>
<th>Total N (%)</th>
<th>Diabetes N (%)</th>
<th>CP N (%)</th>
<th>ASD N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remained in child service</td>
<td>49 (18)</td>
<td>19 (17)</td>
<td>10 (14)</td>
<td>20 (23)</td>
</tr>
<tr>
<td>Transferred to adult service</td>
<td>148 (54)</td>
<td>89 (80)</td>
<td>35 (47)</td>
<td>24 (27)</td>
</tr>
<tr>
<td>Transferred to primary care</td>
<td>76 (28)</td>
<td>3 (3)</td>
<td>29 (39)</td>
<td>44 (50)</td>
</tr>
</tbody>
</table>

CP: cerebral palsy; ASD: autism spectrum disorder

*One young person with missing information

Of those with diabetes, almost all transferred to an adult service; whereas for those with CP the proportion that transferred to primary care was substantial and even greater for those with ASD.

Baseline and subsequent changes in the outcome measures
304 (81.3%) of the young people took part in the second visit (128 with diabetes, 85 with CP, 91 with ASD). 259 took part in the third visit and 243 in the fourth visit.

Satisfaction with services
Satisfaction with services was generally good as the ‘gap’ scores (difference between the respondent's ideal and current care) were small. Parents’ satisfaction was significantly lower than their children’s. Over the four visits, satisfaction with services did not change for those with diabetes but for those with CP or ASD it steadily worsened (Figure 2).
Wellbeing
The median baseline wellbeing scores of those with diabetes or CP were similar to each other and to those in the general population; and significantly higher (p<0.001) than for those with ASD. In the general population of 13-16-year-olds, the median scores on Warwick Edinburgh Wellbeing Scale was 48.8.\textsuperscript{76} In those over 16 in the general population in England, the median was 50.7.\textsuperscript{81} Over the four visits, the wellbeing scores of those with diabetes and CP or ASD were steady. Those with ASD continued to have significantly lower wellbeing (p<0.001) (Figure 3).
Rotterdam Transition Profile

On every domain of the Rotterdam Transition Profile, except for ‘education and employment’, significant differences were found between the three conditions (most p values < 0.01). A larger proportion of young people with diabetes were in a more independent phase of participation than those with ASD or CP. Over the four visits, young people steadily moved to a more independent phase of transition on every domain. Those with diabetes remained further ahead than those with ASD or CP (Figures 4a and 4b). As the phase for the domain ‘using specialist services for condition’ was determined entirely by the structure of the services and could not be influenced by the young person; we dropped it from this and further analysis.
Figure 4a. Rotterdam Transition Profile: percentages at Baseline, by condition group

Baseline

Figure 4b. Rotterdam Transition Profile: percentages at visit 4, by condition group

Visit 4
Social participation

The mean score of the ‘Getting on with people’ domain was significantly lower (p<0.001) for participants than in the general population whereas the score for the ‘Community recreation’ domain was similar (Table 2). Those with diabetes had higher mean scores than those with ASD or CP for ‘Getting on with people’; and higher scores than those with ASD for ‘Community recreation’. Scores for ‘Getting on with people’ improved by visit 4 for all three conditions but remained lower than in the general population.

Table 2: Social participation scores at visit 3, by domain in general population and study population

<table>
<thead>
<tr>
<th>Factor</th>
<th>General population</th>
<th>Study population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Getting on with people</td>
<td>478</td>
<td>0.004 (1.37)</td>
</tr>
<tr>
<td>Community recreation</td>
<td>479</td>
<td>0.27 (0.15)</td>
</tr>
</tbody>
</table>

Independence in Appointments

The Independence in Appointments questionnaire was added from visit 2 onwards. At visit 2 the average score was 8. Those with diabetes had higher scores than those with ASD or CP and these differences persisted, even though all scores increased, indicating more independence (Figure 5).

Figure 5. Independence in Appointments scale: change over time, by condition group
**Time from final paediatric appointment to first appointment in adult service**

We could only examine this for young people with diabetes. For those with CP it was usually unclear with which professional the first appointment should be. For example, sometimes a young person had transferred to an adult physiotherapist but was still seeing a paediatrician. For those with diabetes who had transferred, the mean time to adult appointment was 5.2 months (SD 4.9). The median time was 3.7 months (IQR 3-6). The proportion seen by adult services within 6 months of final paediatric appointment was 75%.

**Diabetes condition-specific measure of clinical course**

The proportion of young people with diabetes with satisfactory clinical course reduced over the study period (clinical course was determined from a composite score from HbA1c value, eye screening, clinic attendance and no diabetic ketoacidosis (see our published paper with URL in Appendix 6).

By visit 2, 65/128 (51%) had satisfactory clinical course

By visit 3, 49/112 (43%) had satisfactory clinical course

By visit 4, 32/108 (29%) had satisfactory clinical course

These results and further reporting in our published paper (for which we only report on the 108 who had full data to visit 4) indicate that the well-being of young people with diabetes and their satisfaction with transition services were not closely related to the condition’s clinical course.

**CP condition-specific measure of unmet need**

As reported by parents, the proportion of young people with CP with some unmet needs increased during the follow-up on the ‘daily living healthcare’ and ‘medical care’ domains (see our published paper with URL in Appendix 6). As reported by the young person, an increase in unmet needs was seen only in the ‘daily living healthcare’ domain (Figure 6). When considering only those with some unmet needs, mean scores decreased a little for the ‘daily living healthcare’ domain and remained the same for the ‘medical care’ domain, as reported by both young people and parents. These results were for the 64 young people who provided data at every visit. The results were similar when we examined data from each visit, whether or not data were available from other visits.
These results draw attention to the need for more coordinated care in adult services for those with CP. We discuss this further in our published paper and compare UK practice to that of other countries.

Figure 6a. Young person report

Figure 6b. Parent report

**ASD condition-specific measure of anxiety and depression**

The proportion of young people with ASD and an associated mental health problem with an ‘abnormal’ score on the ‘anxiety’ and ‘depression’ domains (as measured by the Hospital Anxiety and Depression Scale) remained similar between baseline and visit 4 (‘abnormal’ means above the recommended threshold score for a likely disorder) (Figure 7). The results were similar for those with data at every visit and those at each visit, whether or not data were available from other visits.

Figure 7. Proportions of normal, borderline and abnormal from the Hospital Anxiety and Depression scale at baseline and visit 4

Further analysis of those with ASD is in Appendix 6 Draft Paper. Having an additional diagnosis of ADHD or taking medication were predictors of transfer to adult mental health
services. Overall, the young people in our sample appeared to be doing reasonably well, with 67.5% in full time education (either school or college) at the end of the study. Under a third were in neither education nor employment. Analysis of HADS trajectories found that some young people were doing well, managing their mental health, and able to engage successfully with services. However, the majority were experiencing episodes or continued levels of high anxiety. Qualitative data revealed that many young people struggled when faced with more challenging academic and social educational environments.

Proposed beneficial features (PBF)

The PBFs that services reported they provided over the first year (ie before visit 2)

The following paragraph is covered in more detail in our published paper with URL in Appendix 6. Overall, the nine PBFs of services for transitional healthcare were often not offered to young people in our study by NHS services. Fewer than half of the 35 services stated they provided an ‘age-banded clinic’, ‘written transition plan’, ‘transition manager for clinical team’, ‘protocol for promotion of health self-efficacy’, or ‘holistic life-skills training’. Features were offered most often by services for young people with diabetes and least often for those with CP (Figure 8).

Figure 8. Percentage of ‘yes’ responses from each service by condition, stating whether the proposed beneficial feature was offered

The PBFs that young people reported that they experienced over the first year (before visit 2)

The content of the following paragraph is covered in more detail in our published paper, with URL in Appendix 6; it integrates findings from this WP and the qualitative work of WP
2.2. At visit 2, young people often reported that they had not experienced the features that services said they provided. Agreement between the young person report and what the service said it offered was: 30% for ‘written transition plan’, 43% for ‘holistic life-skills training’ and 49% for ‘key worker’. Agreement was better at 77% for ‘appropriate parent involvement’, 77% for ‘age-banded clinic’, 80% for ‘promotion of health self-efficacy ‘and 69% for ‘coordinated team’

**Associations of PBFs with outcomes**

Two approaches were adopted to assessing the associations of PBFs with outcomes. In both approaches we used the young person’s account of whether they had experienced a PBF, rather than what the service reported that it provided or aspired to provide.

In the first approach, it was established at each research visit whether the young person had experienced each PBF at least once in the previous year and was recorded as Yes or No. A separate analysis was then conducted for each PBF (as the independent variable) against the outcomes. This was undertaken for each annual period. Thus, this approach is a series of analyses which examine associations over one year, directly related to what the young person is experiencing at the time.

In the second approach, a consolidated indicator was compiled for each PBF for the duration of the study. The criteria for being optimal or sub-optimal varied by PBF and was calculated as outlined in Methods. The proportions of young people experiencing optimal or sub-optimal consolidated indicators are shown in Table 3. In the analyses, the independent variable was whether the consolidated indicator was optimal or sub-optimal for each PBF; the dependent variables were the outcomes captured at the ‘Final’ visit.

All models were adjusted for age, sex, condition and potential for clustering by site. Significant associations (p < 0.05) from these models were further adjusted for transfer status, time since transfer to final visit (if applicable) and time to first adult appointment (if applicable).

In examining the Rotterdam Transition Profile, we performed the logistic regression by comparing phases 1 and 2 to phase 3.

Table 4 sets out the effect sizes for all associations that reached p≤0.05 significance. Coefficients and odds ratios ‘year-by-year’ and for the consolidated PBF indicator have sub-optimal PBF delivery as the reference group.

A larger Mind the Gap score means less satisfaction with services than a smaller score.
Table 3: Consolidated indicator of Proposed Beneficial Features at final visit, by condition group

<table>
<thead>
<tr>
<th>Proposed beneficial feature</th>
<th>Consolidated indicator</th>
<th>All n</th>
<th>%</th>
<th>Diabetes n</th>
<th>%</th>
<th>CP n</th>
<th>%</th>
<th>ASD n</th>
<th>%</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-banded clinic</td>
<td>Optimal</td>
<td>145</td>
<td>53</td>
<td>109</td>
<td>97</td>
<td>16</td>
<td>22</td>
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<td>23</td>
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</tr>
<tr>
<td></td>
<td>Sub-optimal</td>
<td>111</td>
<td>40</td>
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<td>Written transition plan</td>
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<tr>
<td>Both young person and parent happy with parent involvement</td>
<td>Optimal</td>
<td>93</td>
<td>34</td>
<td>36</td>
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<td>28</td>
<td>38</td>
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<td>Key worker</td>
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<td>47</td>
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<td>Coordinated team</td>
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<td>Optimal</td>
<td>132</td>
<td>48</td>
<td>74</td>
<td>66</td>
<td>18</td>
<td>24</td>
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<td>45</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>Sub-optimal</td>
<td>117</td>
<td>43</td>
<td>28</td>
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<td>70</td>
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<td>27</td>
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<tr>
<td></td>
<td>Sub-optimal</td>
<td>143</td>
<td>52</td>
<td>67</td>
<td>60</td>
<td>34</td>
<td>46</td>
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<td>112</td>
<td>42</td>
<td>74</td>
<td>23</td>
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### Table 4: Associations of PBFs with outcome measures

<table>
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<tr>
<th>PBF</th>
<th>Period</th>
<th>Outcome</th>
<th>Coefficient or odds ratio*</th>
<th>95% confidence interval</th>
<th>p value</th>
<th>Outcome</th>
<th>Coefficient or odds ratio*</th>
<th>95% confidence interval</th>
<th>p value</th>
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<tr>
<td></td>
<td></td>
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<td>PBFs by ‘year-by-year’ visits</td>
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<td></td>
<td></td>
<td>Consolidated PBF indicator at final visit</td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>MTG: total</td>
<td>-0.48</td>
<td>-0.76 -0.19</td>
<td>0.001</td>
<td>MTG: total</td>
<td>-0.67</td>
<td>-0.97 -0.37</td>
<td>&lt;0.001</td>
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<tr>
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<td>MTG: environment</td>
<td>-0.57</td>
<td>-0.92 -0.21</td>
<td>0.001</td>
<td>MTG: environment</td>
<td>-0.71</td>
<td>-1.17 -0.26</td>
<td>0.006</td>
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<td></td>
<td>MTG: provider</td>
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<td>RTP: domestic</td>
<td>[0.14*]</td>
<td>0.03 0.67</td>
<td>0.01</td>
<td>RTP: finances</td>
<td>[0.6*]</td>
<td>0.92 0.39</td>
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<td>RTP: healthcare</td>
<td>[0.35*]</td>
<td>0.17 0.72</td>
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<td>WEMWBS</td>
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<td>0.21 4.15</td>
<td>0.03</td>
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<td>RTP: services and aids</td>
<td>[0.42*]</td>
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<td></td>
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<td>MTG: total</td>
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<td>MTG: environment</td>
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<td>-1.08 -0.21</td>
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<td>2</td>
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<td>MTG: provider</td>
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<td>-0.90 -0.06</td>
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<td></td>
<td>MTG: process</td>
<td>-0.82</td>
<td>-1.32 -0.31</td>
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<td>WEMWBS</td>
<td>4.47</td>
<td>1.96 6.97</td>
<td>0.001</td>
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<td>3</td>
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<td>MTG: total</td>
<td>-0.87</td>
<td>0.45 1.29</td>
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<td>MTG: environment</td>
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<tr>
<td>3</td>
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<td>MTG: process</td>
<td>-0.63</td>
<td>-1.18 -0.07</td>
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<tr>
<td>3</td>
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<td>WEMWBS</td>
<td>3.45</td>
<td>0.92 5.99</td>
<td>0.008</td>
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<td></td>
<td>Promotion of health self-efficacy</td>
<td>-0.51</td>
<td>-0.87 -0.15</td>
<td>0.006</td>
<td>MTG: total</td>
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<td>-0.62 -0.03</td>
<td>0.04</td>
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<tr>
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<td>-1.06 -0.18</td>
<td>0.005</td>
<td>MTG: environment</td>
<td>-0.57</td>
<td>-1.03 -0.11</td>
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</tr>
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<td>MTG: provider</td>
<td>-0.47</td>
<td>-0.85 -0.09</td>
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<td>MTG: process</td>
<td>-0.37</td>
<td>-0.70 -0.04</td>
<td>0.03</td>
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<tr>
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<td>MTG: process</td>
<td>-0.46</td>
<td>-0.91 -0.01</td>
<td>0.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>RTP: finances</td>
<td>[0.26*]</td>
<td>0.07 0.93</td>
<td>0.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>RTP: domestic</td>
<td>[0.04*]</td>
<td>0.01 0.21</td>
<td>0.001</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td></td>
<td>MTG: total</td>
<td>-0.51</td>
<td>-0.91 -0.11</td>
<td>0.01</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2</td>
<td></td>
<td>MTG: provider</td>
<td>-0.49</td>
<td>-0.90 -0.08</td>
<td>0.02</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>MTG: process</td>
<td>-0.70</td>
<td>-1.21 -0.19</td>
<td>0.007</td>
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<td>MTG: total</td>
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<td>-1.01 -0.20</td>
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<td>MTG: environment</td>
<td>-0.90</td>
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<td>MTG: provider</td>
<td>-0.52</td>
<td>-0.95 -0.11</td>
<td>0.01</td>
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<td></td>
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<tr>
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<td></td>
<td>Meet adult team before transfer</td>
<td>6.29*</td>
<td>1.60 24.80</td>
<td>0.009</td>
<td>RTP: education/employment</td>
<td>2.33*</td>
<td>1.21 4.55</td>
<td>0.01</td>
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<tr>
<td>1</td>
<td></td>
<td>RTP: healthcare</td>
<td>2.71*</td>
<td>1.24 5.90</td>
<td>0.01</td>
<td>RTP: finances</td>
<td>2.78*</td>
<td>1.10 7.14</td>
<td>0.03</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>RTP: services and aids</td>
<td>5.15*</td>
<td>2.08 12.78</td>
<td>&lt;0.001</td>
<td>RTP: services and aids</td>
<td>2.50*</td>
<td>1.06 5.88</td>
<td>0.04</td>
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<tr>
<td>1</td>
<td></td>
<td>RTP: transport</td>
<td>2.01*</td>
<td>1.06 3.79</td>
<td>0.03</td>
<td>Autonomy in appointments</td>
<td>1.60</td>
<td>0.32 2.87</td>
<td>0.02</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>RTP: education/employment</td>
<td>3.24*</td>
<td>1.09 9.65</td>
<td>0.04</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>1</td>
<td></td>
<td>Autonomy in appointments</td>
<td>1.69</td>
<td>0.80 2.58</td>
<td>&lt;0.001</td>
<td></td>
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</tr>
<tr>
<td>2</td>
<td></td>
<td>RTP: finances</td>
<td>2.64*</td>
<td>0.92 6.62</td>
<td>0.02</td>
<td></td>
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<tr>
<td>2</td>
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<td>RTP: transport</td>
<td>2.08*</td>
<td>1.11 3.90</td>
<td>0.02</td>
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<tr>
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<td>Autonomy in appointments</td>
<td>1.00</td>
<td>0.01 2.0</td>
<td>0.05</td>
<td></td>
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</table>
Note 1 Coefficients and odds ratios ‘year-by-year’ and for the consolidated PBF indicator have sub-optimal PBF delivery as the reference group.

Note 2 A larger Mind the Gap score means less satisfaction with services than a smaller score.

MTG Mind the Gap; RTP Rotterdam Transition Profile; WEMWBS Warwick Edinburgh Mental Wellbeing Scale.

[ ] negative association - i.e. satisfactory PDF was associated with worse outcome.

**Bold indicates p<0.01**

<table>
<thead>
<tr>
<th>3</th>
<th>3</th>
<th><strong>RTP: healthcare</strong></th>
<th>2.11*</th>
<th>1.03</th>
<th>4.34</th>
<th>0.004</th>
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</thead>
<tbody>
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<td>3</td>
<td>3</td>
<td><strong>Autonomy in appointments</strong></td>
<td>1.46</td>
<td>0.34</td>
<td>2.59</td>
<td>0.01</td>
</tr>
</tbody>
</table>

| Key worker | 1 | **RTP: leisure** | [0.56*] | 0.32 | 0.96 | 0.04  |
| 2 | **MTG: provider** | −0.66 | −1.04 | −0.28 | 0.001 |
| 2 | **MTG: process** | −0.69 | −1.17 | −0.21 | 0.005 |
| 3 | **RTP: education/employment** | [0.40*] | 0.20 | 0.95 | 0.02  |

| Holistic life-skills training | 1 | **RTP: domestic** | [0.19*] | 0.04 | 0.93 | 0.04  |
| 1 | **RTP: services and aids** | [0.34*] | 0.12 | 0.94 | 0.04  |
| 2 | **MTG: provider** | [0.43] | 0.03 | 0.84 | 0.04  |
| 3 | **MTG: total** | −0.46 | −0.87 | −0.05 | 0.03  |
| 3 | **MTG: provider** | −0.57 | −0.99 | −0.14 | 0.009 |
| 3 | **RTP: domestic** | 2.47* | 1.10 | 5.58 | 0.003 |
| 3 | **RTP: romantic relationships** | [0.52*] | 0.26 | 0.98 | 0.04  |

| Written transition plan | 1 | **RTP: romantic relationships** | [0.43*] | 0.19 | 0.96 | 0.04  |
| 2 | **MTG: total** | −0.72 | −1.39 | −0.04 | 0.04  |
| 2 | **MTG: process** | −1.19 | −1.39 | −0.04 | 0.007 |

| Coordinated team | 1 | **RTP: domestic** | [0.19*] | 0.04 | 0.93 | 0.04  |
| 3 | **RTP: healthcare** | [0.17*] | 0.04 | 0.82 | 0.03  |
| 3 | **RTP: services and aids** | [0.22*] | 0.06 | 0.81 | 0.02  |

| Transition manager for clinical team |  | No associations |  |  |  |  |

| Age-banded clinic | 1 | **WEMWBS** | 3.08 | 0.18 | 5.98 | 0.04  |
| 1 | **Autonomy in appointments** | 1.44 | 0.48 | 2.4 | 0.003 |
| 2 | **RTP: education/employment** | 5.22* | 1.21 | 22.53 | 0.03  |

Note 1 Coefficients and odds ratios ‘year-by-year’ and for the consolidated PBF indicator have sub-optimal PBF delivery as the reference group.

Note 2 A larger Mind the Gap score means less satisfaction with services than a smaller score.

MTG Mind the Gap; RTP Rotterdam Transition Profile; WEMWBS Warwick Edinburgh Mental Wellbeing Scale.

[ ] negative association - i.e. satisfactory PDF was associated with worse outcome.

**Bold indicates p<0.01**
Interpretation of the associations of PBFs with outcomes

This is presented in more detail in our published paper with URL in Appendix 6.

Three PBFs of transitional healthcare had significant (p ≤ 0.01) positive associations with better outcomes, namely ‘appropriate parent involvement’, ‘promotion of health self-efficacy’ and ‘meeting the adult team before transfer’. The b-coefficients indicated changes of approximately 0.5 SDs with respect to the satisfaction with services scale (SD 1.5 in our population), wellbeing (SD 7.0 in our population) and autonomy in appointments (SD 3.0 in our population). The odds ratios indicated increased likelihoods of being in a more independent phase of transition.

The other six PBFs had few statistically significant positive associations (p ≤ 0.01) with better outcomes in the year-by-year analysis, had a number of negative associations, and had no positive associations with the consolidated indicator of exposure to PBFs.

‘Appropriate parent involvement’ and ‘promotion of health self-efficacy’ were reported to have been experienced satisfactorily by less than half of participants across transition across the three conditions. However, they were experienced by more young people with diabetes than by those with CP or ASD. For ‘meeting the adult team before transfer’, around two-thirds of young people with diabetes reported that they had met a member of the adult team but it was less than a quarter, for those with CP or ASD. Thus, we found a different quality of experience of transitional healthcare for young people with a long term illness (diabetes) compared to those with a long term disability.

Strengths and limitations

Looking first at the strengths, our study drew 374 young people from across the UK and from many NHS Trusts. This is the largest sample for research in the UK in terms of examining transition longitudinally and collecting hypothesis-driven data from young people at home visits (compared to data-linkage studies from administrative datasets). Although we cannot be certain of representativeness and therefore generalisability across UK regions and NHS Trusts, we studied individuals from greater London, northern, south-eastern and south-western England, and Northern Ireland. Further, we drew individuals from 27 NHS Trusts, and the Trusts varied greatly in the number and variety of the PBFs they offered (Figure 8). We recruited from all young people with cerebral palsy in two population registers and all young people with diabetes or ASD with mental health problem in nine NHS Trusts widely
distributed across England (all such young people are seen in secondary care). Thus, complete populations of individuals with one of the three conditions were sampled from (rather than for example those attending particular schools, specialised tertiary health care services or voluntary support groups).

The three conditions chosen were exemplars of chronic illness (diabetes), complex physical impairment (CP), and neurodevelopmental impairment (ASD); these were deliberately chosen to be varied in terms of health needs, psychosocial complexity, and availability of adult services. Thus we consider that generalisability to other conditions is likely.

The 374 participants did not differ significantly from those declining to take part. The distribution of severity of the three conditions was similar to that in national samples. Those with the conditions had a wide range of severity; for example, the young people with cerebral palsy ranged from wheelchair users to those with independent ambulation. Attrition did not appear to create bias as there were no significant differences between those remaining and not remaining in the study with respect to sex, age, condition, diabetes site or ASD site. In Northern Ireland, there was a small effect of deprivation on attrition of those with cerebral palsy. Thus, we think that after non-participation and attrition, our study group continued to be representative of those we aimed to recruit.

Turning to the limitations, our study did not include young people with learning disability because in the UK there is already a lifespan service for such individuals, and we would not have been able to base our quantitative studies on self-completed questionnaire, nor our qualitative work on interviews with young people. However, the exclusion of such individuals means our results cannot be generalised to them.

Recruitment, especially of those with CP was more difficult than we expected. A possible explanation may be the method of recruitment which was to send letters of invitation, rather than for their clinician to approach young people directly as was undertaken for those with diabetes or ASD. Overall retention at 70% was acceptable in comparison to other longitudinal studies of adolescent populations.

It might be desirable to follow young people for longer in adult services to assess later outcomes of transitional healthcare, but this would be unlikely to be feasible. The fact that some young people were still in child services does not invalidate analyses; our study was about transition, not specifically healthcare transfer. Table 1 showed the number still in child services.

There was variability in precisely when the young people were seen by researchers due to their personal circumstances. This is one reason why we chose the ‘Final visit’ to be visit 4 or
visit 3 (if that young person did not have a visit 4). Some of the visit 3s were considerably delayed and too close to a fourth visit to justify further data collection within the duration of the study. We examined the association of exposure to a PBF over the previous year in relation to outcomes. However, what constitutes optimal exposure over three years when, for instance, exposure occurs in one year but not the others? We made a clinical judgement about this for each feature for the consolidated longitudinal analysis. The decisions were agreed amongst our group, but others might have made different judgements. Some PBFs, such as ‘written transition plan’, were infrequently provided and therefore we had less statistical power to detect associations with outcomes.

**Key findings**

- There were striking mismatches between the PBFs of transitional healthcare which a service said it provided and the features young people reported they had experienced.
- PBFs were both provided and experienced less often in services for those with CP and ASD than for those with type 1 diabetes.
- Average satisfaction with services was reasonable at baseline (rating of ideal service only slightly higher than rating of actual service). It remained steady for those with type 1 diabetes but worsened significantly over the study period for those with ASD or CP.
- The wellbeing scores for each group remained similar over time. For those with type 1 diabetes or CP their average subjective wellbeing at baseline was similar to that of the general population. Those with ASD and an associated mental health problem reported significantly lower wellbeing compared to the other two groups and this difference persisted over the course of the study.
- For participation in life activities, there were significant differences between the three conditions, with young people with type 1 diabetes being in more independent phases of transition than those with ASD or CP. All made progress over time but those with type 1 diabetes remained more independent.
- Condition-specific outcomes worsened over the course of the study for those with type 1 diabetes or CP. The proportion of young people with ASD with so-called ‘abnormal’ anxiety and depression scores remained the same from baseline to visit 4, with over a third having abnormal levels of anxiety.
Features of services for transitional healthcare associated with better outcomes were: ‘Appropriate parent involvement’, ‘Promotion of health self-efficacy’ and ‘Meeting the adult team before transfer’.

**Interrelation to other parts of the Programme**

We were guided by advice from the UP group (*WPs 1.1 and 1.2*) in determining the wording of some questionnaires, which PBFs to include, how to approach young people, and how to interpret the differences between what PBFs services said they provided and what young people experienced.

A sub-sample of the cohort in this WP were recruited to the qualitative longitudinal sample for *WP 2.2*.

*WP 2.3* constructed the Discrete Choice Experiment which was administered at visit 3.

This WP addressed the main hypothesis of the Programme. In drawing conclusions about the clinical significance and validity of the findings (*Conclusion section*), we were further influenced by discussions with UP (*WPs 1.1 and 1.2*); and we triangulated the findings with the results of the qualitative work in *WP 2.2* and the health economic analysis in *WP 2.3*.

The findings of this WP informed the content of the DAH toolkit in *WP 3.1b*.

The findings of this WP contributed directly to the Implications of the Programme, No. 6.
WP 2.2 Longitudinal study (qualitative)

Addressing Objective 2: to identify the features of transitional healthcare that are effective and efficient

Recent reviews have explored different aspects of transitional healthcare, focusing on the experiences of young people and parents. This work shows how transitional healthcare disrupts the lives of young people and their families. Lugasi’s shows how young people describe child services as ‘a familiar and comfortable environment, and reported feelings of trust toward their health care providers’. A young person’s feeling of certainty within child services and uncertainty about what to expect in adult services was confounded by direct or second-hand experiences of sub-optimal care from adult services. Transfer can be experienced as an ‘abrupt event’ by young people, through lack of knowledge and information about what to expect. Reviews of models and strategies of the delivery of transitional healthcare have offered ideas about how specific practices might minimise this disruption.

Aim
- To investigate how young people with long term conditions experience services for transitional healthcare

Methods

More information about methods is in Appendix 7 Report WP 2.2, which includes the interview guide.

A longitudinal multi-method qualitative study was conducted with young people recruited from the longitudinal quantitative study (WP 2.1). Young people were initially approached by member of WP 2.1 study team and, if they wanted more information, they were contacted by phone or email by WP 2.2 researchers previously unknown to them.

Data collection took place between June 2013 and June 2016. Recruitment was driven by criterion sampling (diagnosis, age, service) and theoretical sampling (experience of service, co-morbidities, social network). Young people were aged between 14 and 18 at the first interview. Each young person identified a ‘significant other’ person in their life and a health professional significant to their healthcare that they wished to include in this qualitative study, and to nominate one consultation that the researcher could observe. Thirteen young people took part in this study. Family members included ten mothers, three fathers/step-
fathers and one brother. Nineteen health professionals were also identified - seven paediatric consultants, five paediatric nurses/allied health professionals, three adult consultants and four adult nurses/allied health professionals. We interviewed thirteen of these, nine from child services and four from adult services.

Thirteen young people received a first interview, of which four were interviewed again at least eighteen months later. They were interviewed on their own or with a relative, if they wished, at their home or clinic. Fourteen family members received a first interview, of which eight were interviewed again at least eighteen months later. In total, we undertook 40 first interviews (see Table 5). For 30 of these, the young person was pre-transfer to adult services, for 12 they were post-transfer.

Table 5: Participants recruited by condition, identity and method of data collection

<table>
<thead>
<tr>
<th>Participants for first interview</th>
<th>Diabetes</th>
<th>Cerebral palsy</th>
<th>Autism spectrum disorder</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young person</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Family member</td>
<td>4</td>
<td>6</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Health professional</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>15</td>
<td>13</td>
<td>40</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants observed in consultations</th>
<th>Diabetes</th>
<th>Cerebral palsy</th>
<th>Autism spectrum disorder</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young person</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Family member</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Health professional</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>8</td>
<td>6</td>
<td>26</td>
</tr>
</tbody>
</table>

Observations were recorded in contemporaneous field notes. Formal interviews (face-to-face or telephone) lasting between 30-120 minutes were audio-recorded, transcribed, edited to ensure respondents’ anonymity and then analysed alongside anonymized field notes. All analysis was conducted according to the standard procedures of qualitative analysis. We used procedures from first-generation grounded theory (coding, constant comparison, memoing), and from analytic induction (deviant case analysis). Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones, including in follow-up interviews. We undertook independent coding and cross checking, team data sessions and data triangulation (different times and persons) and between-method triangulation (interview, observation).
Analysis
The full report is in Appendix 7 Report WP 2.2. The report focusses on the observational data and interviews with accompanying commentary and quotations in relation to the nine PBFs. The work is summarised below under three headings:

- Disrupting relationships of trust
- Supporting successful transfer
- Enabling in(ter)dependence

Disrupting relationships of trust: As one parent outlined, the actual process of transfer from children’s to adults’ services, ‘takes five minutes’. However, crossing this organisational boundary was reported to take practical, cognitive and emotional work, often over a long time.

The family, especially the mother, had usually developed good understanding of how to support the management of the young person’s health condition, and how to navigate the child health service. The child health professionals often had significant knowledge of the young person and their wider psychosocial context. In most cases young people had a long relationship with a particular service, and so built up trust over time with health professionals they saw regularly.

The organisational process of transfer ended those relationships of trust with known child health professionals and so called into question the expectations, knowledge and practices of the young people and their families. Transfer is a disruption, or following Garfinkel, a breach in taken-for-granted experiences, knowledge and expectations. It involves young people and parents having to adapt to a new set of circumstances.

Supporting successful transfer: All professionals were aware of the implications of ‘unsuccessful’ transition and how people could ‘drop off the system’ or ‘disengage’. All child health care professionals had implemented formal or informal plans for transfer that sought to prepare the young person and their family (see Table 6, in relation to evidence of implementation of PBFs). Child health professionals stated that they sought to introduce the idea of transition and transfer within consultations over time. Plans about transition were generally, ‘something we talked about, there wasn’t really anything written down’ and, ideally, ‘tailored to the young person’s needs’. Such plans might also be ‘weaved into clinic letters’.
Table 6: Factors that promote or inhibit implementation of the proposed beneficial features

<table>
<thead>
<tr>
<th>Proposed beneficial feature</th>
<th>Evidence of implementation</th>
<th>Determinants of implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-banded clinic</td>
<td>Limited: only seen in diabetes services.</td>
<td>Often not feasible due to logistics of managing appointments, space restrictions or low numbers of young people. In practice, situated alongside other adult clinics, with parents and professionals alarmed by visibility of ill adults. Young people report ‘not being fuzzed’.</td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>Variable: some services offer single joint meeting or shared appointments.</td>
<td>Dependent on relations with adult team(s). In services that provide it, meetings do not always happen. Problematic when low frequency of meetings, young person moved away (e.g. University), adult practitioner not person who will provide care, or general practitioner not known to young person (i.e. transfer to primary care).</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>Variable: some services provided but in an informal, ad hoc way.</td>
<td>Can occur in context of long term, trust-based, relationships with a specific health professional. Minimal health promotion if lack of continuity of personnel, low frequency of visits, or when not part of service culture.</td>
</tr>
<tr>
<td>Written transition plan</td>
<td>Very limited: one service offered formal plan.</td>
<td>One service had implemented, but withdrew due to lack of resources and motivation. Some professionals resisted written plans saying they get forgotten or lost; and personal interaction is far more important. However, informal practices can lead to lack of awareness, knowledge and understanding of transfer process.</td>
</tr>
<tr>
<td>Parents engaged appropriately</td>
<td>Extensive: all services report engaging parents.</td>
<td>Service norm for some practitioners. Some see interdependence as demonstrating problematic attachment, and so seek to minimise parental involvement, often referring to legal issues around patient confidentiality.</td>
</tr>
<tr>
<td>Key worker</td>
<td>Variable: services may report key worker, but young people and parents often unaware.</td>
<td>In practice, most young people and families name ‘their’ de facto key worker as someone they trust, see consistently, and are supportive and accessible. Often, a parent – usually mother – takes this role.</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>Variable: some services demonstrated some aspects.</td>
<td>Largely dependent on service structures. Collaboration and coordination between team members can occur formally and informally.</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>Very limited: some services provided elements albeit in an informal, ad hoc way.</td>
<td>Some services had not considered this, whilst others had but thought it not to be their responsibility. Education, social services, charities, and family often provided this – if not, young people, parents and services thought they should. All thought young people should be signposted to relevant services outside NHS.</td>
</tr>
<tr>
<td>Transition manager for clinical team</td>
<td>Very limited: one service reported recent introduction.</td>
<td>One service saw this as a need, but was still developing a remit for role. Many services would like to implement, but dependent on resources, and competing demands.</td>
</tr>
</tbody>
</table>

In general, these observations were made by parents, young people and professionals – full details in the report of this WP are in Appendix 7 Report WP 2.2.
Meeting members of the adult team before transfer was crucial for the young people and parents that experienced it; this was generally at a single face-to-face meeting. Such meetings, however fleeting, offered symbolic and practical benefits and initiated relationships. The meetings helped young people and their parents to manage potential anxiety and offered more certainty about the healthcare transfer process.

For young people and families, developing an adequate awareness of the transfer process itself and learning about the people and expectations of adult services was important. Some young people and family members said they had not received any support or information about the process. This was most marked when young people’s appointments were infrequent or where services were in flux. Faced with such uncertainty, some young people and families felt abandoned, and unsure about many aspects of the new service they were about to transfer to.

*Enabling in(ter)dependence:* At the heart of transition is the aim to shift responsibility for managing health and health services from parents to the young person. This WP highlighted that the support of family, especially mothers, was central to enabling such ‘independence’. Family members play a significant role and often contribute much effort to the negotiation of the multitude of transitions the young person experiences, especially the healthcare transition. Within the child health context, family members may act as ‘key worker’ in the clinic and home, providing the young person with some continuity of care, a point of reference and a source of emotional support. They can also act as advocates, offer practical support in managing healthcare needs, facilitate access to services, prompt or ask questions, research available evidence, gather information and check a young person’s understanding. For the most part, health professionals in paediatric and adult contexts are aware of the work of the young peoples’ families in supporting and enabling them. New routines, norms, and expectations evolve over time so that health professionals, families and young people in paediatric and adult contexts can experiment with new ways of being interdependent. Immediately leading up to and after transfer, young people may experience tensions; for example ‘legal’ independence is thrust upon them, but they still prefer interdependence. Some services or health professionals can compound such tension, especially in adult contexts, where parental involvement is considered to be an example of ‘over-attachment’ or ‘over-dependence’ and therefore seen as problematic and to be discouraged. Working with the ‘parent team’ can support a shift towards more ‘partnership’, ‘shared care’ or ‘consulting’ roles.
Strengths and limitations

Conducting serial and triangulated interviews enabled us to confirm stories and capture evolving perspectives. Observing consultations enabled us to compare what people do, against what they said they did in these contexts. Whilst both the form and content of healthcare that is received may differ between the three exemplar groups, the organisation and experiences of the transition and transfer process showed many more similarities than differences.

The findings have face validity as they relate well to the findings in other WPs and other studies in the literature, especially how transition and transfer can be disorientating for young people and their families.\textsuperscript{44, 50, 82} This study strongly echoes work on how young people build relations of trust with health professionals and services,\textsuperscript{44, 50} especially where those relations are consistent and supportive;\textsuperscript{58} as well as work on how the family, especially the mother, have built relations of trust with health professionals and services.\textsuperscript{82}

In its nature, qualitative work is in-depth but small-scale; a consequent strength being the richness of data and a weakness being the low number of case examples. We aimed to recruit fifteen families and achieved thirteen. We had difficulties in recruiting young people, with many seeing the breadth and depth of data-collection as an additional burden whilst already taking part in WP 2.1. Retention of young people for follow-up and/or post-transfer interviews was poor, so learning about the adult context was limited. We were unable to contact some young people and some of those we did contact declined follow-up interviews; they either withdrew, or suggested we speak to their parents or health professionals. Thus, our findings are valid in relation to the data we collected; however, it is possible we did not identify key messages that would have been relevant after transfer to adult services.

Key findings

- Transition and transfer are disorientating for young people and their families. They have practical, cognitive and emotional impacts. Importantly, they disrupt often hard-earned knowledge of how best to navigate the child healthcare system effectively.
- Health professionals need to help young people and their families adjust to and mitigate these disruptions. They key practices that minimise this disruption are: being clear in discussions and documents about processes; discussing how child and adult practices differ; undertaking joint clinics and meetings with members of the adult
team the young person will actually be seeing; and including family members in the process.

- Transition is about enabling young people to become responsible for their own healthcare. However, family members remain crucially important. Such involvement is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members can be helped to adjust their roles to have more partnership and sharing of care and consultation with their son or daughter.

**Interrelation to other parts of the Programme**

This WP 2.2 was informed by WP 1.1 in which the UP group commented on the draft interview schedule and the practicalities of the planned visits to young people and clinic consultations.

The sample for WP 2.2 was a subsample of that in WP 2.1 and so the two WPs worked closely together.

Our published article63 (URL in Appendix 6), on intended provision of PBFs and whether or not they are experienced by young people), integrated quantitative findings from WP 2.1 with qualitative findings from this WP 2.2. Our article directly influenced our decision to use the young person’s experience of each PBF as the exposure in our regression analyses, rather than what the service said it aimed to provide.

The findings of this WP influenced interpretation of the three PBFs associated with improved outcomes in the conclusions section. This discussion informed one of the seven key implications of the programme, No.6.
WP 2.3 Discrete Choice Experiment and Economic analysis

Addressing Objective 2: to identify the features of transitional healthcare that are effective and efficient

This WP examines the economic aspects of transition. It is made up of two parts:

2.3.1 Discrete Choice Experiment

2.3.2 Economic modelling

2.3.1 Discrete Choice Experiment (DCE)

DCEs are regularly used in health economics to elicit preferences for healthcare products and programmes, and in the valuation of preferences for health states. 89-91

See Appendix 8a, DCE Report for further detail.

Aim

- To quantify the strength of young people’s preferences for aspects of health services for transition using a DCE

Methods

A DCE describes a service in terms of a number of characteristics, or ‘attributes’ (e.g. the flexibility of appointments, parental involvement). The extent to which an individual values an intervention is expected to depend upon the ‘level’ these attributes take (e.g. can appointments be made outside office hours or not?). Thus, a DCE explores relative preferences about how services can be organised, by choosing between services with differing levels of their attributes. 92

The design and conduct of the DCE involved four steps:

Step 1: Identification of attributes and levels

Attributes and levels were informed by the Q-sort (WP 1.3). Other information was drawn from prior research about important features of transition. 93 The design and presentation of the DCE were undertaken with the members of the Transition Research Programme’s Collaborative Group and with UP. The chosen attributes and levels are shown in Table 7.
Table 7: Attributes and levels of the DCE

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Number of levels</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility</td>
<td>2</td>
<td>0 = Does not offer appointments outside of office hours</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Offers appointments outside of office hours</td>
</tr>
<tr>
<td>Staff at appointments</td>
<td>4</td>
<td>0 = Do not see the same staff at my appointments and do not have a key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Do not see the same staff at my appointments but have a key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 = See the same staff at my appointments but do not have a key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 = See the same staff at my appointments and have a key worker</td>
</tr>
<tr>
<td>Staff communication</td>
<td>2</td>
<td>0 = Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = No</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>2</td>
<td>0 = Discouraged</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Welcomed ‘if I want it’</td>
</tr>
<tr>
<td>Decisions about care</td>
<td>2</td>
<td>0 = Staff discuss my care with me but they make the decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Staff give me choices but expect me to make the decisions</td>
</tr>
<tr>
<td>Extra support</td>
<td>2</td>
<td>0 = No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Yes</td>
</tr>
</tbody>
</table>

Step 2: Experimental design
The number of attributes and levels described in Table 7 gives 128 possible combinations. Statistical manipulation, using N-gene software,94 reduced the number of scenarios. The resulting D-efficient design had 24 questions, which were further reduced by ‘blocking’ into three groups, so that each respondent needed only to complete eight questions. Young people also answered questions about their current care, defined by the same attributes and levels used in the DCE. In each question, respondents chose between two hypothetical ways a service might be organised (see Appendix 8a, DCE questionnaire for specimen questions).

Step 3: Data collection
The DCE was completed at visit 3 of the longitudinal study (WP 2.1). Several decision aids were piloted and then used to assist young people having difficulty completing the DCE (see Appendix 8a, DCE Report).

Step 4: Data analysis and interpretation
Data were analysed within a random utility model framework using logistic regression techniques. The analysis estimated the predicted uptake of the service; the more an attribute is preferred, then the higher the predicted uptake.
Analysis
247 participants completed at least one DCE question (fully completed by 223, partially completed by 24). 101 participants did not complete the DCE as they had withdrawn or were lost to follow-up. Young people with ASD were significantly less likely to respond than those with diabetes 16/87 versus 7/112 (chi-squared=10.50, DF=2, p≤0.001).

Appendix 8a, DCE Report presents detailed results. In summary, 43 respondents always chose current care and 60 never chose current care. Those not currently receiving any service were significantly less likely to choose current care (p<0.001). Each attribute and level was often preferred by many young people, as was current care. Table 8 shows that in a service where none of the attributes were present the uptake of the service would be 78%. Adding a new service attribute, such as flexible appointments, predicted an uptake of 81%.

Table 8: Predicted probabilities of uptake of services as attributes are added

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Probability of uptake</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Service (none of the attributes)</td>
<td>0.78</td>
<td>0.75</td>
<td>0.81</td>
</tr>
<tr>
<td>New service with flexible appointments</td>
<td>0.81</td>
<td>0.78</td>
<td>0.84</td>
</tr>
<tr>
<td>New service with a keyworker</td>
<td>0.79</td>
<td>0.74</td>
<td>0.85</td>
</tr>
<tr>
<td>New service seeing the same staff at each appointment</td>
<td>0.90</td>
<td>0.85</td>
<td>0.94</td>
</tr>
<tr>
<td>New service seeing the same staff and having a keyworker</td>
<td>0.88</td>
<td>0.84</td>
<td>0.92</td>
</tr>
<tr>
<td>New service with good staff communication</td>
<td>0.93</td>
<td>0.91</td>
<td>0.95</td>
</tr>
<tr>
<td>New service with parental involvement</td>
<td>0.93</td>
<td>0.90</td>
<td>0.95</td>
</tr>
<tr>
<td>New service offering young people decisions about treatment</td>
<td>0.91</td>
<td>0.88</td>
<td>0.93</td>
</tr>
<tr>
<td>New service offering extra support to young people for their future</td>
<td>0.86</td>
<td>0.83</td>
<td>0.89</td>
</tr>
</tbody>
</table>

When demographic characteristics (gender, age at data collection and condition) were taken account of, all attributes were preferred to them not being present, except for flexibility of appointments (Appendix 8a, DCE Report Table 23).

Preference for current care was stronger amongst young men than women. Preference for current care was also stronger for those who had not transferred from child to adult services compared to those who had. Young men had a stronger preference for out-of-hours clinics than young women did, and a weaker preference for making their own decisions about treatment. Young people with ASD had weaker preferences for parental involvement and for being the ones to make decisions about their treatment compared to those with CP.
**Strengths and limitations**

A DCE can be demanding to complete. Whilst most young people were able to respond, proportionately fewer with ASD did so. It is possible that these young people may have different preferences to those that did complete the DCE. Furthermore, it is possible that the DCE failed to accurately capture the preferences of those young people who did complete the DCE. For this latter issue some reassurance was provided by the broad similarities between the DCE findings and the ranking exercise. The advantage of the DCE over the ranking exercise was that the DCE provided an indication of the relative importance of each attribute. DCEs are widely accepted as a methodological approach preferred by many organisations. For example, they form the basis of eliciting EQ-5D-5L population tariffs throughout the world and Centre for Devices and Radiological Health, have stated that DCEs are a suitable method for eliciting patient preferences. The approach we adopted was consistent with best practice. The aids to completion of the DCE might have infringed strict DCE methodology but they enabled young people, with a wide range of confidence, intellectual ability and flexibility of thinking, to complete it. Indeed, the use of aids to completion has been advocated.

A fixed-effects modelling assumed respondents were consistent in their choices over time. Whilst such an approach was not incorrect, more sophisticated econometric modelling could be used to explore heterogeneity and whether participants considered only a subset of attributes when choosing among alternatives. This might help explain why an appreciable proportion of respondents always chose current care.

**Key findings**

- Young people with long term conditions, including those with ASD, could complete a DCE.
- In total, attributes were preferred to them not being present, except for flexibility of appointments.
- Preference for current care was strong and more pronounced amongst young men than women. This preference was stronger for those who had not transferred.
- Most young people (and especially women) least valued being able to have appointments outside of office hours.
- Young people valued services in which: information was passed to the right person; parental involvement was welcomed; staff offered choice and allowed young people to make decisions about their care; the same staff were seen at each clinic; extra
support was available for preparation for everyday life. Young people valued seeing the same staff at each clinic appointment more than having a keyworker.

Interrelation to other parts of the programme
From WP 1.1, the UP group contributed much to the design of the DCE questionnaire. DCEs have not been undertaken often with young people. The understanding of the choice options were therefore discussed and piloted with UP.

The content of the DCE was, in part, informed by the Q-sort study of WP 1.3.

The DCE was administered at visit 3 in the longitudinal study WP 2.1.

This WP 2.3.1 informed WP 2.3.2 on economic analysis.

The results of this WP led directly to one of the Implications of the Programme No. 7, concerning elements of service which would make it more likely that transition services were taken up by young people.

2.3.2 Economic analysis
We assessed the relative efficiency of illustrative models of transition. WP 2.1 captured information from health records on the proposed beneficial features (PBFs) received by young people, their use of health services (and hence cost); and their Health Related Quality of Life (HRQoL). We estimated relative cost-effectiveness and presented the economic data and other study findings in a balance sheet.

The full account of the methods and analysis are in Appendix 8b, Report 2.3.2 Economic analysis.

Aims
- To determine the resource use and costs of the proposed beneficial features
- To assess the relative efficiency of illustrative models of transition

Methods
Using the same decision rule as in WP 2.1, a trajectory for each PBF, deemed satisfactory or unsatisfactory, was assigned to each participant based on the data captured from the health notes.
Costs to the NHS covered the costs of consultations, medication, investigations. Data needed for costing were obtained by the research assistants from the health records, with additional information on service use gathered at each annual visit after the baseline visit. To aid recall, young people had kept diaries of contacts with health and personal social services. A unit cost was then applied to each service accessed using routine sources.\textsuperscript{100, 101} Average pre- and post-transfer costs were then calculated.

Costs were then analysed to estimate the annual cost for a service where there was a PBF and for a service where there was no PBF. These costs were further split according to whether the young person was pre or post-transfer; and if post-transfer whether to primary or secondary care?

Young people completed the EQ-5D-Y at each of the four annual visits. This instrument captures HRQoL for use in economic analyses.\textsuperscript{102} Data from the EQ-5D-Y were converted to utility scores using the value set for adults.\textsuperscript{103} Utility scores range from 0-1, with one indicating best health. A simple scoring system was adopted for the EQ-5D-Y. Each of its five domains was assigned equal weight, and each level of each domain was scored 1, 2, or 3 depending on severity. Thus, each domain scored from 1-3, with three being the worst health. Summing the scores for each domain generated a ‘sumscore’ which ranged from 5-15, with fifteen being worst health. A similar approach to analysing these data was adopted for cost. The data on costs and HRQoL were incorporated into a simple Markov model (Figure 9) in which all young people start in child services, aged 14 years, and are followed for 10 years, the time over which a young person would be expected to be undergoing transition. The model considers a hypothetical cohort of 1,000 young people. Each year they have a probability of transferring from child services to primary care or moving into adult services. If in any year they do not make the transfer then they remain in child services indicated by the ellipse connected to the Child Services state. The chance of being in a given state in a given year (the ‘rate of transfer’ -see Appendix 8b, Report WP 2.3.2 economic analysis) was calculated by considering the number of people who transferred from child services each year, and the ratio of young people transferred to adult services compared to those transferred to primary care.
Figure 9: Structure of the economics model

Those remaining in a given year in the child services state are represented by the ellipse connected to the Child Services state.

For each state in Figure 9, an annual cost, utility and sumscore value was assigned as described above. Cumulative costs, quality adjusted life years (QALYs) and sumscores were estimated for the 10-year time horizon and all costs and effects were discounted at the UK recommended rate of 3.5% per annum.

The results of the model and the DCE were combined with findings from other areas of the Research Programme in a balance sheet analysis. In this analysis we present those outcomes that could favour a hypothetical intervention compared to a situation where there was no support during the transition from child to adult services.

**Analysis**

**Estimation of use of health services and costs**

There were 7,755 healthcare contacts over the study period. A further 627 scheduled contacts were cancelled in advance or without enough prior notification (classified as ‘did-not-attend’). The number of participants providing data was 286 (76.2%) at visit 2, 249 (66.4%) at visit 3, and 216 (57.6%) at visit 4.

The median number of healthcare contacts across all years was 19 (IQR: 20). This varied by condition, ranging from 14 (IQR: 27.8) for those with CP, to 16 (IQR: 23) for those with ASD and to 23 (IQR: 13.8) for those with diabetes. Over time, the median number of visits decreased. Visits for those with CP dropped from 7 to 5, for diabetes from 8 to 7, and for ASD increased from 5 to 6. Full details are in Appendix 8b.
Combining data on use of services with unit cost data allowed estimation of cost of care for each young person. Data were available on 301 young people (78.6%). The overall median cost per participant was £4,954 (IQR: £6,103). Diabetes was the costliest condition, and CP the least costly, with considerable variation between individuals. The difference between the cost for those with diabetes and those with ASD was statistically significant (p<0.001). The difference in pre and post transfer costs was not statistically significant (p<0.05), although there was a trend both overall and by each condition (Table 9).

Table 9: Estimated median costs by condition, both overall and pre and post transfer

<table>
<thead>
<tr>
<th></th>
<th>All (IQR)</th>
<th>ASD (IQR)</th>
<th>Cerebral palsy (IQR)</th>
<th>Diabetes (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>301</td>
<td>96</td>
<td>77</td>
<td>125</td>
</tr>
<tr>
<td>Median total costs</td>
<td>£4954 (£6103)</td>
<td>£2351 (£4211)</td>
<td>£2394 (£5606)</td>
<td>£7003 (£3667)</td>
</tr>
<tr>
<td>Median total costs per annum</td>
<td>£2307 (£2705)</td>
<td>£1659 (£2573)</td>
<td>£1447 (£2725)</td>
<td>£2915 (£2422)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>All (IQR)</th>
<th>ASD (IQR)</th>
<th>Cerebral palsy (IQR)</th>
<th>Diabetes (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>279</td>
<td>88</td>
<td>67</td>
<td>121</td>
</tr>
<tr>
<td>Median pre-transfer costs</td>
<td>£2420 (£4506)</td>
<td>£1694 (£2454)</td>
<td>£1370 (£4215)</td>
<td>£4434 (£5136)</td>
</tr>
<tr>
<td>Median pre-transfer costs per annum</td>
<td>£1673 (£2242)</td>
<td>£915 (£1277)</td>
<td>£949 (£1974)</td>
<td>£2410 (£1587)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>All (IQR)</th>
<th>ASD (IQR)</th>
<th>Cerebral palsy (IQR)</th>
<th>Diabetes (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>194</td>
<td>56</td>
<td>48</td>
<td>87</td>
</tr>
<tr>
<td>Median post-transfer costs</td>
<td>£2080 (£3470)</td>
<td>£1262 (£2540)</td>
<td>£1395 (£3015)</td>
<td>£3114 (£3440)</td>
</tr>
<tr>
<td>Median post-transfer costs per annum</td>
<td>£1371 (£1862)</td>
<td>£645 (£1883)</td>
<td>£707 (£1673)</td>
<td>£1849 (£1193)</td>
</tr>
</tbody>
</table>

IQR Inter quartile range  ASD Autism Spectrum Disorder

Estimation of HRQoL

Data were available from the EQ-5D-Y for 373 respondents at baseline, and 244 by visit 4. The median sumscore score was 5 for every domain at every time point; (i.e. half the respondents reported ‘no problems’). The mean sumscores increased over time (i.e. health worsened), as did the scores for each domain. Over the follow-up period the proportion of individuals experiencing problems on each domain (a score of 2 or 3) increased significantly (p<0.001) for each of the five domains (See Appendix 8b for further details).

The median sumscore for all participants across all time points was 6 (IQR: 2.79), which indicates at least half of participants experienced a problem on at least one domain. Average sumscores were not associated with gender, nor were pre or post-transfer scores. In addition,
there were significant differences in sumscores by condition, as diabetes participants had significantly lower scores (i.e. better health) (p<0.001) at all time points (Table 10). The median utility score across all participants was 0.83 (IQR: 0.30). Average utility scores were not associated with gender, pre or post-transfer scores. However, the scores of those who had transferred were significantly higher for those transferring to adult services (median 0.86, IQR: 0.37) compared to primary care (median 0.78, IQR: 0.38). As we found for the sumscore, participants with diabetes had significantly higher sumscores (p<0.001) at all time points (Table 11).

Table 10: Summary sumscore and utility score by condition, pre- and post-transfer

<table>
<thead>
<tr>
<th></th>
<th>All (IQR)</th>
<th>ASD (IQR)</th>
<th>Cerebral palsy (IQR)</th>
<th>Diabetes (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>301</td>
<td>96</td>
<td>83</td>
<td>122</td>
</tr>
<tr>
<td>Median sumscore</td>
<td>6 (2.79)</td>
<td>7 (2)</td>
<td>7 (2.98)</td>
<td>5.20 (1)</td>
</tr>
<tr>
<td>Median utility score</td>
<td>0.83 (0.30)</td>
<td>0.75 (0.26)</td>
<td>0.70 (0.43)</td>
<td>0.94 (0.14)</td>
</tr>
<tr>
<td>Number</td>
<td>269</td>
<td>86</td>
<td>70</td>
<td>113</td>
</tr>
<tr>
<td>Median pre-transfer sumscore</td>
<td>6 (2)</td>
<td>7 (2)</td>
<td>7 (3)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Median pre-transfer utility score</td>
<td>0.85 (0.27)</td>
<td>0.75 (0.26)</td>
<td>0.72 (0.43)</td>
<td>0.95 (0.13)</td>
</tr>
<tr>
<td>Number</td>
<td>230</td>
<td>68</td>
<td>66</td>
<td>96</td>
</tr>
<tr>
<td>Median post-transfer sumscore</td>
<td>6 (3)</td>
<td>7 (2)</td>
<td>7 (2.75)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Median post-transfer utility score</td>
<td>0.82 (0.29)</td>
<td>0.76 (0.24)</td>
<td>0.70 (0.33)</td>
<td>0.95 (0.16)</td>
</tr>
</tbody>
</table>

IQR = Interquartile range; ASD = Autism spectrum disorder

**Experience of proposed beneficial features (PBF)**

Data on experience of the PBFs are reported in Table 34 in Appendix 8b Report Economics analysis. These and the economic evaluation used two methods to determine whether a PBF had been experienced.

A form was completed each year by the research associate from data in the young person’s health records. It consisted of details of clinic visits, professionals in attendance, medical tests undertaken and whether PBFs had been experienced. This was called the ‘Final Account of Consultation’. Following the home visits with further discussion of appointments and PBFs and completion with the young person of a questionnaire, it became clear that the Final
Account was incomplete for some young people. Therefore analysis was also undertaken with data combined from both sources.

**Economic evaluation model**

The parameter values used in the economic model are reported in detail in *Appendix 8b*. The analysis considered each PBF separately and, given the limited data available, should be considered exploratory. Given the exploratory nature, probabilistic sensitivity analysis was not conducted as there was considerable imprecision in results. The results are best considered as either illustrative of the approach taken or as hypothesis generating about possible PBFs to consider when developing an intervention to improve transition.

*Appendix 8b* reports estimated costs and effects (sumscore and QALY). Table 11 shows the incremental cost-effectiveness for a service incorporating each PBF alone compared to a service where no features were present. We could not compare individual PBFs with a situation where all PBFs were provided, as only one participant experienced all PBFs. As the presence of PBFs is based on face-to-face discussions and health records, a sensitivity analysis was performed using both data sources.

Table 11: Incremental cost per quality adjusted life year gained

<table>
<thead>
<tr>
<th></th>
<th>ICER* using PBFs captured from final account</th>
<th>ICER* using PBFs captured from both sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet adult team before transfer</td>
<td>Dominated**</td>
<td>7121</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>36487</td>
<td>13176</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>10991</td>
<td>5618</td>
</tr>
<tr>
<td>Key worker</td>
<td>15259</td>
<td>4811</td>
</tr>
<tr>
<td>Transition manager for clinical team</td>
<td>64359</td>
<td>12592</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>7070</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>5127</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>52100</td>
<td>8596</td>
</tr>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>11259</td>
</tr>
</tbody>
</table>

**Cost per 1 unit change in sumscore**

<table>
<thead>
<tr>
<th></th>
<th>ICER* using PBFs captured from final account</th>
<th>ICER* using PBFs captured from both sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet adult team before transfer</td>
<td>15092</td>
<td>7011</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>22693</td>
<td>12662</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>5692</td>
<td>4563</td>
</tr>
<tr>
<td>Key worker</td>
<td>13363</td>
<td>3878</td>
</tr>
<tr>
<td>Transition manager for clinical team</td>
<td>23364</td>
<td>7114</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>5345</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>5341</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>12746</td>
<td>7700</td>
</tr>
</tbody>
</table>
**Transition plan**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>8947</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>8947</td>
</tr>
</tbody>
</table>

*ICER Incremental cost-effectiveness ratio

**PBF on average more costly and less effective. Therefore it is dominated by a service without that PBF.

**Experience of PBFs**

The data reported in Table 34 of Appendix 8b Report WP 2.3.2 and in Table 11 above illustrate that the results are sensitive to the methods used to decide whether a PBF was experienced. The higher the incremental cost-effectiveness ratio (ICER), the less likely an intervention would be considered value for money.

Several PBFs performed better regardless of whether the determination of 'satisfactory' PBF exposure was based on final account or the data from both sources. These PBFs were: ‘Provision of holistic care’, ‘Having a key worker’, and ‘Promotion of health self-efficacy’.

‘Meeting the adult team’ was sensitive to the source of data and was considerably more advantageous when the estimates were based on the data from both sources. ‘Having a written transition plan’ and ‘Having a transition manager for clinical team’ performed relatively poorly.

**Balance sheet**

Using data from the economic analyses and elsewhere in the Programme, a balance sheet was developed to summarise the pros and cons of providing a service with a PBF compared to a service without PBFs (Table 12). The development and implementation of a service containing one or more PBFs would incur a cost, with a magnitude determined by how that PBF was delivered.

The limited data available from the economic model suggest that implementation of a new service will increase the use of NHS services at least over a 10-year time horizon for a young person aged 14 entering a ‘transition’ service. There appear to be no harms to the young person from any of the PBFs.
<table>
<thead>
<tr>
<th>Table 12 Balance sheet</th>
<th>Favours service containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.</th>
<th>Favours service not containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Favours service containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.</strong></td>
<td>Avoided the currently unknown costs of providing beneficial features. Costs of some may be modest e.g. a ‘written transition plan’ whilst others are substantial e.g. adoption of a multi-disciplinary team.</td>
<td>Costs not estimated</td>
<td><strong>Q-sort (WP 1.3) and DCE (WP 2.3.1)</strong></td>
</tr>
<tr>
<td><strong>A service should be flexible enough to meet the need of individuals – one size does not fit all and needs may change over time. Service needs to consider the condition, the stage of development, and the young person’s personality.</strong></td>
<td></td>
<td></td>
<td><strong>DCE (WP 2.3.1)</strong></td>
</tr>
<tr>
<td><strong>Predicted uptake of a service higher when the service included parent involvement; a service where the same staff are seen at each clinic appointment; where the young receive good communication and are offered the opportunity to make decisions.</strong></td>
<td>From the DCE a strong preference for current care; no strong preference for a ‘key worker’ or flexibility of appointments</td>
<td></td>
<td><strong>DCE (WP 2.3.1)</strong></td>
</tr>
<tr>
<td>- Increasing engagement may help prevent deterioration in the young person’s condition over time</td>
<td></td>
<td></td>
<td>Anticipated impact not measured in study</td>
</tr>
<tr>
<td>‘Appropriate parent involvement’, ‘Promotion of health self-efficacy’, ‘Meeting the adult team’ improved outcomes.</td>
<td>Estimated additional cost to health services of adopting any of the proposed beneficial features</td>
<td>Estimated additional benefit to health service of adopting any of the above features, except care by a co-ordinated team</td>
<td><strong>Analysis of longitudinal data (WP 2.1)</strong></td>
</tr>
<tr>
<td><strong>Estimated additional benefit to health service of adopting any of the above features, except care by a co-ordinated team</strong></td>
<td></td>
<td></td>
<td><strong>Economic model analysis (WP 2.3.2)</strong></td>
</tr>
<tr>
<td><strong>Longer term model cautiously suggests ‘holistic life-skills training’; ‘having a key worker’, and ‘promotion of health self-efficacy’ might be value for money.</strong></td>
<td>Longer term model cautiously suggests that a ‘transition manager for clinical team’, ‘age-banded clinic’ or ‘meeting the adult team before transfer’ might not be value for money’.</td>
<td></td>
<td><strong>Economic model analysis (WP 2.3.2)</strong></td>
</tr>
<tr>
<td><strong>No evidence of a difference</strong></td>
<td>Lack of clarity over what was meant by a health passport, which might be valued but rarely used</td>
<td>Works conducted by UP (WP 1.2)</td>
<td>Analysis of longitudinal data (WP 2.1)</td>
</tr>
<tr>
<td>During transition, no evidence of any effect on outcomes of ‘having a transition plan’, ‘attending an age-banded clinic’, ‘being cared for by a coordinated team’; ‘being part of a service with a transition manager for clinical team’; ‘having access to holistic life-skills training’</td>
<td></td>
<td></td>
<td>Analysis of longitudinal data (WP 2.1)</td>
</tr>
<tr>
<td>Over the duration of the longitudinal study, no evidence of any effect on costs or health related quality of life of ‘having a transition plan’, ‘attending an age-banded clinic’, ‘being cared for by a coordinated team’; ‘being part of a service with a transition manager for clinical team’; ‘having access to holistic life-skills training’.</td>
<td></td>
<td></td>
<td>Analysis of costs and EQ-5D data in the economic analysis (WP 2.3.2)</td>
</tr>
</tbody>
</table>
Strengths and limitations

A concern was whether the HRQoL instrument was sufficiently sensitive to capture an influence of PBFs. The study was not powered on the EQ-5D-Y but rather on the outcomes used in WP 2.1. We did have sufficient power to identify clinically significant changes in the EQ-5D-Y but, for analysis by condition, sample size meant that some real effects of difference may not have been detectable. In relation to the PBFs, power was limited if a feature was often absent.

Alternatively, the HRQoL instrument might have been sufficiently sensitive but follow-up time was too short to capture any influence of PBFs.

The DCE suggested that experiencing some of the PBFs might increase young people’s engagement with health services, which in turn might alleviate longer term harms (and costs) due to inadequate healthcare. The economic evaluation was exploratory and only compared services with individual PBFs to a service with no PBFs. Therefore, no probabilistic sensitivity analysis was conducted as is normally recommended for health technology assessment economic evaluations; a quantified estimate of the effect associated with various combinations of PBFs was not possible. Therefore the economic conclusions should be interpreted with care.

It was necessary to annuitise the cost data for participants to compare with the EQ-5D-Y data. Thus, certain costs for participants for items mentioned occasionally but likely to apply over the course of the study were calculated as a daily rate following aggregation of the visit data. For example, as insulin prescriptions were not consistently reported in the data, these were costed separately according to existing literature and then inflated to the current price year. We think this made best use of the available data and is unlikely to have distorted the results.

The data collected on outcomes, costs and health service use were complex to interpret because there was loss to follow up, differing healthcare transfer arrangements and the intervals between the annual visits by the research assistants were not always exactly one year. Strict econometric modelling, despite considerable efforts, proved intractable to undertake. Therefore, a less robust exploratory analysis was adopted which drew out key implications and generated a balance sheet. Conclusions were not wholly in concordance with some conclusions from other parts of the Programme, but triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

Key findings

- There were significant differences in both costs and HRQoL between conditions.
• The average utility and sumscores were similar in those pre- and post-transfer.
• The median annual cost (covering the costs of consultations, medication, investigations) for an individual with diabetes was £7,003, with CP was £2,934 and with ASD was £2,350.
• Both costs and HRQoL declined over time for all conditions.
• A service involving a PBF is unlikely to reduce NHS costs over a 10-year time horizon but might increase them.
• We have examined the potential consequences of a service with flexible appointments and which encourages ‘appropriate parental involvement’, ‘promoting health self-efficacy’. A judgement is needed whether such a service would be worth the extra cost given that it may increase engagement with health services and prevent deterioration in health in the long term.

**Interrelation to other parts of the Programme**

Data collected during *WP 2.1* (the quantitative longitudinal study) about costs of consultations and exposure to PBFs were essential for the economics analysis.

The results from the DCE (*WP 2.3a*) contributed to interpretation of the economic analysis.

The results of this WP led directly to one of the Implications of the Programme No. 7, concerning value for money.
WP 3.1 Introduction of Developmentally Appropriate Healthcare

Addressing Objective 3: to determine how transitional healthcare should be organised, provided and commissioned

This WP examined how Developmentally Appropriate Healthcare can be introduced across NHS Trusts. It consisted of two parts:

WP 3.1.1 Identification and description of factors that enable or inhibit the introduction of Trust-wide Developmentally Appropriate Healthcare.

WP 3.1.2 Development of a toolkit for the introduction of Developmentally Appropriate Healthcare

From our work, there are two published papers\textsuperscript{3,4} with URLs in Appendix 9. Also in Appendix 9 is Report WP 3.1 on implementation of DAH.

WP 3.1.1

There is a need to provide healthcare which meets the needs of young people. Youth-friendly health services\textsuperscript{104,105} is one concept discussed in the literature. However, we need to move from the ad hoc provision of youth-friendly services to youth-responsive health systems\textsuperscript{106} which respond to young people’s changing developmental needs.\textsuperscript{25} ‘Developmentally Appropriate Healthcare’ (DAH) recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, DAH focuses on the approach of healthcare professionals to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.’ DAH offers a foundation for good practice in the healthcare of young people and so should underpin transitional healthcare.

Aim

- To identify, describe and understand the factors that enable or inhibit the introduction of Developmentally Appropriate Healthcare across NHS Trusts

Methods

We convened a one-day seminar in Birmingham on DAH. This brought together twenty-nine delegates with expertise and experience from health services research, public health, social policy, clinical practice and the voluntary sector.
A scoping review, using recognised methods,\textsuperscript{107} was conducted to explore the use and meanings attributed to the concept of DAH. Articles were subjected to manifest and latent content analysis.\textsuperscript{108}

More detail about methods is in Appendix 9, Report WP 3.1, which also includes the interview guide.

A qualitative, multi-site, ethnographic study was then conducted across three hospitals in England: a district general hospital, a paediatric tertiary hospital and an adult tertiary hospital. Health professionals were recruited through six medical and surgical specialties (Diabetes, Emergency Care, General Paediatrics, Outpatients, Rheumatology, and Trauma and Orthopaedics) chosen to represent the heterogeneous services found in NHS hospitals. In addition, chaplaincy, psychology, radiology, and youth-work and those leading training sessions were engaged to explore a broader range of staff and contexts young people are engaged with. Managers were recruited at each site if their roles were relevant to the provision of services for young people in paediatrics and/or adult care.

Data collection took place over three phases between June 2013 and January 2015. Recruitment was initially through gatekeepers, then a mixture of snowball, criterion and theoretical sampling. 192 participants were recruited. Approximately 1,600 hours of non-participant observations were conducted, alongside 65 formal qualitative interviews (Table 13). Observations of interactions between staff, young people and family members and between staff (in departments, wards, clinics, team meetings, training workshops) were recorded in contemporaneous field notes. Interviews were audio-recorded, transcribed, edited to ensure anonymity and then analysed alongside field notes.

Table 13: Participants recruited by site, type of staff and method of data collection

<table>
<thead>
<tr>
<th>Participants observed</th>
<th>District general hospital</th>
<th>Paediatric tertiary hospital</th>
<th>Adult tertiary hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professional</td>
<td>65</td>
<td>27</td>
<td>11</td>
<td>103</td>
</tr>
<tr>
<td>Manager</td>
<td>57</td>
<td>0</td>
<td>15</td>
<td>72</td>
</tr>
<tr>
<td>Total</td>
<td>122</td>
<td>27</td>
<td>26</td>
<td>175</td>
</tr>
<tr>
<td>Participants interviewed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health professional</td>
<td>13</td>
<td>18</td>
<td>10</td>
<td>41</td>
</tr>
<tr>
<td>Manager</td>
<td>13</td>
<td>6</td>
<td>5</td>
<td>24</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>24</td>
<td>15</td>
<td>65</td>
</tr>
<tr>
<td>Overall participants</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health professional</td>
<td>78</td>
<td>45</td>
<td>21</td>
<td>144</td>
</tr>
<tr>
<td>Manager</td>
<td>70</td>
<td>6</td>
<td>20</td>
<td>96</td>
</tr>
<tr>
<td>Total</td>
<td>148</td>
<td>51</td>
<td>41</td>
<td>240</td>
</tr>
</tbody>
</table>

Participants who were both 39 5 4 48
<table>
<thead>
<tr>
<th>interviewed and observed</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of participants</td>
<td>109</td>
<td>46</td>
<td>37</td>
<td>192</td>
</tr>
</tbody>
</table>

Analysis used qualitative methods\(^{85}\) from first-generation grounded theory (coding, constant comparison, memoing\(^{86}\)); and procedures from analytic induction (deviant case analysis\(^{87}\)). Because data collection and analysis occurred concurrently, issues raised in earlier phases of fieldwork could be explored in subsequent ones. We undertook independent coding and cross checking, team data sessions and member validation with some of the participants in the fieldwork. The analysis was informed by Normalization Process Theory.\(^{109}\)

**Analysis**

Our scoping review,\(^3\) with URL in *Appendix 9*, found that there was no agreed definition of DAH. DAH was linked to domains of adolescent medicine, young people, chronic conditions and transitional healthcare but there was much diversity in conceptualisation, terminology and age ranges.

The following summary is described in more detail in *Appendix 9 Report WP 3.1* on implementation of DAH. This cites many quotations from the interviews and observations and has accompanying commentary.

The core of DAH was that the young person’s developmental stage should be the starting point for appropriate provision of services. We also found a wide variety of understandings of DAH across clinical and managerial staff in all the sites (see Farre, 2016 #2497) with URL in *Appendix 9*). Some did not recognise it as a concept, for some it made little sense and for others it was difficult to conceptualise, it is ‘a bit amorphous’. Many focused on the need to create a more age-appropriate, youth-friendly environment\(^{106}\) in the physical spaces of waiting room and wards (e.g. age appropriate leaflets and computer games). Others, especially those who worked with young people, were more likely to mention interpersonal aspects such as developmentally appropriate communication, norms around confidentiality and a holistic focus. Using the concepts of Normalisation Process Theory (NPT), we identified little coherence across sites and staff, use of a variety of definitions (‘differentiation’) lack of shared understanding of purpose of DAH (‘communal specification’) and diverse understanding of potential impact of DAH on their work (‘individual specification’).

There were also different views on the worth of DAH (‘internalization’) across sites and staff (see *Appendix 9 Report: Introduction of Developmentally Appropriate Healthcare*). The
numbers of young people accessing health services were often perceived to be small, so in organisational terms they may be ‘just below the radar’. Compared to the elderly, they were considered to be ‘rarely unwell’. This may be compounded by the intermediate status of young people within the UK healthcare system: ‘adult services don’t really want them because they are too young and the child services don’t really want them because they are too old’. None of the sites had a senior clinical or management lead for young people. Whilst young people’s champions were considered to be important, there were dangers in relying too much on key individuals. It should be ‘about consistency of approach, not a person’. So, in NPT terms, there were key people driving DAH forward (‘initiation’) but these where rarely senior members of staff. At times, we observed that when a young people’s champion left a specific team there was then a reduction in team members becoming involved and staying committed (cognitive participation) to the implementation of DAH.

Across the three sites, local networks tailored services to the needs of young people. However, in all the sites, DAH was unevenly distributed. Some thought no ‘special arrangements’ were required and that by implication DAH was not a legitimate part of their work (legitimation). Informal networks of trust existed at each site, where certain people or teams were understood to have the right skill-mix, or mind-set, or access to resources, to work effectively with young people. In this way, specific groups of people or teams were willing to work with others to enable DAH (enrolment), motivated to deliver DAH over time (activation), had the relevant mix of skills (skill set workability) and were able to deliver DAH (relational integration). Young people tended to be directed to such teams. Thus, some of the inequities in skills and experience across the organisations were self-sustaining.

In all sites, service development for young people rested with the informal, organisation-wide group of young people’s champions. Such groups promoted initiatives to raise awareness across the organisation, create change, offer support and learn from each other.

In two of the sites, training took place at an annual study day. At another site, we observed training about DAH being planned and delivered by a group of managers, clinicians and allied healthcare professionals who met every few months. At this site, dissemination reached well beyond the special interest group; it was clearly supported by the organisation (‘contextual integration’). The training was linked to the development of a DAH strategy and consisted of ‘delivering key messages’ from various government policy initiatives such as the
‘You’re Welcome Criteria’. This strategy was supported with resources from senior management. The focus of the strategy and training was on:

- Organisational-level factors such as provision of age-banded clinics and staff appraisal, which included training goals around young people.
- Clinic and consultation-level factors such as signposting to sexual health, drug and alcohol services, and copying clinic letters to young people.
- Training and awareness factors such as adolescent development and confidentiality

**Strengths and limitations**

As detailed in-depth work was required, it was realistic to work in a small number of sites - three sites in two UK regions were studied. A limitation was that only three sites in two UK regions were studied. A significant number of staff participated and a wide range of settings were encompassed including outpatient, inpatient and emergency care. Although the hospitals had a history of championing research and innovative service provision for young people, this did not include a defined service for adolescent medicine. Also the clinical specialties at each site were at different stages of understanding of DAH, thus providing the study with ranges of experience. We think, therefore, that we captured a broad range of relevant views but it is likely that not all were covered.

**Key findings**

- Although there were different understandings of DAH in the literature and across clinical and managerial staff, common themes led us to propose a working definition: ‘Developmentally Appropriate Healthcare recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms Developmentally Appropriate Healthcare focuses on the approach of healthcare professionals to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.’
- DAH is needed equally in adult and child services
- The organisational barriers to introducing DAH were:
  - No single group was responsible for young people
  - There was perceived (incorrectly) to be a small number of young people attending hospital; and also a perception that young people were rarely unwell
  - The mind-set and skill-set of many staff were not ready
Good practice led by enthusiasts was not sustainable

- The organisational solutions to introducing DAH were:
  - To move beyond pockets of good practice to buy-in and formal support at NHS Trust Board Level; and from senior managers in both child and adult services.
  - Ensure planning engages from the outset adult and child services
  - Ensure a Trust-wide strategy and training about DAH.

**Interrelation to other parts of the programme**

The preliminary findings of this WP together with the video created by UP were presented at an external seminar held in Birmingham for invited delegates.

The immediate effect of this WP was to influence the content of the toolkit for implementation of DAH (*WP 3.1.2*). The findings shaped the format of the toolkit in terms of:

- The emphasis on different domains – e.g. consultation, team and organisation
- The content – explicit description of DAH, references to resources used by people at sites, including training
- The examples of good practice

Developmentally Appropriate Healthcare was an important topic in the discussions we had with commissioners (*WP 3.3*) and one of the key implications, No 2, of our research is that the introduction of DAH across an NHS organisation be considered by commissioners and NHS provider organisations.

**WP 3.1.2**

**Aim**

- The development of a toolkit for the introduction of Developmentally Appropriate Healthcare

**Methods**

We consulted with the Association of Young Person’s Health (AYPH) as it had experience in developing similar resources. We supplied AYPH with the content and websites to which the content could be linked. After three revisions the toolkit was piloted by requesting comments from ten senior NHS managers, adult and paediatric healthcare professionals, the research associates who undertook the ethnographic work and the Royal College of General
Practitioners. The toolkit was revised again and then launched at the Dissemination conference of the Research Programme in October 2017. The toolkit is downloadable from the website of the sponsoring Trust, Northumbria Healthcare, which also holds the copyright. Every three months we will ensure that the websites linked to the toolkit remain active; and every twelve months revise content if necessary. The URL for the toolkit is in Appendix 9 and is http://research.ncl.ac.uk/transition/
WP 3.2 Commissioning: Interviews and case studies

Addressing Objective 3: to determine how transitional healthcare should be organised, provided and commissioned

‘Commissioning’ is the process by which public services are organised and contracted to meet population needs. Healthcare commissioners follow a cyclical process of: assessment of population needs, setting priorities, developing strategies in line with objective outcomes, procuring services and measuring outcomes.\(^\text{10}\) The need for better commissioning for transition was highlighted in the Kennedy Report\(^\text{12}\) in recommendation 32 which stated: ‘Ensuring a smooth transfer between children’s and adults’ services should be a priority for local commissioners’. NHS England’s Research and Development Strategy 2013-2018\(^\text{111}\) has as its first Objective ‘To identify and prioritise commissioning health services research topics and co-ordinate this work with the Department of Health, NIHR,…’.

From this work, we have published two papers\(^\text{112, 113}\) with their URLs in Appendix 10. There is also a Report WP 3.2 in Appendix 10.

Aims

- To identify the structures, processes and relationships between commissioning entities in the NHS and other agencies relevant to transitional healthcare
- To identify the facilitators of and barriers to commissioning for services for transitional healthcare
- To identify how services for transitional healthcare could be better commissioned

Methods

This work was overseen by an invited Steering Group which met on four occasions.

The work was undertaken sequentially in six stages:

Stage 1. Literature review. A systematic review was undertaken to identify published peer-reviewed evidence about commissioning for Transition.

Stage 2. Qualitative interviews with stakeholders. Twenty-nine interviews were conducted by telephone (n=3) or in person (n=26) with individuals from Clinical Commissioning Groups (CCGs), Health and Wellbeing Boards, Local Authorities, General Practitioners, and the third sector. The interviews were conducted mainly with people in Northeast England. A second site in the Midlands was selected because the local Health and Well Being Board had
transition as a priority, and there was a Commissioning Support Unit. Further details of the methods are in Appendix 10 Report WP 3.2, which includes the interview schedule, and in our published paper with its URL in Appendix 10.

Stage 3. Case studies. Using the findings of the literature review and the interviews, criteria were developed for seeking sites at which transition was being formally addressed. Three sites, covered by three CCGs, were visited in the northwest, southwest and West Midlands of England. Across the three sites, eleven semi-structured interviews were conducted. The details of the methods are in Appendix 10 Report WP 3.2.

Stage 4. Seminar in London on Commissioning for Transition. This brought together additional expertise and experience from public health, social policy, commissioning and research into commissioning. Thirty invited delegates attended.

Stage 5. Interviews with adult commissioners. We realised that we had talked with few adult commissioners. Therefore, we arranged face-to-face interviews (n=5) with commissioners for adults’ services in two CCGs in Northeast England (n=3), a CCG in Southeast England and a regional specialised adults’ service commissioner for NHS England in the Midlands.

Stage 6. Synthesis and conclusions

**Analysis**

Stage 1. Literature review

No published papers on commissioning for transition were identified. Of 66 publications whose full-text was reviewed, 17 were potentially informative for the wider work of the Transition Programme, in particular recommendations for providers. The grey literature was then reviewed and revealed nothing of additional of significance. The details of the analysis are in Appendix 10 Report WP 3.2 and in our published paper with its URL in Appendix 10.

Stage 2. Qualitative interviews

A number of issues related to commissioning were identified, which clustered around four meta-themes: i) Policy and legislation; ii) Organisational structures, processes and pathways; iii) Professional roles and relationships, service-level co-ordination, sign-posting, and support; iv) Commissioning process and practice, including outcomes planning and delivery, and contract evaluation. From this work, key factors were identified that seemed likely to facilitate commissioning for transitional healthcare. These were:
• Commissioning within a CQUIN\textsuperscript{114} framework.
• Commissioning for Transition co-ordinators, within a framework of Developmentally Appropriate Healthcare, to work across all services in an organisation rather than for a particular condition.
• Joint commissioning either as cross-sectoral in Education, Health and Social Care; or as within-health, including involvement of general practice.
• Commissioners and Providers jointly agreeing what should be commissioned

A further issue raised frequently in the interviews was the need for ‘outcomes-based commissioning’. We found great variability in what this meant and how outcomes might be measured. Further, we could not identify a setting where outcomes-based commissioning was happening.

Full details of the analysis are in \textit{Appendix 10 Report WP 3.2} and in our published paper\textsuperscript{112} with its URL in \textit{Appendix 10}.

\textbf{Stage 3. Case studies with site visits (full report is in Appendix 10 Report WP 3.2, with some of their implications reported in our published paper\textsuperscript{113} with its URL in Appendix 10.)}

\textbf{Case Study A:}
At this site, a CQUIN was considered a necessary first step to quality improvement as it helped develop a culture, at least within children’s services, of shared purpose and value around transition. The CQUIN was also perceived to be a useful for standardising the introduction and use of the ‘Ready, Steady, Go, Hello’ forms,\textsuperscript{115} a set of documentation supported by NHS England. Participants reported that the implementation of the CQUIN contributed towards raising the profile and visibility of transition amongst clinicians.

Reported barriers included a lack of engagement of general adult services. Sometimes, this was compounded by the lack of a specific adult service for children to be transferred to. In other cases, the need for some young people to be transferred to other Trusts was reported as difficult to plan. Further, because CQUINs were assessed by numerical targets, rather than factors shaping quality and innovation; this might negate quality improvement. Finally, concerns were raised that transition extends for many years beyond the timeframe of a one-year CQUIN.
Case Study B:
At this site, a lead nursing manager, funded by the Strategic Clinical Network, played a central role as a regional champion facilitating the implementation of a region-wide CQUIN. This leader worked across fourteen NHS Trusts. All participants reported that this leadership played an important role in raising awareness and best practice about transition amongst commissioners and providers. At Trust level, the CQUIN contributed to the development of a Transition Steering Committee and a Trustwide Transition Coordinator responsible for collaborating with professionals across specialties.

Reported barriers included a lack of engagement of adult services in the meetings of the Transition Steering Committee and a lack of clarity about the role and responsibilities of commissioners of adult care. Young people’s participation and feedback was limited and fragmented across different services. Finally, echoing the findings of Case Study A, conceptualising the CQUIN in terms of indicators and targets did not necessarily translate into meaningful conversations about quality and innovation.

Case Study C:
At this site, there was a partnership whose overall aim was to develop and implement an integrated mental health service for 0-25 year-olds. This involved decommissioning the existing Child and Adolescent Mental Health Services (CAMHS) and co-production of a new service specification. Participants reported that a key feature of the new service was the enthusiasm and commitment of commissioners to improve transitional healthcare. Further, participants emphasised the importance of health, social and third sector involvement and co-production with service users of the new service specification. It was supported at national level by the National Clinical Director for Children, Young People and Transition to Adulthood, and at regional level by the Collaboration for Leadership in Applied Health Research and Care.

Reported barriers included uncertainty about transition after age 25 and challenges relating to engagement of adult services. Also, negotiating the decommissioning process with the outgoing provider had been challenging. Participants thought that there was reluctance to adopt the new service by some stakeholders. Finally, inadequate information sharing procedures were evident following configuration of the new service.
Stage 4. Seminar

Many views and insights were expressed which are summarised in a report. The main benefit to the Programme was how much the co-applicants learned about the NHS Commissioning Framework and how to influence Commissioning.

Stage 5. Further interviews with commissioners of adult services

Further interviews with adult commissioners in CCGs revealed that transition did not get ‘onto their radar’. Transition was acknowledged to be important but, as there was no national imperative, other priorities over-ruled it. This is despite the introduction of a national CQUIN on transition in mental health services\textsuperscript{116} introduced part-way through our Research Programme. The only meetings at which transition was ever mentioned were those about diabetes. The overarching opinion was that contracts with Trusts covered broad strategic approaches to clinical care and were not specified at the level of detail that would include arrangements for transition. Rather, CCGs would assume that a healthcare provider would deal with decisions about transition and transfer of healthcare as it sees fit.

Participants suggested that reasons why transition did not get ‘onto the radar’ included: i) Commissioners had no ‘levers’ such as national quality indicators or resources for transitional healthcare (just talking with a Trust does not make better transition happen); ii) Commissioners could not show ‘Return on Investment’ - i.e. improved transition would not convert easily to more activity for the same money or less activity for less money; (iii) Other competing urgent priorities.

Most commissioners were aware of NICE Guidance on Transition but acknowledged that, like other NICE guidance, new guidance was considered in the context of local priorities. Further, it was suggested that NICE Guidance about a particular condition or disease is easier to use than guidance directed towards the operation of a complex intervention.

Commissioners, who were also general practitioners, made two important points. Firstly, long term conditions, like non-severe asthma, allergy, and some mental health disorders, are often currently managed entirely by primary care. Although transition occurs, there is no need for transfer of healthcare. Secondly, even for conditions that need secondary care ‘the role of primary care should start at the time of diagnosis’. The general practitioner commissioners were concerned that in some instances child health services appear to exclude primary care. This lack of joint working risks creating for children, young people and their parents a lack of confidence in their primary care team and over-dependency on secondary paediatric care, which in turn leads to a strong desire for secondary adult care.
Commissioners of adults’ services were well aware of the small number of young people with very complex care needs that required expensive, bespoke clinical and inter-agency care but were often not aware of the much larger numbers of adolescents with long term conditions who were negotiating transition and attending community and hospital based services.

Commissioners for specialised services at NHS England suggested that most specifications for children’s services included transition; and for some conditions such as diabetes and renal services, a broad expectation about transition was also included in contracts for adults’ services. However, they acknowledged that most adult service specifications contained little if any reference to transition or healthcare transfer. Further, there was no monitoring of service delivery by commissioners of either transition more broadly or transfer of healthcare from children’s to adults’ services. For some conditions, national audits of practice, which include examination of transition, were undertaken by professional groups.

Stage 6. Synthesis

We prepared a first draft of our synthesis and proposals for discussion with recommendations for commissioners, which was then refined. It is reported in WP 3.3.

Strengths and limitations

Despite increased awareness about transition since the publication of the NICE Transition guideline and quality standard in 2016,14,117 commissioning for transition is a new field of enquiry. This means that our research conclusions and recommendations are primarily based on the evidence generated during the Research Programme through research interviews, site visits and discussions with commissioning groups.

Given the fast pace of policy change and with over 200 CCGs across England, one of the challenges for this WP was to capture a wide range of contemporaneous views and perspectives. We think that the combination of the range of methods employed (interview, seminar, site visits), the relatively broad geographical distribution across the UK, and engagement with CCGs and Specialised Commissioning at NHS England, gave us a reasonably comprehensive understanding.
Key findings

- Commissioners and providers of adult services regard transition as being the responsibility of commissioners and providers of child services to deal with and improve.

- Whether contract specifications include transition very broadly or in detail, implementation of transition is not usually then monitored by commissioners – partly because there are no nationally agreed outcome and quality indicators to use.

- Whilst a CQUIN for Transition can raise the awareness of service managers and clinical teams about transition, the short term requirement for indicators to be documented can make the introduction of a CQUIN a box ticking exercise, rather than a commitment to organisational change which may in turn lead to quality improvement.

- A Transition Steering Committee and Trustwide Transition Coordinator in an NHS Trust are effective at discharging an organisation-wide commitment to improving transition.

Interrelation to other parts of the programme

Our understanding of commissioning processes developed from this WP allowed us to ensure, as far as possible, that we were well informed when we visited commissioners in WP 3.3. We were able to approach commissioners with specific questions and specific suggestions and then test these out. As will be shown in WP 3.3, we then formulated definitive conclusions with specific implications for commissioners. Our final conclusions are relevant, possible to implement and likely to be adopted by commissioners because of this sequential process of identifying issues and then testing them out with commissioners.

The findings of this WP informed the content of the DAH toolkit in WP 3.1b.

Through its effect on WP 3.3, the results from WP 3.2 directly determined what we included and how we framed Implications Nos 1, 2 and 6 of the Programme.
WP 3.3 Commissioning: Seeking consensus
Addressing Objective 3: to determine how transitional healthcare should be organised, provided and commissioned

Aims

- To synthesise learning from the Programme on what and how to commission
- To learn about the most useful way to provide research based evidence to inform commissioners, through local and national meetings and visits

Methods

Using results from WP 3.2 on commissioning, from WP 3.1 on Developmentally Appropriate Healthcare and from WP’s 2.1 and 2.2 on features of services for transitional healthcare associated with better outcomes, we developed two brief documents setting out for commissioners the preliminary key research findings and implications of the Programme. We wanted to learn from commissioners whether we were presenting material that they thought was relevant and useful, and in an appropriate manner. We presented these documents to the following groups and individuals, modifying their contents as we proceeded:

- An academic at a university in Southwest England who had undertaken research into evidence-based commissioning and what influences commissioners’ decision-making
- A child health commissioner (also general practitioner) in a CCG in northeast England
- Chief Executives of a CCG consortium in Northeast England
- Chief Executives of a CCG consortium in Southeast England
- The Clinical Leadership Committee for specialist services at NHS England
- Three telephone interviews with members of the above Clinical Leadership Committee
- A commissioner of specialist services for mental health in North England
- A commissioner of specialist services for long term conditions in adults in the Midlands

During the consultation meetings we presented the key findings about the outcomes and lessons from the Programme, focusing on the commissioning pathway and guidance. We encouraged, through discussion with various stakeholders, critical reflection to ensure the relevance of the emergent findings, identify key lessons learned, and explore the implications of these lessons for developing a nationally consistent and comprehensive approach to
commissioning for transition. The discussion were central to challenging, modifying and enhancing our guidance for commissioning for transitional healthcare for young people with complex health needs.

We kept notes of the content of all the meetings.

**Analysis**

Below are summaries of our discussions based on the notes of the meetings. We used an iterative process, based on the advice and suggestions we received, to modify and revise the summary documents and the way we presented our proposals to Commissioners.

**Discussion with academic in southwest England**

This person explained that commissioners are likely to be interested in our broader knowledge of transition, not just the research findings. Commissioners regularly seek advice from colleagues and trusted experts. By showing that we were also keen to learn from them, we may come to be regarded as a trusted source of information.

We should avoid jargon and make sure our messages are demonstrably relevant to patients. We should aim to present three or four key messages that are clear, practical, evidence based and cost neutral or will save money. If we wish to draw the attention of commissioners to a particular problem, especially one they may not have been aware of, then we also need to propose a solution – preferably one that reduces cost or at least does not cost more.

**Discussions with CCGs**

In general, CCG commissioners said our proposed summary documents were useful, well written and articulated. Several commissioners were enthusiastic about our work and recognised the implications for their commissioning practice. We were advised to be explicit about how proposals from the Research Programme would yield improved outcomes.

All commissioners welcomed the concept of Developmentally Appropriate Healthcare, though many had not encountered it before.

Commissioners asked us how they would know that providers were improving transition in their services, or at least doing what they had been commissioned to do.

**Discussions with commissioners for specialist services at NHS England, both at regional level and centrally:**

The Research Programme should focus on solutions.

Although the key implications of the Programme could be implemented within existing service provision, with little or no extra cost, we were advised that senior managers and
Healthcare providers tended to request extra funds whenever change was proposed; we should try to anticipate such arguments.

We were advised to set out the risks of ‘not transitioning well’ as well as highlighting the potential longer term poor health outcomes.

The toolkit on Developmentally Appropriate Healthcare was considered an excellent idea. Although directed to NHS organisations (managers, teams and individual clinicians), it should also be educational for commissioners.

For those young people where there was no equivalent specialist tertiary adult service, they might be transferred to the CCG for secondary care or to primary care. These pathways should be stated explicitly by commissioners through service specifications and contractual arrangements.

Some specifications for specialist child and adult services do include specific mention of transition. However, commissioners may not then follow it through to hold Trusts to account. There is a need for quality standards or indicators for transition.

There was general agreement that transition is currently considered to be the responsibility of child commissioners and child healthcare providers. To achieve change, this underlying premise needs challenging so that arrangements for transition include adult commissioners and adult providers. All agreed the approach to improving transition should be owned at Trust Board level.

**Synthesis**

Almost all the commissioners we visited thought now was an opportune time to focus on transition, in the context of the recent publication of the NICE Guidance and Quality Standard for Transition.¹⁴,¹¹⁷

Many commissioners stated that they had been aware of the need to address transition but were not clear how best to achieve this; having a relatively small number of specific evidence-based proposals from our Research Programme was timely and useful.

Participants acknowledged that transition is currently considered the responsibility of child commissioners and child healthcare providers; they thought that this should change, and that commissioners and providers of adult healthcare should be equally responsible.

There was also recognition of the need to achieve an integrated approach to working relationships within health and between health and social care commissioning to support shared responsibility and ownership for transitional healthcare of young people. In the light
of the recent publication of the National Institute for Health and Care Excellence guidance on transition, commissioners acknowledged the potential impact of integrated commissioning for transitional healthcare.

There was a general but not universal view that it was easier to be prescriptive in service specifications if there was evidence to support it. However, it depends upon what is meant by evidence. Those trained in public health were more likely to use research evidence but other commissioners were more likely to use local information and local experiences, with research evidence influencing only 20% of them.\textsuperscript{118} It was, however, acknowledged that the commissioning proposals recommendations from our Research Programme could support the development of evidence-based commissioning for transitional healthcare.

\textbf{Strengths and limitations}

This is, as far as we are aware, the first work to study commissioning for transition. We were able to identify some major issues for commissioning, gain an understanding of the context in which commissioners work and the parameters they use to direct healthcare provider organisations for commissioning transition.

As most commissioners we talked with agreed that transition was important and that now was an opportune time to introduce change, it would have been useful to meet with commissioners who were more sceptical about the importance of transition.

Our presentations to commissioners focussed on a small number of implications for commissioners; these were refined as discussed above. This inevitably meant that we could not share the detail and complexities of all the findings of the Research Programme.

We have published two papers on commissioning\textsuperscript{112, 113} with their URLs in Appendix 10 and we are preparing a third.

\textbf{Key findings}

Box 2 contains the final version of the document, after all its modifications, which we had discussed with commissioners. It is also the final version of the document for commissioners which we presented at the dissemination meeting at the Kings Fund in October 2017.
Box 2: Implications for Commissioners

We do not suggest new or additional services, nor in general a move of resources between budgets; rather a change in clinical practice in both children’s and adults’ services.

Successful transition is a priority for all children with long term conditions, not just the small group of young people with very complex needs who require integrated commissioning across CCGs, Health and Wellbeing Boards, Education and Social services to fund bespoke multiagency packages of care.

1. Our findings indicate that there is an important role for commissioners of adult services to commission transitional healthcare, in addition to commissioners of child services with whom responsibility for transitional healthcare currently lies. Commissioners and providers regarded transition as the responsibility of children’s services. This is inappropriate, given that transition extends to approximately age 24.

2. ‘Developmentally Appropriate Healthcare’ is a crucial aspect of transitional healthcare. Our findings indicate the importance of health services being commissioned to ensure providers deliver DAH across all healthcare services, and that this will be facilitated by commitment from senior provider and commissioner leaders. Responsibility for implementation resting with the Boards of NHS Trusts.

Developmentally Appropriate Healthcare (DAH) is the subject of a toolkit we have developed, where DAH is defined and which is a resource for education and training. http://research.ncl.ac.uk/transition/

One important element of Developmentally Appropriate Healthcare is that young people, in both child and adult services, need to be seen by themselves for at least some of the consultation. However, our research shows that involvement of parents in a manner which suits both parties (and this will vary between different young person/parent dyads) leads to better outcomes – in terms of satisfaction with services, disease control, continuity of healthcare and maturation to adult roles. Currently, adults’ services often exclude parents from consultation on grounds of confidentiality. This should not happen provided a young person gives permission for a parent to be present for some of the consultation.

3. Where an adult service to which to transfer young people with a long term condition is not commissioned, our findings indicate an important role for commissioners in setting out explicitly that the transfer arrangements will usually be to primary care, and
require appropriate documentation and assistance to the young person to make their first appointment.

4. Our findings indicate the importance of commissioning to ensure a young person and family meet the adult team before transfer.

Our research shows that meeting the adult team before transfer of healthcare predicts better adult outcomes. The joint appointment would involve the staff who will be caring for the young person in the adult service or primary care.

5. Our findings indicate an important role for commissioners in ensuring that healthcare provider organisations establish a Transition Steering Committee with a Trust-wide Transition Coordinator.

Our research suggests that this enables an organisation to develop and deliver an organisation-wide approach. We found good practice led by enthusiasts rarely generalised to other specialties or adult services.

All the above is consistent with the NICE Guidance on Transition (ng 43, February 2016), which sets out guidance and principles. However, our suggested implications are fewer in number and supported by research evidence from the Transition Research programme.

A summary of all our results and their implications are on our website http://research.ncl.ac.uk/transition/ Some research articles are published (downloadable from our website) and more will follow.

**Interrelation to other parts of the programme**

The above summary of findings for commissioners includes proposals about Developmentally Appropriate Health care that were explored in WP 3.1 and about the proposed beneficial features which were explored in the longitudinal study WPs 2.1 and 2.2.

What we learned about the commissioning process in WPs 3.2 and 3.3 has directly informed what our conclusions are about how commissioning might be improved; and directly informed how best to present this evidence to those responsible for Commissioning healthcare in different NHS settings.

This WP directly determined what we included and how we framed Implications Nos 1, 2 and 6 of the Programme.
Involvement of patients, voluntary sector and the public

Work of UP
The Research Programme worked with a young person’s advisory group that met once a month (named by the young people as UP). It was facilitated by Dovey-Pearce, co-applicant and clinical psychologist who also provided regular updates to the Programme Management Board. The work of UP is reported under WPs 1.1 and 1.2 and in Appendices 3 and 4.

Voluntary sector
The Council for Disabled Children (CDC) was a co-applicant to the Programme and received a budget from the Programme. Represented initially by Wheatley as co-applicant and then by Bennett, the CDC attended Programme Management Board meetings quarterly in Newcastle. The CDC:

- Worked closely with McDonagh and Dovey-Pearce to establish UP; and plan the first external seminar in September 2014 on Developmentally Appropriate Healthcare
- Was a key member of the groups leading WPs 1.1 and 1.2 on young person involvement; and WPs 3.2 and 3.3 on commissioning
- Disseminated to 75 young people through discussion groups between autumn 2015 and spring 2017. These meetings enabled UP to disseminate early results of the Programme on the Q-sort study, health passports and Developmentally Appropriate Healthcare (WPs 1.3, 1.2 and 3.1 respectively). They were preceded by a planning meeting in Newcastle by a steering group of young people including two members of UP. The meetings took place with: CHAT group in North Tyneside; two Croydon groups; Together for Short Lives; Transition2 group in Derby; and Chatterboxes youth group in Bournemouth. The meetings generated three workbooks (Appendix 11) for other groups to use, especially voluntary organisations in the health sector. The resources have been disseminated to 469 young people’s organisations (as of 25 September, 2017) and have been shared with the memberships of CDC’s networks.

Association of Young People’s Health (AYPH); Toolkit for introducing Developmentally Appropriate Healthcare across an NHS Trust
AYPH to advised on and set the format and style of the toolkit, based on similar work it had undertaken with the Royal College of General Practitioners. The development of the toolkit is reported in WP 3.1 and Appendix 9.
NIHR meeting in Exeter on PPI involving young people, November 2013

Dovey-Pearce represented the Programme at this meeting. She jointly led with Chris Morris from Exeter a workshop on engagement of young people in PPI. The presentation included a video produced by UP.

Patient and public involvement (PPI) representation on the External Advisory Board (EAB)

The membership of the EAB included representation from one charity, two parents of disabled children, and two young people with long term conditions. The Board met five times during the Programme. Meetings were arranged to accommodate the availability of its members and at points where the input of the EAB would be useful. UP to send a rotating representative to each meeting. An informal meeting was held on the morning of the EAB in which only topics of likely interest to the young people and parents were discussed. The afternoon session followed a formal agenda.

Newsletters and circulation list

We distributed a four-monthly newsletter to all registering interest in the Programme. This included the voluntary sector and, in particular, the five organisations that had provided letters of support for the Programme. We also circulated seven newsletters written specifically for participants in the longitudinal study WP 2.1 (example in Appendix 11).

Two External Seminars funded by The Health Foundation

We applied successfully to The Health Foundation for funding for two external seminars. Their purpose was to help us consider two important aspects of our Research Programme – Developmentally Appropriate Healthcare and Commissioning for Transition. We brought together professional experts, the voluntary sector and young people from a much wider range of disciplines and expertise than were in the Programme’s team. Each seminar had about thirty invited delegates.

The first seminar, on Developmentally Appropriate Healthcare, was held in Birmingham in October 2014. UP and the Council for Disabled Children contributed much to the planning and presentations of this seminar.

The second seminar, on Commissioning for Transition, was held in London in June 2016.
NIHR Website
Based on the annual reporting of our PPI work to NIHR and the representation of UP on the External Advisory Board, NIHR placed details of the work of UP on the NIHR website in November 2014 as an example of excellent practice.

Plain English Summary for Final Report
The UP group and lay members of the External Advisory Group reviewed this summary.

Impact of UP
The sponsoring Trust (Northumbria Healthcare NHS Foundation Trust) funded a satellite study, led by Dovey-Pearce, to examine and understand the factors that influenced involvement of young people in the Programme and what the perceived impact and benefits were.

There are no pre-defined standards to measure PPI work against; the field is still working towards defining the processes of involvement and the ‘quality’ of involvement work. In this mixed-methods study, the views of the adult researchers and young people working on the Programme were explored. The evaluation drew upon existing proposals and theories, including the Medical Research Council’s Public Involvement Impact Assessment Framework. Members of the Transition team, with knowledge of most aspects of the Programme’s work, carried out the data collection using qualitative methods. A draft of the paper submitted to a peer-reviewed journal is in Appendix 11.

Having witnessed the impacts of young people’s input, the adult researchers said they attached increasing importance to it; they valued the ‘authentic voice’ that UP provided. The adult researchers noted the evolving process that took the work forward and the importance of not taking an over-mechanistic approach with over-defined, a priori goals.

The young people said they thought they had received a structure with overall aims but with freedom to work within those parameters. They experienced less anxiety than the adult researchers, who had raised questions about how this process would work in practice. The young people considered that they developed personally and professionally, and that they were making a difference to the NHS and to other young people using services.

Recently, there has been a call to move away from studies of ‘what’ involvement achieves, to ‘how’ does good involvement happen. The findings of this satellite study suggest that cycles of active work allow involvement, thinking and practice to progress during a project.
Every research study has its own opportunities and challenges to achieve active and meaningful involvement.

**Conclusion to the PPI section**

Overall, we consider that young people were involved throughout the Programme, with defined input to most of the WPs. They received support and developed skills to be able to take active roles in partnership with the adult researchers. A ladder of young person engagement, proposed by Hart,\textsuperscript{121} is shown in Figure 10. Our Research Programme moved flexibly between the rungs of meaningful and active involvement (rungs 4-8), whilst avoiding the levels that are closer to tokenism and decoration (rungs 1-3).

There are no agreed methods for involving young people in a long-term health research programme. We were fortunate to have well-funded involvement resources to support young people, and this was key to carrying out a detailed analysis of our involvement work. We could have adopted a less time-consuming and less costly approach, which could have drawn on expertise from already established young people’s special interest groups. We do not know whether such an approach would have been as successful.

Figure 10: Hart’s ladder of young people’s participation

Reproduced with permission from CommonAction Consulting and FreeChild, 23 August, 2017\textsuperscript{122}
What was and was not successful?

What was successful?
Integration of work packages
We achieved our aim to have a set of nine work packages which were closely integrated. Our conclusions and their implications were informed by the input of young people, the longitudinal study and the work on implementation in Trusts and with commissioners.

Patient and public involvement
Our PPI was of a high quality. We formed this view based on the interest NIHR showed in highlighting the work of UP on its website; on the invitation from the Department of Health England to UP to attend the ‘take over’ day; on the views of the External Advisory Board; and on the internal evaluation undertaken by Dovey-Pearce (reported in the PPI section and Appendix 11).

Small number of feasible implications
We succeeded in our intention to conclude with a small number of feasible implications that will have utility for NHS commissioners, and those responsible for the delivery of clinical services. During consultations, we were advised that documents containing large numbers of recommendations and aspirational statements are difficult for commissioners and chief executives to use.

What was not successful?
Administrative challenges
Research and Development permissions
Obtaining NHS Ethics permissions for the various WPs was relatively straightforward. However, Research and Development permissions from individual NHS Trusts was time-consuming and frustrating, not least because every Trust had different procedures and expected different amounts of detail. Especially time-consuming was obtaining ‘research passports’ and ‘letters of access’ for staff who worked across University and Trusts.

Human resource issues
We experienced many staff changes over the five years at co-applicant, local principal investigator and research assistant level. The reasons included: career break, maternity leave,
change of job, physical illness, mental illness, and merging of NHS organisations. Despite our best efforts (which included new research assistants receiving detailed training at each change), these manpower disruptions led to some loss of continuity of contact with some young people. This may have had some adverse impact on retention rates in the longitudinal study.

Recruitment and retention of young people as research participants
While recruitment rates were reasonably good for the ASD group (50.9 %) and diabetes group (64.7 %), the rate of recruitment of those with CP was lower (25.6 %). The overall retention rate at 70% was in keeping with other studies.

Working with Principal Investigators at each site
The Principal Investigators had a genuine interest in research and in the Transition Programme but some had not appreciated how much time was needed to spend with their research assistant for high quality supervision. Some of this had therefore to be done from Newcastle, which was sometimes challenging – not least because we could not directly influence human resource issues in each Trust.
Conclusions

Introduction
Our research has taken a comprehensive approach to transition in the UK. We have involved young people; we have investigated key components of transitional healthcare rather than specific models and have identified components associated with better outcomes; we have examined how transition is commissioned (or frequently not commissioned); and we have examined how improving transitional healthcare in NHS Trusts could be managed.

A key theme in the qualitative research literature is that young people look forward to growing up, look forward (albeit with some anxiety at times) to further education or training, having a job and leaving children’s health services. Most studies, that include young adults a year or so after transfer, find that young adults say that they are pleased to have transferred to adult healthcare and that most earlier anxieties have gone away.123

Poor outcomes after transition cannot all be attributable to poor transitional healthcare. Young people may demonstrate poor outcomes and worrying health related behaviour before their transition starts, which may then amplify during transition. For example, young people with poor adherence to medication for liver transplant after transfer had had poor adherence before transfer;124 and young people with cerebral palsy have poor participation when aged 8-12.125 In our Research Programme we found in our baseline assessment of those joining the study that the participation of those with CP or ASD was already lower than for those with diabetes, and that the mental wellbeing of those with ASD was already lower than for those with diabetes or CP. Further, young people’s lives may be disrupted for reasons of their mental health or family or social circumstances. Such young people need specialist care but the potential for poor outcomes should not solely be attributed to poor transitional healthcare but rather to the difficult problems the young people pose for health services, regardless of their age or whether in transition.
**Strengths**

External evaluation of real world rather than internal evaluation of a locally developed intervention

Most groups undertaking research into transition evaluate their own interventions – essentially, they undertake an audit or clinical evaluation of their service. However, we have successfully completed a hypothesis driven, longitudinal, observational study of features being provided or not across twenty-seven NHS settings. We had a large cohort and this was the first study of its kind.

Prospective data collection during transition

We captured data from young people while they were in transition and across their point of transfer. Therefore, we have information about young people’s experiences and outcomes at the time they were receiving services, rather than on what they thought afterwards about what they had or should have received. This has rarely been done before and gives us confidence that our conclusions recommendations will be helpful to young people who are in the midst of transition.

Seeking findings relevant to a broad range of long term conditions

We sought to identify the features of good transitional healthcare which were appropriate to those with any long term condition. Although we selected specific conditions for the longitudinal study, they were deliberately chosen as conditions giving rise to a wide range of different health needs, psychosocial complexity, and availability of adult services.

Engagement with commissioners

Our examination of commissioning is a novel aspect of the Research Programme. Arrangements for commissioning NHS services have continued to change over the time period of the Research Programme and will continue to do so. However, the commissioning focus of our research concerns ‘what’ and ‘how’ to commission. Thus our findings should be relevant to any commissioning structure, including whether or not commissioning and service provision are brought together in the same organisation.

Outcomes and processes measures (indicators) of transition

The range of outcomes we chose was informed by the International Classification of Functioning\(^{73}\) and by discussion with international transition researchers, and conformed with many of the recommendations of later international Delphi surveys\(^{42, 43}\) as set out in Table 14.
Subjective wellbeing and participation in life (social, educational, workplace) are generic outcomes, i.e. not specific to a particular condition. Wellbeing has been emphasised as an important and often neglected outcome in the evaluation of transitional healthcare.\textsuperscript{126}

Few studies have addressed such generic, distal outcomes. Assessing such outcomes brings some attendant difficulties: i) poor adult outcomes are not necessarily due to a failure of transition. For example, in complex physical problems such as cerebral palsy, participation outcomes for adults are particularly poor for those with more severe impairment;\textsuperscript{127} yet participation is already much reduced in 8-12 year old children with cerebral palsy;\textsuperscript{125} ii) many chronic illnesses such as diabetes, renal failure or cystic fibrosis generate more medical complications the longer the individual has the condition. Thus, even where process measures of optimal care may be satisfactory, health outcomes may worsen.

Process measures of transitional healthcare usually assume that providing services that young people like and maintaining a young person’s contact with health services will yield better outcomes. However, Betz\textsuperscript{128} recognised that such measures may be relatively easy to collect but we do not know if they lead to improvement in more distal outcomes.

Non-attendance at appointments might seem an easily captured and interpretable process measure but we found it was not. There are many reasons for non-attendance, many of which are logical and valid, rather than indicating disengagement with services. Also, rating by number or percentage of missed appointments is difficult to interpret. The number of expected appointments per year varies by condition (individuals with diabetes may expect at least four a year) and by disease activity (for example, is the appointment for a routine follow-up or because of a worrying deterioration of disease control?)

In investigating relationships between process measures and outcomes, Cramm\textsuperscript{129} found that satisfaction with transitional care was associated with better social and emotional quality of life one year later in those with diabetes or neuromuscular disorders. Sattoe and van Staa\textsuperscript{130} found that process measures such as ‘patient not lost to follow-up’, ‘attending scheduled visits’, ‘satisfaction with care’ were not related to social participation. In their study, ‘continuing attention to self-management’ was the only process measure associated with better health-related quality of life.
Table 14: Outcome and process measures of transition

<table>
<thead>
<tr>
<th>Framework</th>
<th>Outcome or process measure</th>
<th>Captured by Research Programme</th>
<th>Instrument</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS Outcome framework</td>
<td>Preventing premature death</td>
<td>No</td>
<td>Warwick-Edinburgh Scale Rotteram Transition Profile Social participation questionnaire EQ-5D-Y</td>
</tr>
<tr>
<td></td>
<td>Enhancing quality of life for those with long term conditions</td>
<td>Yes</td>
<td>Warwick-Edinburgh Scale Rotteram Transition Profile Social participation questionnaire EQ-5D-Y</td>
</tr>
<tr>
<td></td>
<td>Helping people to recover from episodes of ill health</td>
<td>Yes</td>
<td>Condition specific outcomes.</td>
</tr>
<tr>
<td></td>
<td>Ensuring that people have a positive experience of care</td>
<td>Yes</td>
<td>Mind the Gap questionnaire</td>
</tr>
<tr>
<td></td>
<td>Treating and caring for people in a safe environment</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>US Triple Aim</td>
<td>Experience of care</td>
<td>Yes</td>
<td>Mind the Gap questionnaire</td>
</tr>
<tr>
<td></td>
<td>Health of the specific population</td>
<td>Yes</td>
<td>Condition specific outcomes.</td>
</tr>
<tr>
<td></td>
<td>Cost of care</td>
<td>Yes</td>
<td>EQ-5D-Y Capturing healthcare provider contacts (and thus costs) Economic modelling</td>
</tr>
<tr>
<td>Delphi North America</td>
<td>Quality of life</td>
<td>Yes</td>
<td>Warwick-Edinburgh Scale Rotteram Transition Profile Social participation questionnaire EQ-5D-Y</td>
</tr>
<tr>
<td></td>
<td>Understanding one’s condition, knowledge of medication, self-management, adherence to medication, understanding health insurance</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Attending healthcare appointments</td>
<td>Yes</td>
<td>We captured first appointments in adult services</td>
</tr>
<tr>
<td></td>
<td>Avoiding hospitalisation</td>
<td>Yes</td>
<td>Diabetic ketoacidosis in Diabetes</td>
</tr>
<tr>
<td></td>
<td>Social participation</td>
<td>Yes</td>
<td>Social participation questionnaire</td>
</tr>
<tr>
<td>Delphi International</td>
<td>Patient not lost to follow-up</td>
<td>Yes</td>
<td>We captured appointments in adult services</td>
</tr>
<tr>
<td>Indicators</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>---</td>
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<td></td>
</tr>
<tr>
<td>Attending scheduled visits in adult care</td>
<td>Yes</td>
<td>We captured appointments in adult services</td>
<td></td>
</tr>
<tr>
<td>Patient building a trusting relationship with adult provider</td>
<td>Yes</td>
<td>Mind the Gap questionnaire</td>
<td></td>
</tr>
<tr>
<td>Continuing attention for self-management</td>
<td>Yes</td>
<td>One proposed beneficial feature was ‘promotion of health self-efficacy’</td>
<td></td>
</tr>
<tr>
<td>Patient’s first visit in adult care within 3-6 months of transfer</td>
<td>Yes</td>
<td>We captured date of first appointment in adult service</td>
<td></td>
</tr>
<tr>
<td>Number of A&amp;E visits for regular care in the past year</td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient and family satisfaction with transfer of care</td>
<td>Yes</td>
<td>Mind the Gap questionnaire</td>
<td></td>
</tr>
<tr>
<td>Maintain/improve standard of disease control evaluation</td>
<td>Yes</td>
<td>Condition specific outcomes.</td>
<td></td>
</tr>
<tr>
<td>NICE Quality Indicators</td>
<td>Planning for transition should start by age 13</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Young people should have an annual transition review meeting</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Young people should have a ‘named worker’</td>
<td>Yes</td>
<td>One proposed beneficial feature was ‘having a key worker’</td>
</tr>
<tr>
<td></td>
<td>Young people should meet adult team before transfer</td>
<td>Yes</td>
<td>One proposed beneficial feature was ‘meeting adult team before transfer’</td>
</tr>
<tr>
<td></td>
<td>Young people who miss their first appointment in adult services should be contacted and given further opportunities to engage</td>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>
Limitations

Quality of delivery of PBFs
The nine PBFs we studied were carefully defined and captured but we could not assess the quality with which each feature was delivered. For example, ‘Meeting the adult team before transfer’ might have been tokenistic in some Trusts and carefully planned in others. However, we examined exposure to each PBF across many Trusts and on three occasions, and we think that much variation in quality will have been ironed out by the statistical method we adopted.

Longitudinal representation of PBFs
It was relatively straightforward to examine the association of exposure to each PBF over the previous year with generic and condition-specific outcomes. However, it was more difficult to decide how to represent each PBF over the duration of the longitudinal study. What constitutes optimal exposure over three years when, for instance, exposure occurs in one year but not the others? We made a pragmatic, clinically informed judgement about this for each feature. The decision tree (WP2.1) was agreed by the team of the Transition Programme but others might have come to different judgements.

Social participation
After one year, we realised that the Rotterdam Transition profile was not sufficient to capture some aspects of social participation. We added a social participation questionnaire but it could only be administered at the third and fourth visits, so limiting our longitudinal analysis of this outcome.

Self-reported questionnaires
Most outcome data is from self-reported questionnaires. We recognise that this may be influenced by individual reporting styles, which make valid comparisons more difficult. However, we used questionnaires that were well validated; we had a large sample size that tends to minimise the impact of variation due to reporting style; the questionnaire completion was manualised and repeated each year so that any reporting styles would be consistent for each participant; we used a number of different instruments with score ranges suitable for group statistical analysis; and finally the constructs about which we were largely concerned were about young people’s perceptions of their health, wellbeing and social participation.

Statistical power
In line with our original calculations, we had sufficient power to identify clinically significant changes in the outcomes. However, for analysis by condition, sample size meant that some
real effects of difference may not have been detectable. In relation to the proposed beneficial features, power was limited if a feature was often absent.

**Economic modelling**

The data collected on outcomes, costs and health service use were complex to interpret because there was loss to follow up, differing healthcare transfer arrangements and the intervals between the annual visits by the research assistants were not always one year (young people have a lot going on in their lives and often visits had to be rescheduled). Strict econometric modelling, despite considerable efforts, proved intractable to undertake due to the nature of the data. A less robust exploratory analysis was adopted. This was able to draw out some key implications and generated a balance sheet. This was not wholly in concordance with some conclusions from other parts of the Programme, but triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

**Generalisability of our findings**

*With respect to young person involvement.* Our work represents the views of young people because we consulted over five years with the UP group; UP disseminated findings to young person groups across the UK; in the longitudinal study, young people with long term conditions completed the questionnaires; in the qualitative research work, young people were interviewed.

*With respect to the longitudinal study.*

This is the largest sample for research in the UK in terms of examining transition longitudinally and collecting hypothesis-driven data from young people at home visits (compared to data-linkage studies from administrative datasets). Although we cannot be certain of representativeness and therefore generalisability across UK regions and NHS Trusts, we studied individuals from greater London, northern, south-eastern and south-western England, and Northern Ireland. Further, we drew individuals from 27 NHS Trusts, and the Trusts varied greatly in the number and variety of the PBFs they offered. We recruited from all young people with cerebral palsy in two population registers and all young people with diabetes or ASD with mental health problem in nine NHS Trusts widely distributed across England (all such young people are seen in secondary care). Thus, complete populations of individuals with one of the three conditions were sampled from (rather than for example those attending particular schools, specialised tertiary health care services or voluntary support groups).
The three conditions chosen were exemplars of chronic illness (diabetes), complex physical impairment (CP), and neurodevelopmental impairment (ASD); these were deliberately chosen to be varied in terms of health needs, psychosocial complexity, and availability of adult services. Thus we consider that generalisability to other conditions is likely. This is supported by the fact that studies of young people with specific conditions usually conclude that the important issues are generic rather than about the specific disease e.g. diabetes, inflammatory bowel disease, cystic fibrosis, ADHD, Urology, disabilities.

However, as intended in our protocol, we did not include individuals with significant learning disability and our findings cannot generalise to this group. Nor did we include those with degenerative conditions. If progression is slow, as for instance in cystic fibrosis, transition is similar to that in other conditions and a formal transfer of healthcare needs to take place. If progression is rapid, as for instance with some brain tumours, then the wider social and educational aspects of transition take place very differently. Further, it may not be appropriate for transfer of healthcare to occur because it would be unnecessarily disruptive, with the young person likely to become incapacitated and/or die fairly soon after transfer; rather advance care planning should be in place as recommended by Together for Short Lives.

The 374 participants did not differ significantly from those declining to take part. The distribution of severity of the three conditions was similar to that in national samples. Those with the conditions had a wide range of severity; for example, the young people with cerebral palsy ranged from wheelchair users to those with independent ambulation. Attrition did not appear to create a bias as there were no significant differences between those remaining and not remaining in the study with respect to sex, age, condition, diabetes site or ASD site. In Northern Ireland, there was a small effect of deprivation on attrition of those with cerebral palsy. Thus, we think that after non participation and attrition, our study group continued to be representative of those we aimed to recruit.

With respect to commissioning. Our work is novel. We interviewed, carried out case studies and consulted widely with: commissioners and senior managers; CCGs and specialised commissioning; Regional and National specialised commissioning; many locations across the UK. Thus, we think our findings are generalisable for the UK and settings with well-developed healthcare provision.
With respect to the economic analysis. As we state in our account of WP 2.3, strict econometric modelling, despite considerable efforts, proved intractable to undertake due to the nature of the data. A less robust exploratory analysis was adopted. This drew out some key implications and generated a balance sheet. This was not wholly in concordance with some conclusions from other parts of the Programme, but triangulation of findings allowed key consistent conclusions and implications to be identified and reported.

Interpretation of our findings in the light of current policy, practice and research

Policy context
We summarised in the ‘Setting the scene’ at the start of the synopsis, the policy context that led to our application for a Programme of research. Since then there have been a number of key developments in England. NICE Guidance on transition was published in 2016.14 A national CQUIN for Transition of those with Mental Health problems35 was introduced by NHS England in 2018. Guidance on commissioning for transition for individuals with special educational needs was published by NHS England in 2018.140 Following the death of an individual with ASD just before transfer of their care, the Health Safety Investigation Branch published in July 2018 a report with recommendations for improving the services for young people in transition with mental health problems.141

The Chancellor of the Exchequer has indicated there will be considerable financial investment in the NHS over the next ten years. NHS England is drawing up a 10-year plan and we were asked, based on our research findings, to contribute a proposal for improving transitional healthcare practice.

Commissioning for transition
Our literature review (Appendix 10 Report WP 3.2) found no published or grey literature about commissioning for transition. Our discussions with commissioners showed that transition has been regarded as the responsibility of child service commissioners and child service providers. This is inappropriate as transition extends to age 24. Commissioners also tend to consider the numbers of young people in transition to be small; this seems to be because commissioners may only be actively engaged with the small number of very complex cases which require bespoke packages of care integrated across healthcare, social care and education. Commissioners also reported that lack of evidence made it difficult for them to be prescriptive about transitional healthcare. We hope that our Research Programme will help in this respect. Similarly, Commissioners found it difficult to be prescriptive
because they lacked indicators with which to assess compliance. Development of indicators is needed and a workshop on indicators for transition was led by NHS England at the meeting in London in October 2017 at which we disseminated for the first time our complete findings.

**Developmentally Appropriate Healthcare (DAH)**

The concept of DAH is now well accepted in the UK and internationally: NICE, Canada, US, Royal College of Physicians. Good practice in adolescent and young adult health, of which DAH is the foundation, therefore applies in particular to the group of adolescents and young adults in transition. Wherever and with whoever a young person is seen, their care should be provided by someone trained in provision of DAH. This is especially important for those with long term conditions who may have additional conditions or complications requiring consultations in a range of settings with a number of specialists. Crucially, DAH should be delivered equally in adult and child services to ensure the ongoing development of young people up to age 24 is recognised; and it should minimise disruption resulting from transfer of care. We have developed the evidence-base for the concept of DAH. We have shown, within England, the key organisational factors that promote and inhibit the implementation of DAH. A consequence of provision of DAH across an NHS organisation is that the potential problem of ‘at what age should a young person transfer’ ceases to be a problem because the young person’s developmental needs are taken account of by both the child and adult services.

In WP 3.1 we identified the barriers to introducing DAH as: i) no single group in provider organisations being responsible for young people; ii) a perception (incorrect) that only small numbers of young people attend hospital; iii) concerns that staff may not have the necessary mind-set or skill-set. We identified potential solutions as the need for responsibility for the introduction of DAH to rest with the Chief Executive and Trust Board; and ensuring there was a Trust wide strategy for training. Our work on commissioning in WPs 3.2 and 3.3 found that commissioners understood the importance of DAH and the need for it to be commissioned.

Whilst these organisational barriers and facilitators would apply to many health systems where change was sought, our work is the first to examine them in the context of DAH. In WP 3.1 we developed a ‘Toolkit’ to support introduction of DAH which is in Appendix 9 and available at: http://research.ncl.ac.uk/transition/ Training of staff in NHS organisations in DAH will be needed. We hope that the toolkit will be useful in itself, and because it points to other training resources.
Engaging with clinical services – ensuring continuity

Our qualitative work in WP 2.2 found that the point of transfer (whatever the adult provision might be) is intrinsically disrupting for families and young people. Families and young people will have been familiar, often for many years, with how to navigate children’s services, who to talk with if worried, where to get medication from etc. Transfer disrupts their knowledge and relationships and thus their confidence and trust, not because the adults’ services are inherently better or worse but because of the change that at first families and young people do not fully understand or feel confident to engage with. Thus, there is a need to move away somewhat from asking how young people are helped to mature and adjust; to asking how might systems and processes for young people and their families enable them to regain as quickly as possible their knowledge, confidence and trust. Such processes might include ensuring parents remain closely involved if the young person wants this (for they provide continuity); and meeting with the adult team before transfer (which may remove some uncertainty, especially if this meeting introduces the professional that the young person will be seeing in future). These are two of the proposed beneficial features which were associated with better outcomes in WP 2.1. The above interpretation reinforces the conclusion of a major study by Allen et al, albeit that it focused solely on those with diabetes.

Improving transition across an NHS organisation

Several the Trusts we visited, or whose managers we talked with in WP 3.2, had a Transition Steering Committee, chaired or convened by a Trust-wide Transition Coordinator. Such arrangements were effective in bringing about change across adult and child services and across specialties. They took advantage of the skills and enthusiasm of those already providing good practice and they organised Trust-wide training which brought together those from different specialties and from child and adult services.

Young people’s approach to transition

In WP 1.3, the Q-sort study identified four interaction styles that young people adopted when approaching transition: ‘laid back’, ‘anxious’, ‘autonomy-seeking’ and ‘socially-oriented’ (welcoming support from and frequent discussions with family, friends and healthcare professionals). Discussing and understanding young people’s views and preferences about and during transition would be likely to help clinicians and young people develop personalised planning for transition, and effective engagement with adult care.

In the discussions led by UP and the Council for Disabled Children with other young person groups (see PPI section), this finding was validated. Young people readily identified with one...
of the styles. However, some also said that their style had changed – for instance when they were younger they might have been ‘anxious’ but some years on they were now ‘seeking autonomy and being in control’.

The literature on asking young people about their transition is large (systematic reviews44,50) and we did not want to repeat such studies. However, ‘Q-sort’ methodology has not been used before in transition and, in identifying these four interaction styles, we have added new findings to the literature.

Changes in outcomes in the longitudinal study (WP 2.1)

Average satisfaction with services was reasonable at baseline (rating of ideal service only slightly higher than rating of actual service). It remained steady for those with diabetes but worsened significantly for those with ASD or CP across the study period. The importance of transition has been recognised by diabetes services for over a decade and the Diabetes Tariff145 includes transition. It is probable that in services for ASD and CP, the transition process is less streamlined with consequent reductions in young people’s and parents’ satisfaction with services.

For those with diabetes or CP, their average subjective wellbeing at baseline was similar to that of the general population and remained so during the study. Those with ASD and an associated mental health problem reported significantly lower wellbeing compared to the other two groups and this difference persisted over the course of the study – almost certainly due to the impact of their mental health problem.

For participation in life activities, there were significant differences between the three conditions with young people with diabetes being in more independent phases of transition than those with ASD or CP. All made progress over time but those with diabetes remained more independent.

Condition specific measure worsened over the course of the study for those with diabetes or CP. The proportions of young people with ASD with ‘abnormal’ anxiety and depression scores remained the same from baseline to the ‘Final’ visit.

Proposed Beneficial Features (PBFs)

We found that provision of our nine PBFs in 2013/14 was patchy. Fewer than half of the health services stated that they provided: ‘Age-banded clinics’, ‘Transition plans’, ‘Transition manager for clinical teams’, ‘Protocols for promoting health self-efficacy’ or ‘Holistic life-skills training’ (all but ‘Transition manager for clinical team’ were recommended by
NICE\textsuperscript{14}). Features were provided less often in services for those with CP and ASD than for those with diabetes. Thus, there is much room for improvement across all the services that the young people recruited to this UK–wide study were attending.

Three PBFs were consistently associated with better outcomes in the longitudinal study WP 2.1. We advise that strong effort be directed to maintaining or introducing them to a high standard. ‘Appropriate parent involvement’, ‘Promotion of health self-efficacy’ and ‘Meeting the adult team before transfer’

‘Appropriate parent involvement’ was found in WP 2.1 to be associated with outcomes concerning satisfaction with services, wellbeing, some aspects of participation and meeting health needs of those with cerebral palsy. Interviews in WP 2.2 revealed how important parents were to the process of transition. Involvement of parents as young people see appropriate is a crucial element of DAH. In WP 2.3.1, the DCE showed that ‘Appropriate parent involvement’ was the second most highly rated choice. WP 2.3.2 (economic modelling) concluded that ‘Appropriate parent involvement’ would be likely to maximise service uptake and may represent good value for money.

Allen’s study of diabetes and transition emphasised the importance of parents during transition.\textsuperscript{146} Heath and Farre’s systematic review of studies of parents’ perceptions of their role in transition\textsuperscript{82} concluded ‘Parents can be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care. Two further recent reports investigated the parent-young person dyad\textsuperscript{147, 148} and reached similar conclusions to ours; that the parent and young person need to share care but this dynamic will continuously change. NICE\textsuperscript{14} emphasised ‘Appropriate parent involvement’ throughout its report; it was an overarching principle in section 1.1.1, and sections 1.2.19 – 1.2.22 were devoted to involvement of parents.

‘Promotion of health self-efficacy’ was found in WP 2.1 to be associated with outcomes concerning satisfaction with services and meeting health needs of those with cerebral palsy. Interviews in WP 2.2 revealed that both parents and young people thought this was a central element of transition. The interviews also suggested that health self-efficacy may not only be about managing one’s condition but also about how to manage one’s health services.

‘Promotion of health self-efficacy’ is a central component of developmentally appropriate healthcare. WP 2.3.2 (economic modelling) concluded that ‘Promotion of self-efficacy’ would be likely to represent good value for money.
Klaasen et al developed a health self-management scale.\textsuperscript{149} Sattoe and van Staa\textsuperscript{150} found that ‘continuing attention to self-management’ was associated with better health-related quality of life. There is conflicting evidence as to whether a structured approach, including motivational techniques to raising health self-efficacy in diabetes, influences glycaemic control.\textsuperscript{151, 152} Mackie\textsuperscript{153} showed the benefit of a one-hour nurse-led intervention to promote knowledge and confidence about one’s condition, in this case congenital heart disease. NICE\textsuperscript{14} (section 1.2.17) recommended ‘Promotion of health self-efficacy’.

‘Meeting the adult team before transfer’ was found in WP 2.1 to be associated with better outcomes in participation and in diabetes management. There was a negative association between having met with an adult team and one of the Mind the Gap subdomains. We infer that lower satisfaction was due to the young person’s lack of familiarity with the adult team. Interviews in WP 2.2 found ‘meeting the adult team’ to be important, though sometimes the arrangements rendered it ineffective because the young person could not attend if the opportunity was only offered once a year, or the young person met someone who was subsequently not responsible for their care. If undertaken well, the meeting really helped with the potentially disrupting and disorientating consequences of transfer described in WP 2.2. WP 2.3.2 (economic modelling) concluded that evidence of the value for money of ‘meeting the adult team’ was ambiguous.

Our definition of meeting the adult team before transfer included having clinics where adult and paediatric physicians consulted jointly. In other studies, such joint clinics have shown improvements in process indicators in renal services,\textsuperscript{154} diabetes services,\textsuperscript{155} urology services\textsuperscript{137} and rheumatology services.\textsuperscript{156} NICE\textsuperscript{14} (sections 1.3.5 and 1.3.6) recommended ‘Meeting the adult team before transfer’.

For one PBF, ‘Having a key worker’, was only significantly associated with greater service satisfaction during the second study period (between visits 2 and 3); it had no associations with longitudinal analysis and some negative associations with participation. Sloper et al\textsuperscript{157} found strong evidence for the value of key workers for families with children with special educational needs. NICE \textsuperscript{14}(sections 1.2.5–1.2.10) called for a ‘Named worker’

The difficulty with ‘key worker’ may be the practicality of operationalising it rather than the principle of having a key worker. Staff change due to leaving post, restrictions in job plans, service restructuring, sickness or maternity leave make it difficult to provide a key worker for all young people with long term conditions, even though it may work well for the few where there is continuity.
For five PBFs, there were few significant associations with better outcomes: ‘Holistic life-skills training’, ‘Transition plan’, ‘Age banded clinic’, ‘Having a transition manager for clinical team’, ‘Coordinated team’. WP 2.3.2 (economic modelling) did not find any benefit in terms of costs or health related quality of life. Nor were the last three recommended by NICE.14

Regarding ‘Having access to holistic life-skills training’, our qualitative work in WP 2.2 found that all parents and young people thought signposting to educational and social services, and charities was essential. Some services were more ambivalent, not even sure it was their responsibility to probe these wider areas of a young person’s life.

‘Having a written transition plan’ was recommended by NICE14 (section 1.3.4) but did not specifically mention that it should be a written document. Qualitative work in WP 2.2 found conflicting views about a ‘written’ plan - they take time to draw up, they get out of date, they get lost, and who should hold them? Some professionals said personal interaction was far more important. On the other hand, lack of a formal plan left many families disoriented and wondering if the service did not have the resources to provide for care after transfer.

These last six PBFs, for which we did not find evidence of benefit, were included in our Programme because there had been a number of small studies, typically internal evaluations of local interventions, which suggested benefit (e.g. benefit of a transition manager for clinical team158). We acknowledge that absence of evidence is not the same as lack of benefit. However, our study was hypothesis driven and had clear, pre-identified outcomes. Even if these five PBFs should not be rejected, our findings indicate that resources (which include training) would be best directed first to embedding into service provision the three beneficial features for which we found convincing evidence of benefit.

Health economics

The short term cost of introducing the three key PBFs we found were associated with better outcomes will depend upon precisely how the feature is delivered. If an NHS organisation intends to adopt a Trust wide approach to transition, including ensuring that services are developmentally appropriate, then it would have to consider allocation of sessions to a coordinator. The role involves chairing a Transition Steering Committee and then assisting Directorates and teams of healthcare professionals. Also, training resources would need to be directed to instruction about DAH. The toolkit we have developed should assist this process (Appendix 9) and at: http://research.ncl.ac.uk/transition/
Arranging for every young person and their parents to meet an adult team member before transfer will require organisation and clinic time. Where there are already clinics at which child and adult clinicians consult together, then such meetings happen automatically. However, where care is being transferred to primary care, a meeting attended by a member of the child services team may enable this feature and support the young person’s confidence to make further appointments.

The Discrete Choice Experiment (WP 2.3.1) suggested that over a 10-year time horizon, a service allowing appropriate parental involvement, where the same staff are seen at each clinic, and where young people have the opportunity to make decisions about care, would maximise uptake. A service involving a ‘Appropriate parent involvement, ‘Protocol for promotion of young person’s confidence in managing their health condition’ may represent good value for money but a service involving a ‘Transition manager for clinical team’ or ‘Age-banded clinic’ might represent less value for money. The results are tentative however as the economic evaluation was exploratory. The balance sheet highlighted that adoption of the new approaches to transition, outlined above, needs to balance the extra cost against the increased engagement with health services and prevention of deterioration in health in the long-term.
Key implications for the practice of commissioners, managers and clinicians

Our findings indicate:

1 an important role for commissioners of adult services in commissioning for transitional healthcare, in addition to the current commissioning which is undertaken almost solely by child commissioners.

Commissioners and providers regarded transition as the responsibility of children’s services. This is inappropriate, given that transition extends to approximately age 24.

Sometimes a specialist secondary care adult service does not exist and transfer will occur from a specialist children’s service to primary care. Our findings indicate an important role for commissioners in setting this out explicitly including the need for appropriate documentation and assistance to the young person to make their first appointment.

2 ‘Developmentally Appropriate Healthcare’ is a crucial aspect of transitional healthcare. Our findings indicate the importance of health services being commissioned to ensure providers deliver DAH across all healthcare services, and that this will be facilitated by commitment from senior provider and commissioner leaders, responsibility for implementation resting with the Boards of NHS Trusts.

‘Developmentally Appropriate Healthcare recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations. In operational terms, Developmentally Appropriate Healthcare focuses on the approach of healthcare professionals to and engagement with each young person and their carers alongside the structure of the organisations in which care takes place.’

3 the importance of NHS organisations adopting a Trust-wide approach to implementation of better transitional healthcare.

In many Trusts good practice led by enthusiasts rarely generalised to other specialties or to adult services. Where organisations had a Transition Steering Committee, chaired by a Trust-wide Transition Coordinator, this takes advantage of the skills and enthusiasm of those already providing good practice; and assisted with training and consistent implementation in adult and child services and across specialties.
4 the importance of joint planning between child healthcare providers, adult healthcare providers and primary care; this is likely to improve both transfers of individual young people and the adoption of ways of working which improve care for this population.

5 the importance of child and adult healthcare providers exploring routinely with a young person how they approach transition, taking account of the young person’s interaction style and personalising the clinical approach thereafter.

Young people adopt one of four broad interaction styles when approaching their transition: ‘laid back’, ‘anxious’, ‘wanting autonomy’, and ‘socially oriented’ (welcomed support from and frequent discussions with family, friends and all healthcare professionals).

6 the features ‘Appropriate parent involvement’, ‘Promotion of health self-efficacy’ and ‘Meeting the adult team before transfer’ were associated with better satisfaction with services, participation, subjective wellbeing and measures of disease control. These findings provide practical content to be considered in NHS commissioning specifications.

‘Having a key worker’ inconsistently predicted better outcomes; ‘Having a transition plan’, ‘Coordinated team’ ‘Attending an age-banded clinic’, ‘Having a transition manager for clinical team’ or ‘Having access to holistic life skills training’ were not associated with better outcomes.

7 maximal service up-take could be achieved by a service which encouraged parental involvement, ensured the same staff were seen at each clinic, emphasised the importance of good communication with young people, and encouraged young people to make decisions about their care. A service involving a ‘Parental involvement that suited both parent and young person’, and a ‘Protocol for promotion of young people’s confidence in managing their health condition’ may offer good value for money but a service involving a ‘Transition manager for clinical team’ or ‘Age-banded clinic’ is less likely to offer value for money.

**Finally**

Parents and young people often have negative impressions of what care will be like in adult services. They may think adult services will be less supportive, more fragmented and not linked sufficiently to child service providers. While such issues may sometimes be true, in general they are not; so it is important that such negative attitudes are not fostered by child health teams. There are benefits and positives to transferring to adult healthcare, advantages that should be planned for and explained to young people and their parents by children’s
services. Transitions are a part of all our lives, although planning for these normal developmentally appropriate changes may be more challenging for those with long term health conditions.
Recommendations for future research

Recent years have seen an increase in research around transition, but most studies are small-scale and difficult to generalise from. Systematic reviews published during the Research Programme highlight the difficulties of drawing conclusions from the studies reviewed. The Cochrane review and NICE Guidance recognised the evidence base was weak. We think the next two years would be too early for a further major literature review.

We suggest, in order of priority, the following areas for further research:

1 How might the findings of the Programme be introduced and implemented by Commissioners and NHS organisations?

Whilst no study can be definitive, we think we have reported sufficient evidence to justify research into observation and evaluation of the implementation of the findings in a range of Trusts and long term conditions. Our conclusions are drawn from triangulation of quantitative, qualitative and health economic studies.

2 The role of primary care. This was also a NICE research priority.

What are the most effective and efficient ways for primary healthcare services to be involved in improving transition, and in following-up young people after transfer, whether or not they meet criteria for adult services?

Such a study would also address the needs of young people with conditions such as moderate asthma or eczema, which are usually looked after entirely by primary care.

A systematic review of primary care interventions around transition found only three articles, of which only one was set in general practice and that was in the US. The review concluded there was a need for intervention studies to guide improved integration of primary and secondary care over the period of transition.

3 Managing one’s health. This was also a NICE research priority.

What is the best way to support young people to manage their health?

We found that promotion of health self-efficacy during transition was associated with better outcomes. Sattoe has completed a body of work investigating how to promote health self-efficacy. Further research is needed to understand how self-management training can be best built into transition planning, across a range of health conditions, including mental health. This therefore is a research question for clinical and health psychology research to understand the context and mechanisms of behaviour change during healthcare transition.
ACKNOWLEDGEMENTS

Healthcare organisations supporting the Programme:
Avon and Wiltshire Mental Health Trust (formerly North Bristol NHS Trust)
Belfast Health and Social Care Trust
Birmingham University
Birmingham Children's Hospital NHS Foundation Trust
Birmingham Heart of England NHS Foundation Trust
Council for Disabled Children
Frimley Health NHS Foundation Trust (formerly Heatherwood and Wexham Park Hospitals NHS Trust)
Manchester University
Newcastle University
Newcastle upon Tyne Hospitals Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
Northern Health and Social Care Trust
Northumberland Tyne and Wear Mental Health Trust
Northumbria Healthcare NHS Foundation Trust
Queens University Belfast
Royal United Hospitals Bath NHS Foundation Trust
South Eastern Health and Social Care Trust
Southern Health and Social Care Trust
Tees, Esk and Wear Valley Mental Health Trust
University Hospital, Birmingham NHS Foundation Trust
Western Health and Social Care Trust

We thank the following for their contributions to the Programme:

External Advisory Board
Chair: Simon Pleydell. Members: Shona Chambers (Cerebra), Lizzie Chambers (Together for Short Lives), Allan Colver (Chief Investigator), Jim Mackey and Chris Price (Sponsoring Trust), Carl May (Medical Sociology), Alison Murray (Parent), Marij Roebroeck (International Advisor), AnneLoes van Staa (International Advisor), Scott Wilkes (Academic
general practitioner), NIHR Advisors, Rotating members from the programme’s young person advisory group, UP.

**Programme Management Board**

Helena Gleeson, Consultant Endocrinologist, who was an advisor to the Board. She liaised with the Royal College of Physicians, presented at meetings and contributed constructive criticism at Board meetings and to the Final Report.

Nichola Chater, Consultant in Rehabilitation Medicine, who was an advisor to the Board. She presented at meetings and contributed constructive criticism at Board meetings and to the Final Report.

Caroline Potts, Research and Development Manager, who represented the sponsor on the Board and facilitated many arrangements with the sponsor.

**Work packages 1.1 and 1.2**

Amy Jones and Dan Notley, Health Play Specialist/Patient Involvement Leads, who helped with the facilitation of UP.

Tracy Scott, Research Associate, who helped with the facilitation of UP; and who also contributed to WP 2.1 through data collection at home visits, maintaining regular communication with the co-ordinating centre and attending training workshops at the coordinating centre.

Sophie Fairgrieve, Sophie Walker, Monica Parker and Molly Pledger who were peer-support workers.

**Work package 1.3**

Helen Mason, Lecturer in Health Economics, for her work assisting with the design and analysis of the Q-sort study and contribution to a published academic paper.

All the young people who took part in this study.

The consultant physicians and surgeons who helped to recruit young people to the study: Alan Anderson, Laura Baines, Steve Ball, Katherine Barlow, William Bliss, Nicola Brown, Su Bunn, Penny Burt, Tim Cheetham, Denise Chisholm, Lucy Craig, Jean Crosier, Anita Devlin, Simon Doe, Peter Dryden, Anna Eden, Rob Forsyth, Helen Foster, Dee Frost, Hany Gabra, Binu George, Helen Hanson, Sally Harding, Yvonne Hart, Karen Heslop, Gareth.
Hosie, Bernard Higgins, Mark Hudson, Margaret Jackson, Ann Kirk, Jill Kisler, Heather Lambert, Nicki Leech, Lorraine Lentell, Raj Lodh, John Macfarlane, Mike McKean, Debbie McParlin, John Mansfield, Margaret Miller, Jackie O'Sullivan, John O'Sullivan, Leila Qizalbash, Trudy Pederson, Rob Pickard, Ben Reynolds, Mandy Robinson, Wendy Robson, Clare Smith, Jayne Straker, Julian Thomas, Matthew Thomas, Mary Vallely, Ramesh Venkateswaran, Lucy Wirz.

Work packages 2.1, 2.2 and 2.3

The Principal Investigators at NHS Sites who supervised the Research Assistants and assisted with recruitment at each site: Amanda Billson, Anastasia Bem, Stuart Bennett, Stephen Bruce, Tim Cheetham, Diana Howlett, Zilla Huma; Mark Linden, Maria Lohan, Cara Maiden, Melanie Meek, Jenny Milne, Julie Owens, Jackie Parkes, Fiona Regan, Nandu Thalange.

The Research Assistants who undertook data collection: Kam Ameen-Ali, Sarah Balne, Shaunak Deshpande, Louise Foster, Charlotte George, Louisa Fear, Kate Hardenberg, Guiio Garcia Jalon, Holly Roper, Tracy Scott, Catherine Sheppard, Louise Ting, Hazel Windmill.

Michaela Fay, Research Assistant, for her work collecting qualitative data in a variety of settings and contribution to analysis of such data.

Rose Watson, Research Assistant, for her work on collecting quantitative data at home visits; and her work collecting qualitative data in a variety of settings, with analysis of such data under supervision.

Julija Stoniute, Research Assistant, for her work on analysis of economic data with Jennifer Hislop.

Mark Deverill, Senior Lecturer in Health Economics, for his work in planning some aspects of the research and setting up of its early phases.

John Macfarlane, Consultant in Rehabilitation Medicine, for his work in planning some aspects of the research and recruiting study participants.

Susan Gray, Trainee in Paediatrics, for her help in preparing our published paper on those with diabetes.

Christopher King, Trainee in Child and Adolescent Psychiatry, for his help in preparing our draft paper on those with ASD.
The Warwick–Edinburgh Mental Well-being Scale was funded by the Scottish Government National Programme for Improving Mental Health and Well-being, commissioned by NHS Health Scotland, developed by the University of Warwick and the University of Edinburgh, and is jointly owned by NHS Health Scotland, the University of Warwick and the University of Edinburgh.

**Work package 3.1**

Elizabeth Rankin who was the Principal Investigator at one NHS site and supervised a Research Assistant in recruitment of participants.

Albert Farre, Research Assistant, who undertook a leading role in conducting ethnographic fieldwork across two NHS sites and led on the writing of two published papers.

Victoria Wood, Research Assistant, who undertook a leading role in conducting ethnographic fieldwork across one NHS site and contributed to two published papers.

**Work packages 3.2 and 3.3**

The members of the Steering Group for this WP: Dr Laura Baines, Dr Steve Ball, Dr Belinda Bateman, Ms Beverley Barclay, Professor Bryony Beresford, Dr Tim Cheetham, Dr Helena Gleeson, Ms Helen Hirst, Dr Mark Hudson, Dr David Jones, Dr Nicola Leech, Prof Robert Pickard, Mr Steve Rundle, Dr Gill Turner, Mr Ian Walton.

Angela Bate, Lecturer in Health Economics, for her work in the planning of the research and setting up of its early phases.

Sara McCafferty, Research Associate, for her work conducting interviews and initial elements of analysis in WP 3.2 and contributing to an academic.

Niina Kolehmainen, Consultant Occupational Therapist, for her work analysing and reporting data from qualitative interviews in WP 3.2 and contributing to an academic paper.

**Overarching**

The Programme’s young people’s group ‘United Progression’ (UP) and the local Child Health Action Team (CHAT).

Secretarial, Financial and Administrative staff: Sarah Nolan, Alison Mulvenna, Jaqueline Story, Norman Marillier.
Student helpers: Sarah Longwell, Rachel Pearse and Folasade Solanke for help with preparation of papers; Vito Puyat, for help with data entry.

We acknowledge the support of the NIHR Clinical Research Network.

We thank the sponsor, Northumbria Healthcare NHS Foundation Trust.

**Data sharing**

All data from the Programme are stored securely at Newcastle University.

Anonymised data will be made available to the scientific community with as few restrictions as feasible. Qualitative data cannot be released due to anonymity and consent concerns. All enquiries and data requests should be submitted to the corresponding author for consideration (using a specific form available on request). Access to data may be granted following review.

**Publications**


65Gray S, Cheetham T, McConachie H, Mann KD, Parr JR, Pearce MS, Colver A on behalf of the Transition Collaborative Group. A longitudinal, observational study examining the relationships of patient satisfaction with services and mental wellbeing to their clinical course in young people with Type 1 diabetes mellitus during transition from child to adult health services. Diabet Med. 2018 May 31. doi: 10.1111/dme.13698.


Solanke F, Colver A, McConachie H; on behalf of the Transition Collaborative Group. Are the health needs of young people with cerebral palsy met during transition from child to adult healthcare. Child: Care, Health and Development. 2018. 1-9 doi.org/10.1111/cch.12549


CONTRIBUTIONS OF THE AUTHORS OF THE REPORT

Allan Colver is Professor of Community Child Health at Newcastle University and a Consultant Paediatrician. He was the grant holder and led the Programme of Research. He led WP 3.3 and was directly involved in all other WPs except 2.2 and 2.3. He drafted the final report and is responsible for the final version and submission to NIHR. He is the corresponding author and guarantor of the work.

Tim Rapley was Senior Lecturer in Medical Sociology at Newcastle University and is now Professor of Applied Health Care Research at Northumbria University. He was a co-applicant. He led WP 2.2, co-led WP 3.1 and was directly involved in WP 1.1. In WPs 2.2 and 3.1 this work involved design of the qualitative work, supervision of research assistants and analysis of the transcripts of qualitative data. He assisted with many aspects of the engagement of young people in the programme’s work. He contributed detailed adjustments to the draft report and approved the final version.

Jeremy Parr is Professor of Paediatric Neurodisability at Newcastle University and a Consultant Paediatrician. He was a co-applicant. He was directly involved in WPs 1.3, 2.1, 2.2 and 3.1. This work involved co-design of these quantitative and qualitative studies, contribution to supervision of research assistants, lead contacts with clinicians for the Q-sort study, oversaw recruitment of people with diabetes for the longitudinal study, assisted with design of the DCE, and co-designed the DAH Toolkit. He contributed detailed adjustments to the draft report and approved the final version.

Helen McConachie is Professor of Child Clinical Psychology at Newcastle University. She was a co-applicant. She led WP 2.1. This work involved included involvement in the design of original programme co-design of the longitudinal study, arranging training of the research assistants, monitoring data collection and completeness, and advising on data analysis. She contributed detailed adjustments to the draft report and approved the final version.

Gail Dovey-Pearce is a Consultant Clinical Psychologist at Northumbria Healthcare NHS Foundation Trust. She was a co-applicant. She led WPs 1.1.and 1.2 and was directly involved in WPs 2.1 and 3.1. Her work involved leading on the engagement and involvement of young people, including setting up and running UP; supervision of the collection of longitudinal data across two sites; facilitating at one site the qualitative interviews. She contributed detailed adjustments to the draft report and approved the final version.
Ann Le Couteur is Professor of Child and Adolescent Psychiatry at Newcastle University and a Consultant Child and Adolescent Psychiatrist. She was a co-applicant. She was directly involved in WPs 2.1, 2.2, 3.2 and 3.3. This work included involvement in the design of original programme, liaising with sites that recruited those with ASD, interviewing commissioners, and critical review of qualitative and quantitative data. She contributed detailed adjustments to the draft report and approved the final version.

Janet McDonagh is a Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology at the University of Manchester. She was a co-applicant. She co-led WP 3.1 and was directly involved in WPs 1.1 and 1.2. This work included involvement in the design of original programme; local principal investigator at one of the three participating sites of WP 3.1; interpretation of data and writing of papers from WP 3.1; direct input and support for the health passport work of WP 1.2; identification and establishing links with relevant organisations elsewhere in the UK for WPs 1.1 and 1.2 to ensure generalisability of the outputs of the Programme. She contributed detailed adjustments to the draft report and approved the final version.

Caroline Bennett is Assistant Director of the Council for Disabled Children, London. She was a co-applicant. She was directly involved in WPs 1.1, 1.2 and 3.1. This work involved regular assistance with the engagement of young people in the programme’s work. She facilitated workshops in London and Newcastle which enabled young people from across the country to discuss preliminary results of the programme. She development facilitator guides for subsequent rollout of these workshops. She contributed detailed adjustments to the draft report and approved the final version.

Jennifer Hislop was a Research Associate in Health Economics at Newcastle University. She contributed to WPs 1.3 and 2.3. This work involved interviewing young people in the WP 1.3 Q-sort study and analysing the data. She contributed to one published paper. In WP 2.2 she developed a Discrete Choice Experiment, and she modelled the health economic data. She contributed detailed adjustments to the draft report and approved the final version.

Gregory Maniatopoulos is a Senior Research Associate in Medical Sociology at Newcastle University. He led WP 3.2 and was directly involved in WP 3.3. His work involved analysis of qualitative data, three in-depth site visits, and contributions to two submitted papers, one of which he led. He contributed detailed adjustments to the draft report and approved the final version.
Kay Mann was a Research Assistant in Epidemiology at Newcastle University. She contributed to WP 2.1. This work involved cleaning, coding and analysis of data from all collection phases. She contributed detailed adjustments to the draft report and approved the final version.

Hannah Merrick was a Research Assistant at Newcastle University. She contributed to WP 2.1, drafted and distributed newsletters, organised internal seminars and identified relevant new publications in the field. The work in WP 2.1 involved collection of data, data checking, analysis of data is work involved. She contributed to two published papers. She contributed detailed adjustments to the draft report and approved the final version.

Mark Pearce is Professor of Applied Epidemiology at Newcastle University. He was a co-applicant. He was directly involved in WPs 2.1 and 2.3. This work involved supervision of a research assistant and detailed discussions about methods of analysis and interpretation of results. He contributed detailed adjustments to the draft report and approved the final version.

Debbie Reape was Deputy Director of Nursing at Northumbria Healthcare NHS Foundation Trust. She was a co-applicant. She was directly involved in WPs 1.1, 1.2, 3.1 and 3.2. This work involved assistance with many aspects of the engagement of young people in the programme’s work. As senior manager in the sponsoring Trust, she facilitated meetings and provided contacts for interviews with commissioners. She participated in data collection in WP 3.2 at meetings with commissioners. She contributed detailed adjustments to the draft report and approved the final version.

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In 2010 we were awarded a Programme Development Grant RP-DG-1108-10015. In summary:

- We learnt from a young person group how to develop and run a young person’s advisory group for a Programme
- We found widespread interest in the research from voluntary organisations; the Council for Disabled Children joined the application
- We identified ten NHS Trusts that would recruit participants to the Programme
- Meetings with Trust Chief Executives led to modifications to the content of the proposal for a Programme
- A literature review found that few studies that evaluated transitional healthcare assessed whether the services were sustainable or what helped Transition in the long term
- We estimated the number of young people our work could benefit in the UK as 25,000 per year group
- We piloted questionnaires. We researched different methods for approaching, recruiting and retaining young people in a Programme
Appendix 2: Management and governance of the Research Programme

An External Advisory Board met once a year, chaired by the Chief Executive of an NHS Trust (see Acknowledgements section).

The Programme was managed by the Programme Management Board. This was chaired by the Chief Investigator and consisted of the Programmes’ co-applicants and two adult physician advisors. It met every three months.

A senior management team, consisting of the chief investigator and the leads for the qualitative, quantitative and health economic work, met every two weeks.

The Programme’s Young People’s Advisory Group (see WP 1.1) met every month.

Each year a report was submitted to NIHR and subsequently approved.

All studies received positive ethics opinions from either the NHS or Newcastle University.

Figure 11

Management structure
Appendix 3: Work of UP group
In this appendix and the next one we present some examples of the work of UP.

UP design: Certificate of achievement for research participants
Presentation Overview

- Welcome (Ed)
- Introduction (Sophie)
- The Role of UP (George)
- The Importance of Our Research & Case Study (Ed)
- Our Completed Achievements (Joseph & Sophie)
- Concluding Statements (Ed)

Introduction

- Led by NHCFT with researchers from Newcastle university
- Funded by the NHIR
- 5 year study involving 500 young people
- Conditions which include Diabetes, Cerebral Palsy, Autism
- Aims – to improve care for teenagers as they move from children to adult healthcare services
The Role of UP

- To represent the voices of young people
- HONEST communication between UP and the PMB
- The opportunity for young people and professionals to work alongside as equals
- Democratic decision making paramount
- Work on serious issues and tasks in partnership with the PMB
- Question the decision making of the PMB
The Importance of Our Research

• We believe the NHS is not getting services right for young people
• We need to get it right for future generations
• We need to keep The World informed on new & important discoveries
• To leave a **GOLDEN** legacy for the future generations, to look UP to us!

Our Completed Achievements

• Peer support workers recruited research staff to assist
• Group formation & familiarization
• Group name and designed logo
• Code of conduct and contract
• Designed certificates
• Informed the Q sort study
Any Questions?
UP Poster: What we’ve been UP to

WHAT WE’VE BEEN UP TO

United Progression: The UP Group
The Young People’s Working Group on the NHS Transition Research Programme

Help With The Other Transition Programme Workstreams

In answer to the question what is “Developmentally Appropriate Healthcare”, UP filmed ‘Transitioning to the Future’, which took a humorous look at the important issues of how health professionals interact with young people. 

https://research.nhs.uk/transitions/TOPP/engagement/Meetingwithyoungpeople.aspx

Developmentally Appropriate Healthcare is young-person centred, flexible, and responsive to the changing developmental needs of young people.

The SDU was shown at a Health Foundation seminar on Developmentally Appropriate Healthcare.

Following the seminar, the National Institute for Health Research mentioned the film on its website, as part of an article showcasing UP’s contribution to health research.

Designed a recruitment poster and booklet for the longitudinal study which followed young people for four years as they moved from paediatric to adult services.

Designed certificates for young people completing every year of the 4-year longitudinal study.

Analysed and commented on the ‘Proposed Beneficial Service Features’, being investigated in the main study, in time with their own experience of transition.

Travelled and commented on the young people’s Preferences Study—preparing, consulting service features rated as important to young people themselves.


Linked With Local and National Organisations

Takeover Day at the Department of Health, London, which allowed young people’s voices to be heard. Showcased Transition & UP’s research and also learned about other young people involvement groups.

Contributed to the Royal College of Physicians talking heads video which is now used as part of their e-learning tool for clinicians.

Provided case study material for the National Network for Adolescent Immunization report into the involvement of young people in health-related research.

As part of the Transition research group our comments were included in feedback on the draft NICE Guidance on Transition, since published in February 2016.

Involved with the Council for Disabled Children’s North East event for Developmentally Appropriate Healthcare.

Created a poster to summarise UP’s involvement in research, and attended the Young Person’s Advisory Group—North of England conference which was centred around the involvement of young people in research.

Running Of The Transition Programme

Four young people were recruited as peer support workers for the newly forming UP group. They had experience of being involved in health services development and supported the researchers to recruit and form the UP group.

Whilst the UP group was forming, these peer support workers were involved with the recruitment of the Transition programme research associates.

They sat on interview panels for the recruitment of Transition research associates and participation worker posts.

They were involved in the training of these Research Associates.

Transition Programme Launch Event: UP created a powerpoint presentation and presented and participated in a Q&A session.

UP provided material and design input for the transition website, including personal blogs and quotes, the inclusion of a young person page with a sub-section of the Young People’s Working Group – UP pages, and a link to the ‘Transitioning to the Future’ film clip.

UP worked with Transition’s External Advisory Board to give the young person’s perspectives to the national and international collaborations that were helping to govern the programme.

Showcasing Involvement Of Young People

Produced press release for local media about the launch of Transition Research and the importance of getting it right for young people.

Past, Present and Future Conference: presentations to local healthcare managers and researchers about involvement experience and health passport research pilot study. UP created an inviting, powerpoint presentation and speeches.

UP member received award from local newspaper in their annual awards ceremony in recognition of his work in the community.

Youth Achievement Awards: UP members chose to capture their work as young researchers to achieve these awards.

UP developed new skills which they were able to transfer into finding employment and other opportunities.

Peer support workers co-authored academic paper on young people’s involvement.

UP were acknowledged as co-authors of research paper on proposed beneficial features of transition services.

Feedback in other research group on video ‘Cricket’, a documentary about young people suffering from psychosis.

Help with the other transition programme workstreams.

Developed a recruitment poster and booklet for the longitudinal study which followed young people for four years as they moved from paediatric to adult services.

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Appendix 4: Health passport

UP Poster: Health passport

Health Passports
United Progression: The UP Group
The Young People’s Working Group on the NHS Transition Research Programme

Background & Aims
We looked at Transition from our personal experiences and thought about what might have helped us as we went through it.

A “survival guide” might have helped.

We looked at a range of Health Passports.

We found that lots of Health Passports were in use, but none had been evaluated.

We discovered that there was no definition of a Health Passport.

We thought there was no point in developing another new Health Passport and decided to evaluate existing ones.

Exploring Current Practice
We examined a range of existing Health Passports and wanted to explore:

WHO?
Who benefits from them?
Who wants them?
Are the views of parents/carers, health professionals and young people different?

HOW?
How are young people supported?
How are the Health Passports used in practice?

WHAT?
What kind of health passports are being used in the UK?
What are the essential elements to making a really great health passport?
Do different groups of people need different things?
What is the potential role of technology, in terms of the design of these tools?

Developing Our Research Tools
UP consulted with healthcare professionals from Birmingham Children’s Hospital and Warrington and Halton Hospitals about their experience of young people using Health Passports.

We examined a number of existing Universal and Condition Specific Health Passports.

We then devised our research questions.

We asked for help in streamlining the questionnaire and a member of the Patient Experience Team helped us look at the processes of our questions and the design of our questionnaire.

1. Is your Health Passport only useful for some appointments?
2. Do you feel you need to take it to your appointment?
3. Why don’t you use your Health Passport?
4. Where else do you use your Health Passport?
5. Do you feel you’ve outgrown your Health Passport?
6. How long have you had your Health Passport?

We got Health Professionals to agree to distribute our questionnaire so that we could gather data from young people who were using Health Passports.

Findings/Conclusions From Young People

100% don’t complete Health Passports alone.
75% agreed they’re useful.
40% sometimes take their Health Passport to appointments.
60% never take them to appointments.
65% always take them to their appointments.
25% were not sure if they were helpful.
28.5% thought they alone benefited from having a Health Passport.
28.5% believed both they and the health professionals benefited.
23% thought health professionals benefited.

There is no defined process in how Health Passports are used.

The process of using Health Passports needs to be clarified and supported.

The way forward........mobile applications?

Useful Links:
https://research.ncl.ac.uk/transition/
https://research.ncl.ac.uk/transition/pdfs/appendix4/transitionsresearchgrouppdf.pdf

Acknowledgements: Laura Brearley, ThinkingLuggage; Council for Disabled Children; ONCH Transition Collaborative Group & Programme Management Board and Teams: Caroline Potts and Verona Cardill

Northumbria Healthcare

Newcastle University
Appendix 5: Q-sort study

URL Q-sort paper
Views of Young People with Chronic Conditions on Transition from Paediatric to Adult Health Services

Green Open Access

http://eprint.ncl.ac.uk/file_store/production/224849/E1A00598-BA4C-48E0-8870-3362E979033B.pdf
Appendix 6: Longitudinal study (Quantitative)

In this appendix we list the URLs of the papers we refer to in the synopsis.

Then we present some additional tables/figures mentioned in the synopsis and then the draft of a paper submitted for publication.

**URL Protocol paper**
Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services.

Gold Open Access

[http://www.biomedcentral.com/1471-2458/13/675](http://www.biomedcentral.com/1471-2458/13/675)


**URL Baseline data paper**
Characteristics of young people with long term conditions close to transfer to adult health services.

Gold Open Access


[https://doi.org/10.1186/s12913-015-1095-6](https://doi.org/10.1186/s12913-015-1095-6)

**URL Delivery of services paper**
How well do services for young people with long term conditions deliver features proposed to improve transition?

Gold Open Access


**URL Health needs of young people with cerebral palsy paper**
Are the health needs of young people with cerebral palsy met during transition from child to adult healthcare?

Gold Open Access


https://doi.org/10.1111/cch.12549

**URL Clinical course in diabetes paper**
A longitudinal, observational study examining the relationships of patient satisfaction with services and mental wellbeing to their clinical course in young people with Type 1 diabetes mellitus during transition from child to adult health services.

Gold Open Access


https://doi.org/10.1111/dme.13698

**URL Features associated with better outcomes paper**
A longitudinal, observational study of the Features of transitional healthcare associated with better outcomes for young people with long-term conditions.

Gold Open Access


https://doi.org/10.1186/s12916-018-1102-y
**Table 15: Proposed beneficial features**

<table>
<thead>
<tr>
<th>Feature</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age-banded clinic.</strong></td>
<td>An intermediate clinic setting such as a young person’s clinic or a young adult team. In child health services, it would mean that children less than about 14 years would not be at the clinic. In adult services it would mean adults over about 24 years would not be at the clinic.</td>
</tr>
<tr>
<td><strong>Meet adult team before transfer.</strong></td>
<td>This could be in a joint clinic where senior paediatric and adult clinicians consult together; or the adult clinician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult team.</td>
</tr>
<tr>
<td><strong>Promotion of health self-efficacy.</strong></td>
<td>The young person is asked ‘Have you received enough help to increase your confidence in managing your condition?’ The clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition.</td>
</tr>
<tr>
<td><strong>Written transition plan.</strong></td>
<td>This should be created some time before transfer. It should include plans for wider Transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated.</td>
</tr>
<tr>
<td><strong>Appropriate parent involvement</strong></td>
<td>in their child’s care, but with changing responsibilities. Parent and young person are asked separately if they think the level of involvement is appropriate. Involvement concerns what happens in the clinic (parent being present or not and who does the talking) and also discussions at home about the young person’s health and how to manage it.</td>
</tr>
<tr>
<td><strong>Key worker.</strong></td>
<td>This is a single person known to the young person whom they could easily contact or go to if there were any problems of co-ordination or misunderstandings that needed to be sorted out. The role could cross into education and social services. Whilst a clinic may have a policy to ‘appoint’ a key worker, the young person may report it is someone else they feel most comfortable with.</td>
</tr>
<tr>
<td><strong>Coordinated team.</strong></td>
<td>Some young people need to see a team of people. Those with diabetes may need to see doctor, nurse, dietician, and psychologist. Those with cerebral palsy may need to see doctor, physiotherapist, and orthopaedic surgeon. The members of these teams need to work together and communicate well together, and demonstrate to the young person that this is</td>
</tr>
</tbody>
</table>
happening. Coordination of appointments on the same day demonstrates this.

**Holistic life-skills training** for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The young person is asked whether they have had any formal life-skill training offered because of their condition. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.

**Transition manager for clinical team.** The individual who coordinates transition in a clinical team may not be known to the young person. The manager will facilitate good working relationships between adult and child services; ensure that there are appropriate materials available for things such as health education or the transition plan; and will monitor whether the young person has a suitable appointment in adult services and whether the appointment is kept.
Figure 12: Recruitment of participants
Figure 13: Retention to visit 4

Work Package 2.1 Longitudinal Study

Reasons for dropout:

<table>
<thead>
<tr>
<th>Reason</th>
<th>N (71)</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not interested in taking part</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>Other commitments</td>
<td>19</td>
<td>School, work, university</td>
</tr>
<tr>
<td>Personal Issues</td>
<td>11</td>
<td>Young person too ill, recent surgery, victim of a crime.</td>
</tr>
<tr>
<td>Family issues</td>
<td>8</td>
<td>Other family member having health issues</td>
</tr>
<tr>
<td>Questionnaires too difficult</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>No reason given/recorded</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Don’t like talking about</td>
<td>2</td>
<td>Young people were coping well with condition and just wanted to “get on with their life” and not talk about their condition.</td>
</tr>
<tr>
<td>condition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems with health service</td>
<td>1</td>
<td>One family withdrew from the study due to problems they were experiencing with the service they attended.</td>
</tr>
</tbody>
</table>

No significant differences across the condition groups in the numbers that withdrew or were lost to follow-up.
Draft paper Young people with autism spectrum disorder

Title: Predictors and experience of transfer of young people with ASD from child and adolescent mental health services.

Authors: Hannah Merrick, Chris King, Helen McConachie, Jeremy Parr, Ann Le Couteur

Abstract

Transition to adulthood can be difficult for young people with ASD, as they juggle the challenges of adolescence and navigate leaving child and adolescent mental health services (CAMHS). This analysis describes the experiences and outcomes of a sample of UK young people aged 14-21 years, with ASD and additional mental health problems, as they were discharged from CAMHS. The young people were followed over 3 years. Measures of mental health and qualitative contextual (clinical, family, social, educational) information was used to capture their experiences. Having an ADHD diagnosis and taking medication were predictors of transfer to adult mental health services. The qualitative themes allowed us to understand the young people’s transition experiences and identify variables associated with positive outcomes and ongoing problems.

Introduction

Transition into adulthood involves a number of different developmental tasks, including entering further education or employment, having meaningful social participation, and developing independent living skills or leaving home. Transition for young people with autism spectrum disorder (ASD) to adulthood has been a topic of increased interest as it becomes evident that it can be a particularly difficult period for individuals and their families. Some of these difficulties include low rates of post-secondary education and employment, low social participation, higher rates of bullying, and struggles gaining autonomy and independence in young adulthood. These difficulties have been identified for young people with high functioning ASD when compared with equally able young people in the general population.

One aspect that may make transition particularly difficult for this group is the presence of additional commonly occurring comorbidities, including mental health problems such as attention deficit hyperactivity disorder (ADHD), anxiety, and emotional disorders. As well as managing several major life transitions, these young people with ASD and additional mental health problems also have to navigate the transition from children and adolescent
mental health services (CAMHS).\textsuperscript{175} Healthcare providers, parents and young people have reported concerns about healthcare transitions, in particular those with high functioning ASD.\textsuperscript{175, 176} Studies of the experiences of young people with ASD (without intellectual disabilities), and their parents, as they negotiate transition into young adulthood, report that the uncertainties about the challenges of accessing appropriate support and services was a worry, particularly in terms of the potential negative impact on the young person’s wellbeing and mental health.\textsuperscript{177} The presence of co-morbidities together with an ASD diagnosis may also be acting as an additional barrier to finding meaningful day time activities and potentially result in lower levels of social participation.\textsuperscript{178}

Most young people in England and Wales attending CAMHS are discharged to primary care services (family practitioner) rather than being referred onto adult mental health services (AMHS).\textsuperscript{179} This can be due to a variety of reasons including no longer needing clinical mental health involvement, presenting problems not meeting criteria for AMHS, or disengagement from services.\textsuperscript{180} For some young people discharge to primary care is an appropriate course of action. However, in a UK study of young people with ongoing mental health disorders, certain groups of young people such as those with emotional, neurodevelopmental (including ADHD and ASD), or emerging personality difficulties were found to be at an increased risk of not accessing adult services and were described as “falling through the CAMHS-AMHS gap”.\textsuperscript{179, 181} There is then a concern that for some of these young people with neurodevelopmental disorders, their unmet mental needs may increase their risks of poorer outcomes with low levels of participation and wellbeing compared to other young people, crisis presentations at accident and emergency departments, or contact with criminal justice system. These young people may then at a later date be at an increased risk of presenting to adult services following a crisis, or with more serious and enduring mental health problem.

For young people with ongoing mental health needs that are referred from CAMHS to AMHS, poorly planned transitions can make the shift from the child-centred developmental approach of CAMHS to the adult-centred care of AMHS difficult for both the young people and their families.\textsuperscript{5} There are also reports of unmet need and dissatisfaction with care.\textsuperscript{182} This applies especially to young people with ASD who report a lack of support for both the ASD and the mental health problem, particularly when services are designed for neurotypical individuals.\textsuperscript{183}
In one UK study investigating predictors of service use outcomes for young people discharged from CAMHS,\textsuperscript{179} found that being on medication at the time of transition and having a severe or enduring mental health condition, such as schizophrenia, bipolar affective disorder and psychotic disorders, were predictors of transfer to AMHS. This might raise an expectation that young people with ASD and ADHD and in particular those in receipt of regular medication, would be referred on to AMHS. However according to the UK NICE clinical guideline for individuals (children and adults) with ADHD (albeit not necessarily with additional ASD), shared care agreements with primary care (family practitioner) should exist.\textsuperscript{184}

Not all young adults with ASD experience an exacerbation of their difficulties when they are transitioning to adulthood. For some, outcomes (e.g. education, employment, independent living and social participation) in adulthood are more positive, for example with meaningful employment and independent living being achieved in adulthood. Farley\textsuperscript{185} in a US study of 41 adults with average or near average cognitive abilities (mean age 32.5 years) highlighted the importance of community support and integration in increasing social participation. Kirby\textsuperscript{186} in a systematic review of predictors of successful social outcomes in young adults with ASD, identified five conceptual categories: ‘personal characteristics’ (e.g. age, gender and race), ‘individual functioning’ (e.g. IQ, diagnosis/severity), ‘family context’ (e.g. household income, educational level of parents), ‘services’ (e.g. career counselling), and ‘other’ (e.g. general heath). The review also identified varying levels of evidence for these predictors of successful outcome and highlighted a need for more high-quality research on outcomes for adults with ASD to inform practice, especially in relation to factors related to the family and services received. However, outcomes need to be defined and assessed in a more nuanced manner taking into account the preferences of individuals with ASD and their families, for instance in terms of what is achievable and preferable for each individual rather than simply comparing across population norms.\textsuperscript{187}

This paper uses data from a recently completed UK longitudinal study of young people with long term conditions (diabetes, cerebral palsy and ASD with additional mental health problems). We were able to review, over a 3-year period, the outcomes of the group of young people with ASD and additional MH problems as they were discharged from CAMHS. The aim of this secondary analysis was to identify those young people with ASD who transferred from CAMHS to AMHS, and to compare their levels of achievement and need with those who were discharged to primary care and those who remained in CAMHS beyond
age 18 years. This analysis is intended to inform future practice, especially in respect to identifying how best to facilitate appropriate transition arrangements for this group of young people as they are discharged from CAMHS.

**Methods**

Young people aged 14-18 years, with a diagnosis of ASD who were accessing CAMHS for an additional mental health problem, were recruited to the Transition Longitudinal project ([http://research.ncl.ac.uk/transition/](http://research.ncl.ac.uk/transition/)) between October 2012 and October 2013. All were referred as in the average ability range, and able to complete questionnaires (with or without support). Young people were recruited from mental health clinical services in three different parts of England. The young people were visited once a year for 3 years (four visits in total) and asked to complete several questionnaires. Full details of the study protocol have previously been published and baseline characteristics of the sample.

The study received a favourable ethical opinion from Newcastle and North Tyneside 1 Research Ethics Committee. Numbers 12/NE/0059 and 12/NE/0284. All young people provided signed consent to join the study. For young people under sixteen years of age, the young people signed an assent form and a parent provided signed consent for their child to join the study.

**Measures**

The following measures were completed at each visit:

* **Sociodemographic Questionnaire**: Using a bespoke questionnaire we collected data on gender, education and employment status, and socioeconomic status (postcodes used to calculate the ‘index of multiple deprivation’ (IMD, higher scores indicate more socioeconomic deprivation).

* **Hospital Anxiety and Depression Scale (HADS)**: a 14-item questionnaire completed by the young people measures the severity of mental health problems with two subscales of anxiety and depression. Total scores can be categorised into ‘normal’ (0-7), ‘borderline abnormal’ (8-11) and ‘abnormal’ or clinical caseness (12-21). An initial validation study of this questionnaire has shown excellent psychometric properties in samples of older adolescents and young adults with ASD.
Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS):76 a 14-item, questionnaire (also completed by the young people), developed in the UK and valid in the age range 13 to 21 years that captures young people’s mental wellbeing. The scale had good internal consistency supporting the suitability of this measure for this group.

The Strengths and Difficulties Questionnaire (SDQ):188, 189 SDQ: was completed by both the young person and the parent.

Social Responsiveness Scale:190 This measure was completed by the parents and was used to confirm autism characteristics.

Information collated by the research assistants:

Information derived from clinical case notes: Before each of the follow-up visits the trained research assistants (RA) with the young people’s consent, accessed the clinical mental health case notes to record details of appointments including whether the appointment was attended, medication prescriptions given, and diagnoses. This information was used to determine a date of final appointment in children’s services (described as date of transfer).

Qualitative Data: At each visit the RAs made notes of contextual information about each young person, their family, and service provision (e.g. family issues, changes in school or service provider, comments about access to and lack of support or problems at school). Information was also recorded from clinical mental health case notes that was relevant to the process of transition, referrals made, and issues discussed during clinical appointments. The RAs recorded descriptions of difficulties and complexities for the young person, their family and relevant professionals together with positive successes and achievements for the young people.

Data Analysis

Quantitative Data Analysis: SPSS version 23 was used for data analysis. Descriptive statistics of education and employment status, age, gender, transfer location, age at transfer, medication use, additional mental health problem(s) and measures of mental health are presented. Logistic regression was used to identify predictors of transfer from CAMHS to either AMHS or discharge to primary care (family practitioner).

Qualitative Data Analysis: Framework analysis191 was used to consider all the available recorded contextual data for young people and their families. Authors 1 and 2 familiarised
themselves with the data, noting initial emerging themes. Themes were informed by the authors’ knowledge of the literature. A thematic framework was then developed and applied to the data. The data were presented as a table with each row representing a participant and each column representing a theme. This allowed each theme to be summarised and for exploration of patterns and associations in the data. A 10% sample was double sorted to ensure consistency and reliability. These themes were then refined into categories which are presented below. Any differences were discussed and resolved through consensus. The themes and categories were reviewed and finalised with the fifth author.

Mental Health Trajectories:

To help us understand further the interaction of the young people’s self-reported mental health and their transition to adulthood over the 3-year study period, we reviewed the trajectory of the young people’s HADS scores for those who completed HADS data on at least three of the four visits (n=87). The HADS is a measure of each young person’s mental health status for the week prior to each research visit. Using the sequence of each young person’s self-reported HADS scores, young people were grouped into three types of trajectories: those doing well with ‘normal’ HADS scores across all visits or showing improvement from abnormal or borderline abnormal scores to normal scores at the final visit; those with continued moderate difficulty, who continued to have borderline abnormal mental health problems over the visits or fluctuated between borderline and abnormal scores; and those who were not doing well where the young person reported continued abnormal HADS scores or had a decrease in scores over the study period ending with a score in the abnormal range. The trajectory of each young person was individually assessed by the first two authors and a consensus agreed.

Results

Baseline Demographics

In total, 118 young people with ASD and additional mental health problems were recruited and completed baseline measures (mean age: 16.1yrs, range: 14yrs-18.9yrs). Eighty-two (69.5%) of the sample were male, 36 (30.5%) female, and nearly all were white British (98.3%). At baseline the majority of young people were in full time education (either school or college; 93.2%). A small number of the young people had a part time job (6%) or did some volunteer work (2.6%).
All the young people had a diagnosis of ASD at recruitment and were accessing CAMHS for support with additional mental health problems. The mean total young person-reported SDQ score at baseline was 17.6 (SD = 6.1), parent reported SDQ was 22.8 (SD = 5.9), and the mean SRS score was 117.2 (SD = 29.7). SDQ scores of our sample were found to be significantly higher (indicating greater severity) than scores of a subset of young people aged 16 years with ASD from the UK Special Needs and Autism Project (SNAP) community sample.\textsuperscript{174} The young people’s median wellbeing score (WEMWBS) at baseline was 47 (IQR: 41–52), significantly below population norms\textsuperscript{192} and remained significantly below population norms at all visits.

Out of the 118 young people recruited, 88 completed a final visit. As previously reported, there were no significant differences between those who remained in the study and those who withdrew from the study in terms of condition severity or socio-demographic factors.

\textit{Transfer Location}

Of the 30 young people who withdrew from the study, information was available for five subjects on their transfer location and so were included in the analyses. For the 93 young people for whom transfer data was available, 20 young people were still accessing CAMHS, 48 had transferred to primary care, and 25 had transferred to AMHS. Table 16 compares the characteristics of the young people by transfer location.
## Table 16: Characteristics of sample by transfer location

<table>
<thead>
<tr>
<th>Transfer location</th>
<th>CAMHS (final visit data)</th>
<th>General practitioner (pre-transfer visit data)</th>
<th>AMHS (final visit data)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16 (80)</td>
<td>31 (65)</td>
<td>16 (64)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (20)</td>
<td>17 (35)</td>
<td>9 (36)</td>
</tr>
<tr>
<td>Age at visit before transfer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>17.7</td>
<td>17.4</td>
<td>18.2</td>
</tr>
<tr>
<td>Range</td>
<td>16.13 - 20.30</td>
<td>14.7 – 19.75</td>
<td>16.5 – 19.9</td>
</tr>
<tr>
<td>SD</td>
<td>0.89</td>
<td>0.89</td>
<td>0.69</td>
</tr>
<tr>
<td>WEMWBS ¹</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>49.4 (7.47)</td>
<td>45.6 (8.00)</td>
<td>46.52 (10.17)</td>
</tr>
<tr>
<td>Range</td>
<td>35-70</td>
<td>29-70</td>
<td>27-70</td>
</tr>
<tr>
<td>IMD at baseline</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>18.98 (11.36)</td>
<td>23.94 (18.133)</td>
<td>24.45 (18.74)</td>
</tr>
<tr>
<td>Range</td>
<td>2.46-38.82</td>
<td>2.17-80.51</td>
<td>3.72-71.83</td>
</tr>
<tr>
<td>Prescribed medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16 (80)</td>
<td>27 (56)</td>
<td>20 (80)</td>
</tr>
<tr>
<td>Education and employment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full/Part Time Education</td>
<td>15 (75)</td>
<td>41 (85.4)</td>
<td>21 (84)</td>
</tr>
<tr>
<td>Employed</td>
<td>4 (20)</td>
<td>1 (2)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Not In Education Or Employment</td>
<td>1 (5)</td>
<td>6 (12.5)</td>
<td>2 (8)</td>
</tr>
<tr>
<td>Number of mental health problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>8 (40)</td>
<td>27 (56)</td>
<td>15 (60)</td>
</tr>
<tr>
<td>≥2</td>
<td>12 (60)</td>
<td>16 (33)</td>
<td>10 (40)</td>
</tr>
<tr>
<td>Mental health problem</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADHD/ADD</td>
<td>12 (60)</td>
<td>8 (16.7)</td>
<td>15 (60)</td>
</tr>
<tr>
<td>Mood a</td>
<td>2 (10)</td>
<td>18 (38)</td>
<td>7 (28)</td>
</tr>
<tr>
<td>Anxiety b</td>
<td>9 (45)</td>
<td>22 (46)</td>
<td>6 (24)</td>
</tr>
<tr>
<td>Odd/Challenging Behaviour e</td>
<td>2 (10)</td>
<td>5 (10)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Sleep disorders d</td>
<td>6 (30)</td>
<td>7 (15)</td>
<td>4 (16)</td>
</tr>
<tr>
<td>Other e</td>
<td>4 (20)</td>
<td>1 (2)</td>
<td>3 (12)</td>
</tr>
<tr>
<td>Self-harm</td>
<td>(5)1</td>
<td>2 (4)</td>
<td>5 (20)</td>
</tr>
<tr>
<td>HADS (Anxiety)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;8</td>
<td>7 (35)</td>
<td>20 (42)</td>
<td>10 (40)</td>
</tr>
<tr>
<td>≥8</td>
<td>13 (65)</td>
<td>28 (58)</td>
<td>15 (60)</td>
</tr>
<tr>
<td>HADS (Depression)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;8</td>
<td>18 (90)</td>
<td>39 (81)</td>
<td>17 (68)</td>
</tr>
<tr>
<td>≥8</td>
<td>2 (10)</td>
<td>9 (19)</td>
<td>8 (32)</td>
</tr>
<tr>
<td>Developmental disorder f</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 (15)</td>
<td>5 (10)</td>
<td>5 (20)</td>
</tr>
</tbody>
</table>
Significantly below population norms across all groups

- Depression, low mood;  
- Anxiety, Obsessive Compulsive Disorder, phobia, social anxiety;
- Oppositional Defiant Disorder, Conduct Disorder, challenging behaviour, behavioural problems, aggression, anger management problems;  
- Insomnia, requiring melatonin
- Conversion disorder, psychosis (1 young person), chronic fatigue syndrome
- Dyslexia, dyspraxia, dyscalculia, Developmental Coordination Disorder
- Asthma, epilepsy (1 young person), allergies, migraines, thyroid dysfunction

CAMHS Child and Adolescent Mental Health Services
AMHS Adult Mental Health Services

The logistic regression findings are presented in Table 17. Overall the model was significant in predicting transfer outcome, $\chi^2(7) = 18.58$, $p=0.010$. Nagelkerke $R^2$ indicates that the model explains 32% of the variation in outcome. The odds of being transferred to adult services were significantly greater for those young people who had a diagnosis of ADHD (OR= 8.22 (95% CI=2.33-29.02) $p=0.001$) and young people who were prescribed medication for their mental health problem (OR=3.99 (95% CI=1.00-15.95), $p=0.05$).

### Table 17: Logistic Regression for predictors of transfer location

<table>
<thead>
<tr>
<th>Variable</th>
<th>N (%)</th>
<th>OR (95% CI)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescribed medication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>47 (66)</td>
<td>3.99 (1.00-15.95)</td>
<td>0.05</td>
</tr>
<tr>
<td>No</td>
<td>24 (34)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional mental health problem</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADHD</td>
<td>23 (32)</td>
<td>8.22 (2.33-29.02)</td>
<td>0.001</td>
</tr>
<tr>
<td>Not ADHD</td>
<td>48 (68)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of mental health problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>45 (63)</td>
<td>1.04 (0.31-3.43)</td>
<td>0.95</td>
</tr>
<tr>
<td>≥2</td>
<td>26 (37)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HADS anxiety</td>
<td></td>
<td>1.06 (0.89-1.25)</td>
<td>0.53</td>
</tr>
<tr>
<td>HADS depression</td>
<td></td>
<td>1.03 (0.85-1.26)</td>
<td>0.75</td>
</tr>
<tr>
<td>WEMWBS</td>
<td></td>
<td>1.04 (0.94-1.15)</td>
<td>0.51</td>
</tr>
<tr>
<td>IMD score (baseline)</td>
<td></td>
<td>0.99 (0.96-1.03)</td>
<td>0.71</td>
</tr>
</tbody>
</table>
Qualitative Analysis

Framework analysis was used to explore the qualitative data using all available visits of the 118 young people who joined the study. Twenty-four themes were identified and then summarised into seven categories that described the young people’s and their parents’ experience of transition during their time in the study (see Figure 14).

Figure 14: Categories from framework analysis

The framework identified a number of themes related to the young people’s mental health including their level of engagement with mental health services, engagement with medication and/or interventions, and times of crisis where their mental health problems resulted in emergency department attendance, self-harm or crisis team involvement. Other themes related to developmental and adolescent factors such as school transitions, seeking employment and managing social relationships, describing both successes in these areas as well as the difficulties experienced by some of the young people. How the young people experienced their ASD symptomology and how this impacted on developmental transitions and their transition from CAMHS was a theme of considerable significance for both young person and families. Some broader themes around family support and family health were raised, as well as the parents’ concerns about the young person’s social/emotional maturity.
and vulnerability as they dealt with the discharge from CAMHS and the wider agenda of transition of their child into adulthood.

**Mental Health Trajectory**

Using the sequence of each young person’s self-reported HADS scores, young people were grouped into three types of trajectories: those *doing well* (N=26), those with *continued moderate difficulty* (N=29), and those who were *not doing well* (N=32). There were no significant differences in transfer outcome, age, baseline SRS scores, or additional mental health diagnoses between the three groups. However there were some differences between the groups in terms of WEMWBS, SDQ scores and gender (Table 18): the WEMWBS scores was significantly lower in the ‘*not doing well*’ group compared to the other groups across all time points; those in the ‘*doing well*’ group reported significantly lower baseline SDQ scores than the other two groups (add test and level of significance), and there were significantly more females in the ‘*not doing well*’ group. Using the combination of the different data sources enabled appreciation of the experiences of the young people, their families and clinicians (see Table 18) across the three HADS groupings.

Table 18: Differences between HADS trajectory groups

<table>
<thead>
<tr>
<th></th>
<th>Doing well</th>
<th>Moderate difficulty</th>
<th>Not doing well</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CAMHS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 (26.1)</td>
<td>5 (17.2)</td>
<td>7 (23.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Transfer location</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 (43.5)</td>
<td>15 (51.7)</td>
<td>16 (53.3)</td>
<td></td>
</tr>
<tr>
<td>AMHS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 (30.4)</td>
<td>9 (31)</td>
<td>7 (23.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 (13)</td>
<td>9 (31)</td>
<td>15 (60)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 (87)</td>
<td>20 (69)</td>
<td>12 (40)</td>
<td></td>
</tr>
<tr>
<td><strong>Mean (SD)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young person SDQ total</td>
<td>14.17 (3.6)</td>
<td>19.49 (4.5)</td>
<td>20.38 (6.7)</td>
</tr>
<tr>
<td>Parent SDQ total1</td>
<td>22.09 (5.3)</td>
<td>22.45 (5.3)</td>
<td>22.23 (6.9)</td>
</tr>
<tr>
<td>SRS scores1</td>
<td>114.41 (19.7)</td>
<td>123.41 (27.9)</td>
<td>109.38 (31.8)</td>
</tr>
<tr>
<td>WEMWBS2</td>
<td>49.96 (7.8)</td>
<td>44.0 (8.2)</td>
<td>42.57 (9.0)</td>
</tr>
<tr>
<td>Visit 1</td>
<td>52.27 (6.9)</td>
<td>45.25 (8.4)</td>
<td>41.89 (9.1)</td>
</tr>
<tr>
<td>Final visit</td>
<td>53.96 (8.1)</td>
<td>46.61 (7.6)</td>
<td>41.32 (10.3)</td>
</tr>
</tbody>
</table>

1 Higher scores reflect more difficulties on the SDQ and greater social impairment on the SRS
2 Higher scores reflect better mental wellbeing

SDQ Strength and difficulties questionnaire
SRS Social responsiveness scale
WEMWBS Warwick Edinburgh Mental Wellbeing Scale
**HADS ‘doing well’ group**

Most young people were described in the clinical mental health case notes as well engaged with mental health services. They were said to be “doing well” and/or coping well with their current treatment regime (with or without medication). There were very few reports about needing to access urgent care or incidents of self-harm or overdoses.

“**Young person now uses Cognitive Behavioural Therapy (CBT) techniques on his own to manage his condition/anxiety/OCD symptoms when needed**”

Notes suggested that individuals in this group were accessing a range of support services in addition to mental health services. These included school counsellors, social services and community ASD teams. Some young people described how they had decided not to attend an assessment in AMHS as their clinician discussed that they may not meet AMHS criteria.

The clinical records also indicated that the clinicians were considering some of the broader needs of young people. For example, there were comments about trying to encourage the young person to increase their independence in appointments and become more aware of their ASD, and how their diagnosis may be affecting them.

“**Discussed...current romantic relationship: "emotional distress tends to be focussed around his girlfriend, who was also a close family friend" - talked about how his Asperger’s might affect his relationship**”

Notes contained evidence that some young people were engaged in developmentally appropriate tasks. Some were beginning to be involved with romantic relationships, several were attending mainstream college following leaving school, but few had made the transition to university by the end of the study. Overall, in addition to positive references to levels of engagement with services, there appeared to be evidence of more stability in terms of education achievements and family life in this group compared to the other two groups. In summary, the data suggest that individuals in this group were learning to manage their mental health concerns, developing an awareness of the impact of their ASD and learning to negotiate, with support, some developmentally appropriate aspects of transition to adulthood.

**HADS moderate difficulty group**

For some young people, the clinical mental health case notes referred to problems with attendance and poor engagement with CAMHS over the three years of the study. In some
cases these problems led to discharge from services. The pattern of the mental health needs appeared to fluctuate, with requests for urgent appointments, changes in types and doses of medication, and sudden events including self-harm attempts.

“*Young person not doing so well at the moment*”

There were also notes about changes in family circumstances, such as parents being ill (physically or mentally) or parents separating. These changing circumstances may well have contributed to some of the fluctuations young people experienced in their mental health.

As with the ‘doing well’ group, there were comments about young people not transferring to AMHS due to not meeting criteria or opting to not go for assessment. However, in this group there were also comments about families feeling unsupported as a consequence of either infrequent appointments or of being discharged from CAMHS.

“The only see someone once every 6 months or so now which parents have indicated that they don’t feel is enough and dad especially would like more help with transitioning to adulthood and support with work etc. Currently see a different doctor every time they go so feel it is very impersonal.”

The young people were recorded as accessing a range of other community services, both in childhood and post 18 years in adult services - counsellors at school or through primary care, psychological wellbeing services and Improving Access to Psychological Therapies (IAPT) services (an adult community Cognitive Behaviour Therapy provision).

In terms of the other activities, there were comments from the parents of young people in this group with concerns about their child’s independence skills (e.g. ability to leave home). Some of the young people had been in vulnerable situations (e.g. one young person had been led into messaging inappropriate images). Many of the young people had made the transition from school to college and some had hopes of applying for university. However, unlike the young people in the previous group, several of these young people had attended special needs schools and so through education services they had received additional support from, for example, occupational therapists and/or speech and language therapists during school hours. Some young people went on to experience considerable challenges as they transitioned to, and also in, their post-school education placements - for example those who had taken up a university placement often took some time to settle in and were accessing available support services.
“Young person is now at university. Had a few panic attacks to begin with but is doing ok. He has a counsellor at university.”

Others had experienced disruptions in their education provision, for example, being out of education for some time as a consequence of bullying or being expelled from a previous school. One young person also expressed feeling unsupported with job applications and requested help with interview skills.

**HADS ‘not doing well’ group**

The young people in this group experienced higher rates of crisis situations (such as episodes of self-harm or overdoses and suicide attempts) than young people in the other groups. Some had experienced episodes of inpatient hospital care while for others, police had been involved due to concerns about their risk-taking behaviour.

Concerns were also raised about poor attendance and compliance at health service appointments. Some young people refused treatment options or support and for some their level of disengagement led to premature discharge from CAMHS. Many young people and their families frequently reported a strong sense of feeling unsupported by services and described negative experiences with clinicians.

“He is now regularly seeing a Psychiatrist for talking therapy to help him deal with his anxiety. Mum feels this could have been avoided if he had received more help following child services rather than having a gap.”

Within this group it also appeared that their ASD was having a greater impact on their progress than the other two groups. There were several comments from the clinical records of the young people being given details of ASD teams to access for support around this. For example, some of the young people were accessing services/support for training in friendships, socialising and independence skills.

“Given literature from NAS [UK National Autistic Society] and list of books specific to ASD. Referral to Social Eyes service designed to help people with ASD to develop their social understanding and social skills.”

This group were also accessing more specialist services such as drug and alcohol support services or anger management teams. Discussions that had been had in appointments were recorded in the clinical notes about how illicit drug use would be interacting with their medication and mental health.
Although many young people were at school and college, there were comments about struggles to find appropriate placements for college or reports about time out from education. Others had been expelled or had dropped out of education due to difficulties. Encouragingly a couple of the young people had been able to obtain full-time work with the help of family members following dropping out of education.

“**Young person was expelled from college so waiting to see if he can go back in the near future or September. He is now working full time with his dad.**”

**Discussion**

The aim of this study was to identify predictors of transfer location and to understand the experience of transition in a sample of young people with ASD and additional mental health problems. In the three-year Transition Longitudinal study just over a third (35.3%) of the young people over 17 years transferred to AMHS and 64.7% transferred to primary care. The logistic regression analysis showed that only a diagnosis of ADHD and taking prescribed medication was a predictor of transfer location, explaining 32% of the variance. The qualitative analysis provided additional insights into potentially important individual, family and wider developmental and contextual themes that related to transfer location and provided valuable insights into young people’s experience of transition.

The finding that an ADHD diagnosis, as well as whether the young person was receiving prescribed medication, predicted whether young people transfer into AMHS may reflect UK ADHD NICE guidelines (NG 87, NICE 2018). NG87 recommends that both diagnosis of ADHD and the initiation of drug treatment should only be initiated by an appropriately qualified healthcare professional with expertise in ADHD, and that continued prescribing and monitoring of drug therapy may be performed by primary care physicians, under shared care arrangement with the specialist services. In an audit undertaken in the North West of the UK, only 15% of young people with a diagnosis of ADHD (from an eligible sample of 104 adolescents) were successfully referred and transferred to a specialist adult ADHD clinic, though it is unclear whether this sample included young people with coexisting ASD. Singh also highlighted the problems for young people with neurodevelopmental disorders (both ADHD and/or ASD) achieving successful transfer to AMHS. Our findings seem to buck this trend. We are aware that within the mental health NHS organisations involved in the Transition Longitudinal Study, local arrangements for the management of young people and adults with ADHD were under review. For example, in one organisation a decision was
made, during the course of the study, for CAMHS to take on the adult ADHD follow up clinics. It still remains unclear whether UK AMHS are adequately resourced to provide diagnostic and follow up clinics for adults with ADHD and additional co-occurring conditions including ASD and other behavioural and mental health problems. Certainly, within our sample, parents and young people commented that six monthly/yearly follow up medication clinic appointments did not meet the wider needs of young people coping with a broad range of concerns about mental health problems and other social and educational needs.

Interestingly, none of the other factors that we had identified as potential markers of severity or vulnerability (number of co-morbid problems, SES, HADS, wellbeing) predicted transfer to AMHS. Much has been written about the limited access to AMHS for young people with a range of mental health problems (ASD and additional mental health problems, other neurodevelopmental disorders (such as ADHD), emotional disorders and emerging personality disorders).\textsuperscript{179, 181} In UK the eligibility criteria for accepting a referral to an AMHS can vary but tends to be restricted to those suffering severe and enduring mental illness such as psychosis and severe depression. This may mean that some young people who reach the age of 18 years may find that, although their mental health problems do not suddenly change, they cannot access an ongoing mental health service.\textsuperscript{14}

Of course, not all young people with mental health problems will either want or need to be transferred to AMHS. For some, discharge to primary care may be the appropriate pathway, especially if the young person is coping well with their ongoing mental health problems, adhering to treatment/medication and doing well at school/college. As was seen in the qualitative analysis, some of the young people and their families opted not to be referred to AMHS due to the likelihood of not meeting criteria, or due to no further clinical need. However, the qualitative analysis also identified a sub-set of young people where the pathway of discharge to primary care was not successful. These young people accessed crisis teams several times or received time-limited support in AMHS before being discharged again.

Further, for some young people and their families in this sample, engagement with services was a more longstanding problem. For these young people, if they had not engaged with CAMHS, this usually resulted in discharge to primary care - a finding consistent with the UK TRACK study.\textsuperscript{180}
Overall, the young people in our sample appeared to be doing reasonably well, with 67.5% in full time education (either school or college) at the end of the study. Under a third of our sample were in neither education nor employment. The analysis of the HADS trajectories also confirmed that some young people appeared to be doing well, managing their mental health, and able to engage successfully with services. These young people and their families also had not apparently experienced additional crises or life events. However, across all HADS groups, the majority of young people were experiencing episodes or continued levels of high anxiety. Thus, despite what appears as positive outcomes for young people (e.g. attending higher education), the HADS trajectories and qualitative data showed that the young people were struggling, particularly when faced with more challenging academic and social educational environments (such as university). Our data also highlight that females seem to be at increased risk of falling into the ‘not doing well group’. This finding needs further consideration in larger samples of able young people with ASD. However, it is in keeping with recent studies and the increased awareness of the social and emotional needs of females with ASD, and especially those of normal ability, who may struggle to understand their own mental health needs.

How should we identify those young people (both male and female) that might be particularly at risk through transition? Our data suggest that engaging with young people, and using a regular self-report check such as the HADS (which the young people in this study were able to complete at each annual follow up visit), may help young people and the professionals supporting them to identify their own trajectory, the impact of individual and family life experiences, and any mental health needs that may be helping or hindering their personal goals and achievements.

The key themes emerging in the qualitative data included engagement, broader ASD social and emotional developmental needs, impact of family, and personal events which seem to adversely affect functioning. Consistent with previous research, positive influences on the young people’s experience of transition seem to be the ability to participate socially, engage consistently and constructively with services, positive support including employment opportunities from family, and other community resources including education.

The qualitative data also revealed a common concern of ‘unmet need’ and/or ‘lack of support’ irrespective of whether the young person had been discharged to primary care or AMHS. These unmet needs were usually around broader aspects of functioning relevant to
the young person’s diagnosis of ASD, rather than just their mental health difficulties. These identified unmet needs reflect findings from other research where young people of normal intellectual ability with ASD can fall short of criteria for access to community learning disability or more specialist ASD services as well as mental health service. Access to local community support around interpersonal support, advice and information especially if the services have expertise in working with young adults with ASD and their families, could help reduce this unmet need.

Strengths and Limitations

This study is a secondary analysis of data collected during the Transition Longitudinal study. The sample of young people with ASD and additional mental health problems is relatively small (93 in total), all were of normal ability and recruited from four mental health NHS clinical services across the UK. This means that the findings have limited generalizability when considering young people with ASD across the ability range. Further, although the qualitative data were consistently collected by the trained RAs from clinical mental health notes and during the interactions with young people and their families, the data were not primarily obtained for the purpose of this analysis. Therefore, some aspects of the young people’s experience of transition over the three years of the study may not have been recorded. Finally, although the young people have been successfully followed up, the sample remains relatively young (aged 14-17 years at recruitment). Thus, although all young people were approaching or had experience of planning for or achieving discharge from CAMHS, 20 young people had not left CAMHS by the end of the study and we do not have follow up information for any individuals over the age of 21 years.

Conclusion

Despite the observations that the young people in this sample (all of whom had one or more mental health problems) consistently reported lower mental wellbeing that other young people of similar age and ability, two-thirds of the sample were in education or higher education by the end of the three year follow up period. For some young people, discharge from CAMHS was seen as a new beginning as they moved onto higher education opportunities, gained a growing understanding about how to manage their mental health difficulties and gradually acquired the adaptive life skills to address their developmental needs. For others, and perhaps especially for the females in the sample, ongoing mental health difficulties, social, emotional and relationship needs (particularly associated with
ASD), and a feeling of lack of understanding and a perceived absence of professional understanding about their and their families’ level of unmet need with regard to both mental health and local authority services, resulted in a negative experience of transition. In our sample, encouragingly, it was a relatively small number of individuals who had multiple negative experiences of services, struggled with engagement, felt unsupported, and presented with multiple crises over the study period. We propose that the use of a tool such as the HADS may be a useful adjunct for individuals and their supporting clinicians to identify patterns of functioning over time; the monitoring may help identify those young people especially at risk of negative outcomes and crisis presentations. Successful transfer to AMHS is one aspect of mental health support but these services currently vary according to local service design. Further, both AHMS and primary care may or may not include expertise in ASD. This study confirms the need to increase community practitioner clinical skills relevant to young people with ASD and additional mental health problems. Our findings also suggest the potential benefit of a more nuanced approach to identifying and prioritising the needs of those young people at greatest risk of poor outcomes. Clinicians and other professionals with specialist expertise could then support these young people and their families identify and prioritise their goals for timely community support before they are discharged from CAMHS. The longer-term impact of this prioritisation of resource use would need to be evaluated.
Appendix 7: Longitudinal study (qualitative)
In this Appendix, we set out the report of the qualitative work in WP 2.2 in which 13 young people’ purposefully sampled from the cohort in the longitudinal study (WP 2.1)’ are interviewed, along with family member(s) and health professional(s) involved in their care. At the end of the report is the interview schedule.

Report WP 2.2
WP 2.2 Addressing Objective 2: to identify the features of transitional healthcare that are effective and efficient

Recent reviews have explored the different aspects of transitional healthcare, focusing on the experiences of young people and parents. This work shows how the process of healthcare transition disrupts the lives of young people and their families. Lugasi’s review of 46 quantitative and qualitative studies, show how patients describe child services as ‘a familiar and comfortable environment, and reported feelings of trust toward their health care providers’. As such, they can develop ‘attachment’ to child services and have problems to ‘detach themselves’. Narratives of certainty within child services and uncertainty about what to expect in adult services were confounded by direct or second-hand experiences of sub-optimal care from adult services. The issue of trust is identified, both trust in adult providers’ abilities and knowledge to manage young people with their specific condition and trust in child service providers’ reports on the competence of adult services. The review also highlights how transfer can be experienced as an ‘abrupt event’, through lack of knowledge and information about what to expect. Knowledge gained through joint clinics was therefore especially valued, as this

‘reduced patients’ fears and concerns about transition and provided them with an opportunity to create relationships with providers in [adult services], to get to know a familiar face before transfer, and improved transition outcomes’

They argue that such meetings, ideally, over time rather than as a one off event, can help young people prepare for transition. Finally, they highlight, the role of shifting responsibilities, given young people’s ‘wish for independence’. At times, parents still offer support, but young people also report that parents will not always ‘let them’ enact such independence.
Lugasi\textsuperscript{50} draw on selected elements of Schumacher and Meleis\textsuperscript{197} conceptual model of transition in a range of developmental, situational and health-illness transitions contexts. They highlight the need to focus on: positive meaning; managing expectations; increasing knowledge and skills to ‘empower’ young people; joint planning with young people; and facilitative environments, including such aspects as transition coordinator and young adult clinic. Fegran’s\textsuperscript{44} review, focuses on 18 qualitative, including many of the 21 qualitative studies reviewed by Lugasi\textsuperscript{50} and highlights four similar elements: facing changes in significant relationships; moving from familiar to unknown ward cultures; being prepared for transfer; and achieving responsibility. Again, we see the centrality of ‘close relationships’ that young people develop in child services and that prior experiences and knowledge is no longer relevant. Also, we again see a narrative of feeling ‘unprepared’ and so a ‘need for guidance and support’. Finally, we see the same focus on developing, enabling and forcing ‘movement to towards independence’ and problems of ‘parents letting go’.

In this way, these reviews, and many of the original studies, echo a core issue of transition, in whatever context, be it tied to the onset of a long term condition, so a transition from health to ill health, to changes in education, from secondary school to college or university.

At the individual level … periods of transition are characterised by disconnectedness from the individual’s current social context, a transient unfamiliarity with a new surrounding environment, the emergence of new needs that must be met, and the replacement of an existing set of expectations with new ones.\textsuperscript{198}

Transition is a disruption, or following,\textsuperscript{88} a breach in taken-for-granted experiences, knowledge and expectations. It involves people having to adapt to a new set of circumstances, to learn from and develop new experiences, knowledge and expectations.

In much of this literature, the disruption of the healthcare, the movement from child to adult services is characterised by a narrative of the young person as moving from ‘dependence’ to ‘independence’. The figure of the parent is seen as central in this process. Heath’s review of 36 qualitative papers about parents’ experiences and views on transition highlights the range of work they engage with. The review focus on how parents are central, especially mothers, in supporting the young person. They work to enable gradual ‘independence-building’ over time, supporting and enabling ‘healthcare autonomy’ to develop, at times engaging in a partnership approach, at other times ‘stepping in to provide respite’. Such work impacts on them, echoing the young people’s experience discussed above, in that they feel uncertain and
anxious and at times reluctant ‘to relinquish control’ and this ‘delayed the onset of young person autonomy’. Again, as with young people, they too go through a process of transition, from ‘managerial role’ to a new ‘consultant role’. Finally, where transition is sub-optimal we see the same focus on the loss of ‘support, resources and trusted relationships’ that parents found available through child services.

Aims
To investigate young people’s experiences of healthcare transition services.
- Explore young people’s experiences of healthcare transition services over time
- Explore the experiences of healthcare transition service provision of lay people who are identified as significant in the young people’s transition journey
- Explore the experiences of healthcare transition service provision of health professionals’ who are identified as significant in the young people’s transition journey
- Describe how healthcare transition services are operationalized in clinical encounters

Methods
A longitudinal multi-method qualitative study was conducted with young people. Young people were recruited from the longitudinal quantitative study (WP2.1). They were also asked to identify a lay person and a health professional significant to their healthcare experience; and a consultation that the researcher could observe.

Data collection took place between June 2013 and June 2016. The recruitment of young people was driven by criterion and theoretical sampling. Young people (n=13) were aged 4-18 at the first interview. Family members (n=14) were identified by young people and included: ten mothers, three fathers/step-fathers and one brother. Health professionals (n=19) included seven paediatric consultants, five paediatric nurses/AHPs, three adult consultants and four adult nurses/AHPs.

The Interview Schedule is at the end of this report.

Thirteen young people were interviewed once, with four of them interviewed again at least eighteen months after first interview. The young people were interviewed on their own or with a relative if they wished. Fourteen family members were interviewed once, with eight of them twice, at least eighteen months after first interview. We also interviewed thirteen health
professionals, nine from paediatric services and four from adult services. We undertook first interviews with 40 people (see Table 19). With thirty of these interviews, the young person had yet to transfer, with twelve, the young person had transferred. We also observed seven consultations, four whilst the young person was in paediatric services and three post-transfer in adult services. Twenty participants took part in interviews only, six in observations only and twenty took part in interviews and observations.

Table 19: Participants recruited for the study by condition, identity and method of data collection

<table>
<thead>
<tr>
<th>Participants for first interview</th>
<th>Diabetes</th>
<th>Cerebral palsy</th>
<th>ASD</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young people</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Family member</td>
<td>4</td>
<td>6</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Health professionals</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
<td><strong>15</strong></td>
<td><strong>13</strong></td>
<td><strong>40</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants involved in observations</th>
<th>Diabetes</th>
<th>Cerebral palsy</th>
<th>ASD</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young People</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Family member</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Health professionals</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
<td><strong>8</strong></td>
<td><strong>6</strong></td>
<td><strong>26</strong></td>
</tr>
</tbody>
</table>

Observations were recorded in contemporaneous field notes. Formal interviews were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymized field notes. All analysis was conducted according to the standard procedures of rigorous qualitative analysis. We used procedures from first-generation grounded theory - coding, constant comparison, memoing - and from analytic induction - deviant case analysis. Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones. We undertook independent coding and cross checking, team data sessions and data triangulation (different times and persons) and between-method triangulation (interview, observation).

Analysis

All names below have been altered to ensure anonymity and maintain confidentiality.

As one parent outlined, the actual process of transfer from children’s to adults’ services, ‘takes five minutes’ (Angela, Family). However, crossing this organisational boundary takes
practical, cognitive and emotional work, work that young people, family members and health professionals engage with, often over a long period of time. The young person has usually been in a specific child service for some time, often since early childhood. The family, especially the mother, have developed good working understandings of the best ways to support the management of the young person’s specific health condition(s), and importantly, how to effectively navigate, manage and engage with the child health service system. The health professionals often have significant knowledge of the young person and their wider psychosocial context. Centrally, they have all worked to build relations of trust. The organisational process of transfer ends those relationships and calls the young people and their families’ expectations, knowledge and practices into question.

All the services worked to support and effectively manage the range of transitions that the young person goes through, including the healthcare transition. They were aware of the implications of an ‘unsuccessful’ transition and how people can ‘drop off the system’ (Carlos, HP) or ‘disengage’ (Pete, HP). As one health professional noted

And I, I suppose that’s my biggest problem with, with transition is, is that I feel that I’m transitioning them to something that isn’t actually going to meet their needs if they’re vulnerable, or at risk, or not robust. And many young people aren’t. (Redgrave, HP)

Some health professionals felt that some young people were not always ‘robust’, not always ready to transfer when they reached a specific chronological. Given this context, they all had some kinds of formal or informal plans and procedures for transition and transfer that sought to prepare the young person and their family. In what follows, we will outline the practical experience of young people, families and health professionals, we will explore the informal and formal plans and procedures that were implemented within and across the services. This will be structured by focusing on each of the proposed beneficial features (PBF). Table 20 offers an overview of implementation issues.

Table 20: Summary of evidence for and determinants of implementation of the proposed beneficial features

<table>
<thead>
<tr>
<th>Proposed beneficial feature</th>
<th>Evidence of implementation</th>
<th>Determinants of implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-banded</td>
<td>Limited: only seen</td>
<td>Often not feasible due to logistics of managing appointments, spatial restrictions or low numbers</td>
</tr>
<tr>
<td>Service Area</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Clinic in diabetes services</td>
<td>of young people. In practice, situated alongside other adult clinics, with parent’s frightened by visibility of ill adults and health professionals aware of visibility ‘problem’. Young people report ‘not being fussed’.</td>
<td></td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>Variable: some services offer single joint meeting or shared appointments</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dependent on relations with adult team(s). In services that provide, meetings do not always happen or are effective. Problematic when low frequency of meetings, young person moving away (e.g. University), adult practitioner not person who will provide care, or general practitioner is missing (e.g. transfer to primary care).</td>
<td></td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>Variable: some services provided but in a very informal, ad hoc way.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can occur in context of long term, trust-based, relationships with specific health professional. Minimal without continuity of personal, with low frequency of visits, and when not part of service culture.</td>
<td></td>
</tr>
<tr>
<td>Written transition plan</td>
<td>Very limited: one service offered formal plan.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>One service had implemented as part of research project, but withdrew due to lack of resources and motivation to continue. Some practitioners resisted a written plan, as saw interaction is key over more forms and that such forms get forgotten or lost. Informal practices can lead to lack of awareness, knowledge and understanding of process.</td>
<td></td>
</tr>
<tr>
<td>Parents engaged appropriately</td>
<td>Extensive: all services report engaging parents.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Interdependence as service norm for some practitioners and so seek to enable appropriate involvement. Some see interdependence as demonstrating problematic attachment, and seek to minimise, often referring to legal issues around patient confidentiality.</td>
<td></td>
</tr>
<tr>
<td>Key worker</td>
<td>Variable: services may report designated key worker, but young people and parents often unaware.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>In practice, most young people and families name ‘their’ de facto key worker – someone they trust, seen consistently, highly supportive and accessible. In practice, a parent – usually mother – takes this role.</td>
<td></td>
</tr>
<tr>
<td>Coordinated team</td>
<td>Variable: some services demonstrated aspects.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Largely dependent on service structures. Collaboration and coordination between team members can occur formally and informally.</td>
<td></td>
</tr>
<tr>
<td>Holistic life skills training</td>
<td>Very limited: few services provided elements albeit in a very informal, ad</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Some services had not considered, others had not considered it their responsibility. Education, social services, charities, and family were already providing this – or, if not, young people, parents</td>
<td></td>
</tr>
<tr>
<td>Transition manager for clinical team</td>
<td>Very limited: one service reported recent introduction.</td>
<td>One service introduced, as realised need, but still developing remit for role. Many services would like to implement, but dependent on resources, managing workload and competing demands.</td>
</tr>
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**Age banded clinic: the organisation of groups or the organisation of clinical mind-sets?**

Within our dataset, formalised age-banded clinics are only reported by young people attending diabetes services. We observed the appointments of two young people with diabetes, as they attended age-banded clinics in adult outpatients’ wards. Neither of the young people reported this experience as being problematic, one outlining that she’s ‘not really fussed by that’ (Ruth). However, both their parents and health professionals discussed a range of concerns. One parent Judy, described it as ‘quite f- frightening I guess is the word’, and Ralph (Family) describes it as ‘not intimidating but’ he thinks that the young people would be ‘more comfortable’ without seeing such older people. He later describes the ward environment as ‘full of fat, old people’. Judy outlined similar concerns

> It is a young adults' clinic, but you go and there's no other young people there. Whether they stagger them. You're sitting with people in wheelchairs, with amputees, the great, big older people that have obviously got type two. It's not a, a young clinic that you sit there and everyone's between 18 and 25. … Everyone's attending other things. So there's amputees there because it's with podiatry. Erm, and then you get the, the lady that can't walk (Judy, Family)

Both parents are concerned about the negative possibilities of such visual interaction with older people with diabetes. The diabetes health professionals raised similar points

> I think what we know is that it can be very off putting for young adults, say, for example, you know, if the waiting room is full of people with a very different demographic, you know, elderly, amputees or blind people, or whatever. Not that they shouldn’t see those people, but I think, you know, it’s partly it plays on their fears for what the future holds (Redgrave, HP)
Young people are seen by their parents and health professionals as needing protection from the issues they may face as adults with a long term health condition, while at the same time recognising that they should not hide the reality from them.

We see a similar narrative of the problems of visual interaction with accounts of parents of young people with other conditions. For example, Daisy, a parent, recounts their first visit to an adult service

the whole atmosphere and everything was different to what he was used to. There was a young lad in the waiting room in a prison uniform who was obviously in a bit of a mood and was stomping about and clashing doors and swearing and what-have-you, it was a bit of a shock to the system from what he was used to (Daisy, Family)

However, the young person offers a more pragmatic narrative, that although he ‘wasn’t used to it’ you ‘just need to get on with it’, that ‘everyone’s going to need help’ (Darryl). In the child services that Darryl visited previously, such age-banded clinics, may occur, but not in any ‘structured way’, but rather a clinic list may, at times, have ‘people of similar ages’ (Delia, HP). One group within a service had historically offered age-banded clinics to young people attending specialist schooling and were beginning to expand the service. Another service reported that such an ad hoc, emergent, version occurred in some of the group sessions allied health professionals ran. In these groups sessions

they have had increased benefits from recognising others with similar needs, feeling part of a group, that they’re not isolated, that they’re not alone and often it’s generated friendships among them (Lucy, HP).

In this way, ideas around peer-support can be enacted in such group sessions. Albeit, we should note the caveat that group sessions often can be poorly attended by young people.

In very general terms all young people reported a preference for the ‘idea’ of appointments in outpatients wards that are set-up to support young people, over spaces that are designed to facilitate the play of babies and children. Some saw it as potentially offering an opportunity to interact with other young people, people that are ‘On the same wavelength about things. So I think … people can socialise better’ (Fran). However, we should note that in practice - as reported by young people and as observed in clinic waiting rooms – very little interaction actually occurs between the young people. They are often only briefly in the waiting room, and, in some contexts, they move from room to room, seeing different health professionals
throughout their time in outpatients. Some also felt that they could potentially also offer the opportunity for a more young person appropriate space – not one with a ‘little kiddie area’ (Fran) full of toys and not one, as experienced in some adult services, that are ‘completely bare’ (Charlie). Finally, some felt that such spaces could begin to enable other young people to feel quite comfortable cos they know I’m not the only one whose got a situation going on in my life, there are other people here, I’m not the only, I’m not weird it happens to loads of people (Sarah).

In this way, such visual interaction is seen as potentially working to normalise understanding of conditions, to offer a sense that young people are part of a broader community of young people like them.

In contrast, some young people – as well as families and health professionals - found the idea to be problematic. Some noted that it would create yet another transition, and so potentially create ‘a lot more change’ (Penelope). Others supported the idea of continuing with mixed spaces, in part so ‘other kids’ of different ages could see how people are ‘getting on’ (Lee). Similarly, a parent outlined that

I, I think it’d be much more useful for them to see, say, for example, a pregnant woman coming in [Int: Hmm] and gleaning information from that than just seeing people who are their own age group, either doing it badly or doing it well. … It gives you an understanding of what the expectations are (Amy, Family)

In this way, some preferred the idea of mixed spaces – in terms of age - to normalise understanding of conditions and to outline potential future trajectories.

Irrespective of the different experiences of age-banded clinics, or different ideas about whether or not they may be desirable, young people all valued the quality of the clinical interactions within the clinic room over the physical (and visual) space of the waiting room. They want health professionals they can ‘trust’, that are ‘nice … helpful if I ask any advice’ (Ruth) that they can build some kind of ‘a rapport’ with over time. They want an interaction where the health professional talks to them about issues that matter to them, and strikes the appropriate level of parental involvement. Where feasible, age-banded clinics are also seen by health professionals as useful.
I think they work well and I think the reason that they work well is that it focuses your mind on adolescent issues. Erm focuses my mind I don’t know whether it works well for the patients but it gets you into a mind-set of thinking about those sorts of things. Whereas if you’re going from 18 months old to an 18 year old you sometimes not in the right zone. (Ardo, HP)

In this way, age-banded clinics focus the interactional order of clinical work so health professionals can invoke and sustain the right ‘mind-set’ to interact with young people as young people.

The idea of offering age-banded clinics – and, for some, running them alongside adult clinics - does appeal to some of the health professionals. However, in practice, they are often not seen as feasible.

   it is quite a small waiting room which we, we’ve- we’re trying to address [Okay]. But there’s that many people going in and out, I don’t know how you would manage it, to be honest. (Dee HP)

Questions about spatial restrictions within outpatients, alongside the distributed physical and organisational geography of services were raised. Relatedly, the organisational logistics of appointments – the practicalities of coordinating support staff, as well as young people and professionals was a concern. One service had historically offered them, but ‘the logistics were hard’ as they could not get ‘sufficient numbers … because they tend to trickle through at different periods’ (Bow, HP). In some contexts and in some services the numbers of young people transitioning at the same period, or within a specific age-band, were relatively low and so coordinating them can be seen as unfeasible.

Meeting the adult team before transfer: first steps in new relations of trust?

In all the services we focused on, the young people moved to an adult service provider with a different set of health professionals that would be offering them care. Given these circumstances, meeting members of the adult team could be key for those that experienced it. When this did occur, it would generally take the form of a single face-to-face joint meeting between specific members of the child and adult teams alongside the young person and members of their family.

   So what we aim to do, which doesn’t always happen, is that, um, we’ll have a joint appointment, um, prior to transferring them. So that they will come and see me and
my adult colleague, um, so that I can introduce them and they know this new face [Int: Mmm] and that it’s not someone completely unfamiliar for when they come (Redgrave, HP)

The young people could meet a single member of the team – often a consultant or nurse specialist – or a range of members of the team, including nurses and allied health professionals. In part, this was about establishing familiarity and trust, and feeling ‘you’re kind of delivering them into safe hands’ (Delia, HP). Some services had a long history of offering this, sometimes this was formalised, and sometimes it was part of the unwritten norms of the culture of the service.

In services that ran young adult and adult clinics alongside one another, where these clinics were physically and temporally co-located, this could offer a range of opportunities for young people. They could become used to the physical and cultural geography of the service – in terms of location in the hospital and the layout, feel and routines of the clinic. They also could offer the young people the opportunity to get to know members of the outpatients’ staff – ‘they meet our clinic staff start doing their bloods, height and measurements and things’ (Jewel, HP). This service also had plans to extend the number of opportunities for the young people to meet the adult team. In one service this co-location could mean a much more extended period of opportunities to meet the new staff

So here we, because we run it alongside the adult clinic, they can meet the adult team several times before they transfer and then we do a transfer appointment where it’s either in our clinic or their clinic, er, we see them together. (Ardo, HP)

However, they go onto note that this ideal is not yet representative of other services in the region.

In [Local Town B] they tend to meet the adult doctor and nurse just once at that transfer appointment, er, and as I say in [Local Town A] it doesn’t happen at the moment. (Ardo, HP)

And such inequity in access to opportunities to meet the adult team is present across our data set. In a few cases, allied health professionals from both child and adult services, may undertake a short series of ‘shared’ appointments, and so handover for these specific aspects of the service may be more gradual and occur over time. Such meetings, however, fleeting, offered the potential for both symbolic and practical gains.
Prior to such meetings, child health professionals would introduce the idea of a joint meeting and seek agreement for them to take place. They would, often over time, also seek to explain the norms and expectations of adult services.

We alert young people to the way adult services are currently provided … “Unlike in [our service] where if you miss a few appointments we’ll still keep trying to contact you, adult services will discharge you rather more promptly.” … I really do feel we have to equip young people (Peters, HP)

Equipping young people with appropriate knowledge about the new service was central. However, what seen as key was enabling young people to actually meet those people whom would be providing them with care.

Young people had, in most cases, a long relationship with a particular service, and so built up, over time, relations of trust with health professionals they regularly saw.

Because I’ve had Fiona [HP] for years, and she’s been absolutely brilliant like. Honestly she’s helped us out and everything and she’s always been there, if I’ve had any concerns, she’s been a brilliant doctor. … And I wish I could keep that, and I think it takes a lot to know your doctor, because obviously you trust them with your medical facts and what you do. (Fran)

As another young person noted, going to a new service means ‘obviously, it’s building relationships’ (Brian). For those young people that experienced it, meeting members of the adult team was central to initiating new relationships with members of the adult service, ones that, over time, could develop into new relationship of trust. Charlie outlines his experience of a process he describes as ‘nice’:

Charlie Yeah, well I mean we did meet Crowley [HP] beforehand didn’t we?
Cilla Yes.
Charlie But he was the only person we met beforehand but that was mainly because he wanted to meet me as well as us wanting to meet him. So that was quite nice, cos obviously then before I even went to my first appointment with him I knew his face, I knew a bit about him, he knew a little bit about me. So it wasn’t like we went into the first appointment and it was like you had to find out about each other, you could still have a conversation, which was nice.
In such meetings, the young person could share something about themselves and begin to gain some sense of the adult practitioner, as well as the norms and expectations of the service they would be transferred to.

For parents, they enabled them to begin to make sense that their child was being transferred to (another) safe pair of hands. For adult health professionals, it also gave them a chance to ‘get to know them’.

It’s a one-hour appointment that we have [Int: Okay] with the joint session. So it just gives you chance to get to know them. … They’re gonna see somebody who’s familiar (Pete, HP)

It also enables them to (re)establish ideas about the norms and expectations of the service, as well as answering any specific questions. Such an event helps young people and their parents to manage potential anxiety and fears and helps to offer more of a sense of certainty about the process.

However, not all services offered such a meeting with the adult team and even in those that did, the meeting did not always happen or were not always effective. In one service, it was seen as ‘sufficient’ to have a ‘joint transition clinic’ only once a year.

Our normal pathway for transition, erm, is that I do an annual transition clinic, with [adult consultant]. So I do that at [Location B]. But we invite in other young people, who are transitioning, simply because, you know, the bulk of them are at [Location B]. But it’s sufficient just to have one, one clinic a year. So we’ve actually got one tomorrow morning, erm, a joint transition clinic. So usually, I would introduce the young person to [adult consultant] face-to-face, in the transition clinic (Carlos, HP)

However, if a young person was unavailable at that time, as ‘for some people, it just isn’t convenient’, they would, therefore, miss out. And this was the case for Carl, whom did not attend the joint transition clinic, and whom felt ‘abandoned’ by the services. In Darryl’s case, the ‘handover’ meeting, although scheduled, did not take place

Yeah there was supposed to be a handover but it never really came off. Em, Yeah. I think some in particular do sort of struggle with changes and routine and that kind of thing, so yeah it could help. … I think that would have been really significant had it worked out. So at least we would have been prepared and if nothing else we had a sort of familiar face. (Daisy, Family).
Darryl, the young person, thought that such a meeting would have ‘would have helped’ and maybe offering ‘even like a second meeting’. Such a meeting would have allowed him to ‘sort of know where you’re going rather than just feeling like you’re being dropped into someone else’s hands’ (Darryl). Those young people that move away for University are faced with a practical dilemma of whether to stay with their current services, transfer to adult services at the new location, or operate a more shared care model, involving primary and secondary care. Unless well managed and coordinated, they can also miss out on such meetings.

Organisational turbulence, be it in staff turnover or due to staff sickness, could also negatively impact on the process, meaning some young people lost out on the opportunity. Health professionals were aware of the often very practical problems that can emerge when trying to coordinate meetings with adult health professionals.

There are practical issues, such as, um, sometimes my adult clinic isn’t there, so, um, we’ve got a joint appointment but they’re not there so we can’t see them. And sometimes they cancel or rebook and then they’ll perhaps end up in an adult clinic without having had a joint appointment, in which case one of our paediatric specialist nurses will accompany them on that first appointment so that there is some sort of shared [Int: Yeah] information, um, and handover. (Redgrave, HP)

In such circumstances, the specialist nursing attending the clinic with the young person is not always seen as ideal. The consultant felt that the specialist nurses often did not always have such a long term relationship with the young person as they did and so did not always ‘know’ the patient as ‘well’. In part this was due to this services having a large number of specialist nurses, and any one of them may be asked to attend, and as well in part, due to staff turnover.

In another service, joint transfer meetings only occurred between professionals and ‘only … for the really high risk cases’ (Peter, HP) were the young person and family invited. However, part way during the fieldwork, this policy had changed to be open to all, although, again, they were aware ‘it’s not always possible’ (Dee, HP). This new service was set up so that

In the last six months, they’ll contact us to arrange an appointment. Erm, and then it, it’s normally a joint transfer. … it would be the patient, erm, normally the patient’s relatives or next-of-kin comes [Int: Yeah], erm, and it would be the consultant from
our team … normally myself, and, and [another AHP] … it’s, it’s just kind of closing one door and opening another, really. (Dee, HP)

In this way, the young person would meet different members of the team. This is important as we know that in some services the health professional actually meeting the young person in this first meeting was not the health professional they subsequently would routinely being seeing. We know that young people, at the very least, value being able to ‘recognise one face, you’re not sent into a room full on entirely new people’ (Angela).

Finally, a missing figure, especially for those who will be transferred to primary care for all or part of their care, was the general practitioner. For example, one young person visited a range of services and, when he turned 16 his family were told that he was “in the transition process”. In a consultation his mother outlined how

I did question, I said, like, “If, once he does go into adult services what ha- what happens if he needs to see someone?” and they say, “Oh, go to your GP.” (Beth, Family)

They had never visited the general practitioner in reference to his long-term condition. As they noted, at a later interview

Brian  I couldn’t even, I couldn’t even name me GP to be honest.
Beth  His GP, he sees a different GP every time he’s there. Nobody knows him and knows him and knows his history.

Unfortunately, the general practitioner is often someone whom the young people had often had little interaction with over the years, yet is meant to be a central figure in coordinating their health care and access to health services.

Promotion of health self-efficacy: learning how to manage your health (services)?

Health services saw it as their role to help young people develop confidence in making sense of and managing their health condition. Such work is understood as ‘kind of always a sideline of the work anyway’ (Lucy, HP). For her, and others, this is ‘quite often that is a big part of our role’ and with her patients
it might be to work on anxiety, which it tends to be for me, but really part of that is feeling that you’re not helpless and hopeless and that you can go forward and that you have got a lot to offer, and so definitely needs that input. (Lucy HP)

However, this was not formalised or based on a specific policy, but rather ‘a sort of gradual process rather than a one off education session in a teenage year’ (Ardo, HP). As such, supporting young people to develop confidence seemed to occur in an ad hoc way over time in consultations and other interactions with a range of health practitioners, including consultants, nurses, psychologists, physiotherapists, occupational health practitioners and speech and language practitioners. In practice, nurses and allied health professionals were often seen as more central to supporting and enabling this informal work, in part as they may see young people more often, they spend more time with the young people, and at times the young people are felt to be more ‘open’ with them.

None of the services reported any form of structured, protocolled, approach to delivery. Such discussions may explicitly be created around specific devices or events. For example, one service used transition questionnaires that included elements that ask, you know, “do you organise your own appointments?” “Do you organise”, er, “do you know how to pick up your prescriptions? “How would you”, wh-“where would you go if you needed a-advice in an emergency, and your, your mum wasn’t around?” [Int: Yeah] That sort of thing. So we, we ask about that, and obviously, if there are gaps in their knowledge, then we try and fill those gaps. But we don’t provide them with any training. (Jones, HP)

In this way, in the space of a consultation, such questionnaires’ may offer a very brief and focused ‘teaching moment’. Another service had offered group sessions, organised meetings for young people to meet outside the space of the clinic, which were led by an allied health professional. These sessions included elements like ‘problem solving’ around disease management. However, they reported that such extra-clinic sessions often suffered from low levels of attendance. Finally, one service was seeking to transform what they had been doing ‘informally for years’ to ensure continuity in provision as the team grew. This was part of a broader peer review process, where they were seeking to look at “What do we want them to know by the time they’ve been educated?” And then looking at the, sort of, that as the curriculum, and then “how are we going to get to that point?” So starting with what it is we would actually like them to know and then
how are we going to teach them that. So they’re trying to put some sort of structure around it. And then how do you deliver that and then how do you check whether they actually know if afterwards. (Ardo, HP)

Their aim for was not to develop new questionnaires or develop checklists to ensure the young person has been talked to about a specific topic, but rather to create a more formalised and cross-team culture that ensures an awareness of and action around such issues.

Some of the young people and parents described receiving support in developing health self-efficacy: ‘we did lots of different activities. It was never sort of formal’ (Penelope). Some young people felt that, at times - ‘obviously sometimes’ (Sarah) - this was a focus of interactions with health professionals. For some, albeit through informal means, this was ‘all the way through’ (Amy, Family) their experience of the service. For young people and parents, a context of longer term, trust-based, relationships with specific health professionals seems key to enable them to develop such confidence in making sense of and managing their condition. Often, in discussing this topic, young people would refer to a specific member of their services team as central to offering such support.

However, some young people and family members felt they had not received any formal or informal support in this area. As one parent outlined, this was from her perspective absent, yet ‘this is what he needs’ (Leanne, Family). Another that

He hasn’t really had any help like that. He has always had, like with Delia [HP] or someone, somebody to talk to. [Int: Yep] The usual checks, height, weight, that sort of thing to make sure that he is not having any kind of adverse reactions to any medications and that sort of thing but no a lot of it has either been down to us or him. (Daisy, Family)

A member of this young person’s clinical team, echoes this absence, noting that such work is not always central to the care provided across their service: ‘I don’t think it is – it’s – I don’t think it necessarily is done; but I think it would be very helpful if it was.’ (Delia, HP).

Distribution of the work across teams and services is not always even. As noted above, often nurses and allied health professionals support this work. For some consultants, such work cannot always be taken on
I think I’m all for assuming responsibility … I’d love to do that. But, um, we are so inundated with managing people. [Int: Yeah] that there is no chance to do that. And ideally that would, is work that was kind of, you know, primordial work (Peters, HP)

The lack of support for self-efficacy, was most marked when young people’s appointments were infrequent and where staff and, or the services themselves, were in flux. However, the key work most young people need, alongside support making in sense of and managing their health condition, is in managing services post-transfer.

Going from Children’s Services to Adult Services. There was no one really to talk to who told you what to do, it was just sort of, we’ve just picked up on it. (Charlie)

As young people are transferred to a new organisational and clinical environment with a new set of health professionals, norms and routines, the core focus they need is support and confidence in the practicalities of managing the adult healthcare system itself.

Written transition plan: gaining awareness of new norms and routines?

Plans about transition can be offered, experienced and valued in different ways. Several services stated that they had formal plans or procedures for transition and transfer of young people. However, in all but one service, health professionals reported that ‘written transitions plan’ were not used. In an already bureaucratic culture, there was some scepticism about the place of such documents. As one practitioner noted ‘I’d like to see patients and facilitate effective transitions, not be filling in plans’ (Peters, HP). Another outlined that

I think unless it’s been, sort of, discussed with the young person it’s, sort of like, completely hopeless. … It’s, it’s one of those things that people look at when it’s written and then never again. And actually does anyone pay any attention to it? I don’t think prof – health professionals do. And I don’t think the young people do. So I’m sceptical about the utility of transition plans, um, I have to say. (Redgrave, HP)

Issues of time, resources and practicalities of fitting into on-going consultations were also seen as barriers. One service had implemented it as part of a research project, but then withdrawn it when that additional research resource was no longer available. However, two positioned them as an ‘aspiration’ (Brown, HP) or a ‘target’ (Delia, HP). For most health professionals, plans around transition were again seen as occurring over a series of
consultations. Services also outlined that they then recorded such discussions in clinic letters. Discussions are

laid out in the kind of letters, which I write to the young person and their parent … And transition is part of that, we don’t have a separate piece of paper that’s called transition, it’s, it’s everything weaved into their clinic letters (Carlos, HP)

Some patients reported experiencing plans about transition over time – ‘It was more just something we talked about, there wasn’t really anything written down’ (Darryl). As we will outline below, such an informal approach was not always effective

Unsurprisingly, none of the young people were aware of ever having been offered any sort of ‘written transitions plan’ or access to ‘health passports’. Sarah did remember discussing plans for specific aspects of her transfer in her recent consultation, but when asked about whether she received any type of written documents about any aspect of the process she noted that ‘Hmm I don’t think so but if I have I don’t remember’. Another young person reported having ‘got loads of transition plans’ (Fran) centred on her move from school to college, but nothing from her health services. However, in one case, a written plan was reported, albeit that only the young person’s mother was aware of it. As the topic was initiated in the interview, Jane, Jonah’s mum said ‘It’s here somewhere’ and then pulled a crumpled document – entitled a ‘transition planner’ - from under a large pile of other documents. Jane said to the interviewer that ‘Jonah should have filled it in’ and then turned to her son and said ‘You’ve only had it about a year to fill in’. In all the other cases, none of the families of the young people had ever heard of such documents. Overall, the young people although less enthusiastic about the concept than family members. The young people were aware of some potential benefits, as well as problems, especially around there ability to ‘loose’ such documents. Family members and health professionals also shared this concern, health-related paper documents do and will get lost.

The lack of awareness did not only extend to such documents, but also about some aspects of the transition and transfer process itself. Albeit a more extreme case, a mother noted,

Well we have nothing at all to the extent that I don’t even know when she goes over. I’m assuming it’s eighteen but I don’t know. (Amy, Family)
Another noted that ‘anything would have been useful … just to give us some direction’ (Beryl, Family). In this case, the family had to actively arrange elements of the transfer of services themselves.

Remember at the time, I had to write to all of the individual services, and say, “Ben is now 18. What do we do?” [Bob: Yeah] And a, a couple of them, I think physio being one of them, I had to chase up a couple of times, to just get letters back saying, “Right, you just ring them.” And that was it, literally. So nobody even sort of came to see us, to say, “Bye bye, this is where you go.” It was just literally nothing, and we had to write to everybody to say “Ben is now 18. Can you point us in the right direction?” (Beryl, Family)

This service had ‘no real formal processes … or leaflet or anything like that’ (Brown, HP) for transition. They discharge most patients from child services, but offer ‘that safety net of the adolescent clinic to come to if and when they need it’ (Brown, HP) – and these clinics are described as ‘occasional’. Young people and their families have to then get themselves referred back into services.

In such a context of a lack of awareness, families stressed the potential value of the concept behind such written plans for young people and, as well as them also receiving information about the process. For Paul, brother of Penelope, ‘it seems pretty obvious really, like, that you would need something like that’. He notes that

There was literally no plan … this letter was meant to be sent, this letter wasn’t received … she was just lost. She was just lost in that middle area. That, that, well obviously that transition … Um, I think the most important thing is just clarity for the young person, for the parent, for the family … as long as people say what they’re going to do, and, you know, be organised and make sure that there is something in place (Paul, Family)

In this case, the young person and the family lacked basic information about the process, they were ‘lost’. His sister also outlined the kind of very fundamental and basic information she felt she needed

Basically just knowing what’s going to happen [Int: Mmm]. Knowing when it’s going to happen. Knowing the process. They should tell you, not us chase them … Instead of just leaving you in the dark. They should tell you all this. (Penelope)
In part, this lack of awareness was a product of a service in flux, with regular changes of staff – and regular changes in whom Penelope would see - and no specific person coordinating information to her about the transfer process. In Penelope’s case, her family were very active in contacting services and seeking the appropriate information; they had sufficient cultural health capital to actively manage the situation.

Some young people, and their families, who had transferred felt unprepared and unsure about many aspects of the new service.

Connie None. We’ve had no word from nobody. Nothing, have we?
Carl No.
Connie It’s like you’ve suddenly, you’ve reached that age and you’re written off. … So we’ve had no word from not one of them. And at the day we went to a meeting, must be two years, and basically they were all saying, “Right, you’re, you, you’re moving onto now to adult services [Int: Mhm], you will hear from them in due course” and we’ve had nothing. Absolutely nothing.

In this case, the young person – Carl - and his family felt ‘abandoned’ after transfer. They were not, as far as they or a representative of child services whom we had also interviewed were concerned, transferred to primary care. They had visited adult services once, but since that point, had received no further contact, appointments or offers of support. They were unsure about what exactly to do or about whom to contact to effectively manage this situation. As such, they felt abandoned both by child and adult services.

It appears that such factors as informal practices and organisational turbulence can lead to a lack of awareness, knowledge and understanding of process. As noted above, young people are transferred to a new organisational and clinical environment with a new set of health professionals, norms and routines. They really need to be able to develop an adequate awareness of the transfer process itself and the people, norms and expectations of adult services.

*Parents engaged appropriately: enabling interdependence?*

At the heart of transition is an ambition to shift the work of managing health and health services from parents to the young person. Central to enabling such ‘independence’ is the support of family members, especially mothers (or if a mother was not present or able to play such a significant role, the person who takes on that role). However, in practice, this is not
about a move from a discrete position of ‘dependence’ to ‘independence’, but rather about supporting and enabling the young person’s autonomy, so a relational autonomy, where interdependence is central. As Fran noted, ‘at the moment I think I like me mum coming to appointments with us, because I still think I need her guidance’ (Fran). Family members, in particular, play a very significant role and contribute often invisible labour to the negotiation of the multitude of transitions the young person experiences, especially the healthcare transition.

They are the central mediators in young peoples’ experiences of health and healthcare services. At different times, over the trajectory of transition, there is a fluidity to their involvement. They routinely act as key workers both within the clinic and home. Daryl, in conversation with his mother, positions the support his had in terms of his healthcare as ‘from you and dad mostly’. Importantly, families provide the young person with some continuity of care and a point of reference and contact. In reference to his new appointments in adult services Charlie outlines what he would prefer.

I’d have rather mum was included cos I just come home and I’ll tell mum everything anyway or I’ll end up bringing her to the appointment so she’s there anyway. But it’s sort of all the letters just all of a sudden got sent to me and I’ll open them and I’ll be like “Well, what’s this? First I’ve heard about it” and mum will end up having to deal with it anyway, so if she’s contacted as well, even if it’s only for sort of the first year of it happening, until they know I’m a hundred per cent confident with what I’m going to be doing (Charlie)

Charlie positions his mother, as a central part of care. He seeks to actively involve her in his care, sharing information about the trajectory of consultations and other information coming from the service. He is clearly aware of her knowledge and abilities in supporting him and values this, especially at time when he is unsure about the practicalities of his care.

Family can also act as advocates for young people in negotiations with healthcare and other services. Ben’s parents, Beryl and Billy are aware that some of the adult services Ben engages with do not want them to continue to be involved in his care. In reference to Ben’s contact with social services about providing support for an aspect of his long term condition, she notes that

I’m not just being shoved to the side-lines so they can go and bully him like they do, or like they try and do when it comes to organising the things that they’re currently
making a mess of organising for him. Unless they think they can get away with it if I’m not there (Beryl, Family)

Most had experience, over the years, of ‘fighting to make sure he has the best of everything’ (Daisy, Family). Their experiences with services meant that

I’ve learnt over the years that I need to ask these questions because I never feel anything’s really offered, you always have to ask for the information rather than it being offered. (Cilla, Family)

All the families in this study would seek to be actively involved in obtaining access to the best care they could get for their young person. However, we did have reports of health professionals trying to work with unengaged parents, the ‘reality also is that we have lots and lots of families where parents, you know, just aren’t involved for love nor money. (Peters, HP).

Families can offer practical support in managing health and facilitating access to services, and cognitive support in terms of prompting or asking questions, doing research, providing information and checking understanding.

em my mum is my major leaning post for memory and all appointments and what’s been said and such … If my mum didn’t know the answer the doctor would or if the doctor didn’t mum would (Sarah)

Other young people described family members enabling such distributed cognition. Family members were often the focus for the practical coordination of appointments, with many young people having to coordinate contacts with different services or organisations. Daryl’s mother took a very active role.

If I know it is an appointment and it’s addressed to him I will open it and then as soon as he shows his face downstairs or whatever I’ll say “this has come for you. Obviously I haven’t given it to you cos it’ll get lost somewhere in your bedroom. It’ll never be seen again so your appointments are here, we’ll get them marked up on the calendar”. At least everyone in the house knows what’s happening and when. (Daisy, Family)

Alongside such informational and coordinating work, they can also offer emotional support, providing reassurance, comfort and encouragement.
The young people and health professionals are very aware of the work of their families in supporting and enabling them. The young people recognise, request, and at times, require and celebrate this support. Penelope notes that her mother has ‘always just been involved … um, she’s just always helped us with everything’. One of her professionals offers a related narrative

    Her mother is really her champion. Uh, very creditable parenting style and ability. She knew when to back off and when to champion Penelope. … She was pushed, but she wasn’t told where to go [Int: Yeah] by her mum, or where she needed to be. Wherever she was, that was celebrated, and yet masterfully pushed. (Peters, HP)

Family members are generally seen as enabling young people’s autonomy over restricting it. Practitioners are aware that often ‘they’re heavily reliant upon their parents still’ (Pete, HP).

However, parents can, at times, be seen as shifting between being understood as supportive and enabling to potentially over-invest. For example, a health professional describes Amy, Angela’s mother in the following ways

    So we’re trying to give Angela a bit of independence but maintaining the support from her Mum who is very, very supportive. [Int: Yeah] Her parents are very supportive. They’ve had some erm bad experience of [long term condition] … erm I think she will always find it hard to erm let go … what we’ve tried to say to her is that actually the best way of avoiding that is to teach the girls how to look after themselves cos she’s not going to be around forever. … I’m sure she finds it hard cos’ she’s that sort of mother who erm is very involved, and not all, all, parents are that supportive but she is. (Ardo, HP)

Parents are very aware of the potential to move from being cast as supportive to being understood as ‘very involved’. As with all young people with or without long term conditions, parents have to work to negotiate with the young person, and with themselves, about how best to enable and support moments of ‘independence’. For example, an interviewer’s question, about whether child services ever asked to see Daryl alone for part of a consultation triggered a new conversation between Daryl and his mother Daisy.

    Daisy  But you know, when we’re going to your appointments and things like that, if you ever feel that you just want to go on your own, I can always wait in the car you know?
Daryl  I always want you to know what’s going on as well cos you know I have an awful memory.

Daisy  Do you know, until you got talking there, it never occurred to me that me being there at every appointment could be too much, but yeah, of course it could, I mean, when I was his age the last thing I ever wanted was to go to the doctors or anything with my mother, I never wanted my mother there by my side.

Two years after the initial fieldwork with Darryl and his family, they then told us that Daryl now only attends appointments on his own. In this way, parents need to learn, over time, new ways to support and enable young people’s autonomy.

Creating new routines, norms, and expectations evolves over time. Families and young people can experiment with new ways of being interdependent. Ruth and her father, Rod, had a very collaborative approach to her taking on more responsibility for managing her care as she got older.

For the last, erm, er, year, 18 months she’s been taking on much more of it herself. … I mean when we first started doing this, you know, she did six months of sort of [managing aspects of her long term condition] … You know, not even six months, maybe just six weeks or something, and she said, “I think I'm getting this all wrong.” You know, “Can you help me out,” sort of thing [Int: Yeah]. And then we went back to what we were doing before and I [managed her care] and then, erm, er, and obviously she was there as well and then when she got more confident again with it, you know, then she went back to doing it herself, and she has done ever since, you know. (Rod, Family)

Clearly, this involves relations of trust, trusting that the young person will remember to undertake specific actions, or remember specific details, and trusting to them to know when to ask for additional support or information from their family or health professionals. Jack’s mother, Judy talked about how her son was taking on responsibility for a new aspect of his care. Specific items needed to be ordered in advance. Jack was supposed to order enough for three months for his time away at university. Initially, Judy reported that she was not going to get involved but she then realised that he did not have enough.

Erm, and then I said, "Are you sure you've got enough stuff?" He said, "Yeah, yeah, I phoned it." And I looked at it and I thought, "You've got five boxes. This isn't gonna last you." I phoned them up, found the number, phoned them up and so I said, "I know, my son's 18, before you say anything, and he should be doing it himself." And the woman's like, "No, I've got a 19 year old." She said, "I know what you're talking
about." ((Laughter)) Erm, I said, "He says he's ordered enough 'til Christmas," and she says, "No, he's ordered enough 'til October." (Judy, Family)

Judy then collected the items and delivered them to her son at university. Judy’s involvement, like other parents, is fluid, moving between wanting to be informed, to checking in with health care staff, to supporting Jack in making decisions about his health care - even when she disagrees with some of his choices - to encouraging him to lead an active, independent life. Such work at times, needs to be done with some delicacy, but often families can feel that they are being understood by the young people as doing different work: ‘he probably thinks I’m nagging him but it’s, it’s just trying to encourage him’ (Beth, Family).

In some services, or with some health professionals, or with some aspects of the healthcare system, such practices, especially in adult contexts, are seen as examples of ‘attachment’ or ‘dependence’ and therefore potentially problematic. Following the incident of Jack not having the specific items he needed to order in advance, Judy describes being told by one of her son’s adult health professional’s that ‘'You've got to step away"

The [health professional] is "But leave him. He's got to sort it out himself." But it's too late if he doesn't sort it out [Int: Yeah] and he hasn't got the item. … I haven't been in for 12 months. I haven't been to any because it got-the, the [health professional] said, "Back away," It was like, "Right, this year we're gonna back away. [Int: Yeah]. He's gotta build his confidence." So I haven't been. I haven't been. (Judy, Family)

In Judy’s case, they have decided to ‘back away’ and not go to any appointments, with the hope that her son will develop more (timely) awareness about self-care. They really want to support him in this process but also ask, ‘why should he have to think about placing an order [Int: Yeah] when n- no one else his age has to think about that sort of thing?’ (Judy, Family).

Some professionals see it as their role to shift the ‘locus of control’.

we try to keep the parents out of [Int: Okay] the consultation but we do offer them, you know, if they want their parents to come in perhaps they could come in at the end of the, the consultation … the sort of parental involved and the, the locus of control in these consultations very much shifts, erm, to the patient [Int: Okay, mm hm], the individual young person, erm, rather than the [service] team and, and the parent team. … Erm, the people who often find it the hardest are the parents [Int: Yes] to go from that position of power come control, er, and they worry desperately about their
children, which is understandable [Int: Mhm] … And I think all parents ex-will experience that to a greater or lesser extent. … (Jewel, HP)

This health professional seeks to give young people the ‘tools and the knowledge’ needed to enable them to ‘be empowered to make their own choices’ (Jewel, HP). However, in practice, families are always involved, albeit at times feeling they are forced do this work in the background. Since moving to adult services, Charlie noted that that his mother is not included in his care.

They seem to have left her out, like completely … Yeah, rather than just doing it, actually saying “Do you want us to cut parents out completely or would you like them to still be involved?” rather than just assuming. (Charlie)

However, as outlined above, Charlie still want his mother to part of his care, he wants her to because for him, ‘having to deal with all of it, is a bit scary’. He still wants his mother ‘kept in the loop’ and in practice does this work himself.

Part of the narrative of (in)dependence, empowerment and attachment appears to be embedded in a broader narrative of legal independence. A child health professional talks about his own experience of his son’s care

the health practitioners won’t speak to me, or engage with me in any way whatsoever, even though he wants me to be involved. Erm, because he’s 18, and is deemed to be an adult [That’s…], so that is the way of the adult world, and it’s, erm, yeah, that’s, that’s, you know, they, they respect the individual’s confidentiality. (Carl, HP)

In this way, working with the family, around communicating issues about appointments of organising aspects of care can become problematic. We have various moments where part of a service will no longer communicate information to family members. For example, Ben’s family outline the problem.

Beryl: everybody's sort of saying, “You're an adult now, Ben, you're an adult now, you've got to do this yourself.” And everyone was saying, “You've got to do that yourself, you've got to ask for [service] yourself.” So everything all of a sudden was lumped back on him. [Yeah] and people were starting to say they can't speak, can't speak to me. “We've got to speak to Ben.” [Yeah] And he was, “I don't want to speak to them. You just sort it.”

Bob They said, yeah.
Beryl  And of course they wouldn't speak to me, because they wanted to speak to him, as the adult.

Young people can, at times, be caught in a tension where (legal) independence is thrust upon them, whereas they have a preference for interdependence. Ben notes, in reference to his parents not being able to speak on his behalf that

I don’t know what to say. I’m not even old enough. I’m not experienced to blimmin’... I’m 19 years old. I’m looking out for other things. I don’t really know what to say to those kind of people (Ben)

Obviously, for these young people having a long term condition is only one of their identities, one they often want to minimize and only engage with at specific times, when it is necessary. Young people can feel, at times, confused about how to best manage doing being independent

I want to try and lead like a normal lifestyle. Like no one wants to ask for help really, you just want to do it and be independent.. But it’s like, it’s confusing ‘cause at one point, I’m like, it’s like, “Oh ask for help” and the next point it’s like, “Well you need to learn how to do it yourself”, so it’s like, which one do you do? (Brian)

Over the process of the interrelated transitions they face, be that stages of life, healthcare, education, they feel that they can receive conflicting messages about how best manage the rights and responsibilities that are embedded in these transitions.

Some services and health professionals, including those embedded in adult services, understand familial work of supporting and enabling, as demonstrating something like interdependence. Ben notes that one of his health professionals embodies this practice ‘He does the both, treats us like an adult but he’ll, he’ll also include me mam just in case I need her for anything’. (Ben). Similarly as Ruth notes,

the doctors always said, you know, “You, you don’t have to have your dad here” or, “You can have you dad here” if he wasn’t there kind of thing [Int: Yeah]. And it, it was always more my dad’s decision than anything, you know, he would say, “Look, you know, you should try this on your own” and I would go, “No, I don’t feel comfortable with that yet” or “yes I would”. And the doctors would go along with it, you know, they’d be [Int: Yeah] supportive if he was there and supportive if he wasn’t kind of thing. (Ruth)
An adult health professional outlines, he is aware that with young people ‘they, they’re in charge of themselves in, in adult services, whereas sometimes they, they still need the guidance and the backup from the parental guidance. (Dee, HP). As such, some services can and do work to recognise, enable, support and accommodate interdependence where possible. One notes that, within their adult service that

the young people will pretty much always bring, erm, one of their parents or carer with them, yeah. Pretty, pretty much 99% of the time. Yeah [Int: Okay]. Erm, erm, as they get- even- well, even when they get older, they tend to bring partners [Int: Yeah] or, or relatives with them, yeah. (Pete, HP)

Some health professionals are aware that the involvement of others is normal, not dysfunctional. The ‘parent team’ is, at times, supported in shifting roles to a more ‘partnership’, ‘shared care’ or ‘consulting’ roles.

Key worker: enabling consistent, supportive, relations of trust?
Very few services reported offering a designated key worker. With those that did, the person the services named seemed to differ from the one the young person and family then went onto suggest. For example, one service outlined their practice

Jones: So they, they have a named specialist nurse … they should know who their named nurse is, and they all know how to get in touch with me, if they need to.
Int: Okay, okay. So would you find they generally would get in touch with you, or they would get in touch with the diabetes nurses?
Jones: Mostly with the nurses, and increasingly … the nurses are actually getting in touch with them.

In this service, as with another, the official role is seen a tied to a nurse. When we asked the young person, he responded that person he would contact would be ‘Jones normally’ (Jack) and not a nurse. Jack’s mother, Judy, offers a similar narrative.

Key worker you see, we don’t even see the same nurse, even now … see I always just phone Jones [HP], because he’s the main person, you phone the nurses and they are all chopping and changing and they don’t work every day ehm and one day “oh I don’t deal with [X], that’s so and so she’s on this day”
In practice, the young people and their families orientate to a specific health professional as their informal ‘de facto’ key worker due to such issues of consistency in relationship, knowledge and accessibility. As such, in nearly all the services, young people could identify someone whom they felt acted in the role of a key worker, albeit without a formal title or responsibility.

The core attributes around which define someone as an informal key worker for young people seems to centre on relations of trust. For example, when asked if she had one a young person responded that

I guess it’s Redgrave [HP] I trust most out of the people, which I guess isn’t really a nurse or anything. But he is the doctor who I trust most to talk to and that (Ruth)

Again, in this service, a nurse was an assigned key worker for Ruth. However, for Ruth and others, knowing someone over time and therefore being known by them is central. Someone whom ‘knows me the most’ (Fran) emerges from such consistency in relationships. The person also needs to accessible and knowledgeable, often that means in terms of contactable via a specific number or replying to a call within a timely manner. A mother outlined how a specific allied health professional was the person she would always go to if she did not ‘quite known who to contact’ as they are the person that her son has ‘seen the most’ (Beth, Family).

These informal key workers are often also positioned as someone whom is described as ‘brilliant … really helpful’ (Daisy, Family). For example, Connie, Carl’s mother, remembers someone child services

Connie I, actually yeah ‘cause she was really good. … So she was good, I mean I tell you what, that woman wants a medal [Int: Mm hm], she really does because she was so good not just at her job but she’d, you know, fit you in somewhere

Int It’s often the [allied health professional] who do, who do all of those things.

Connie Aye, well there’s not many, well honestly all the other ones you used to talk to, “Yes, but there’s naught we can do, goodbye.” You know, [Int: Yeah] and you’d think, “But you’re not saying which way, which route I’ve got to go.”

Post-transfer, the beginnings of such relationships of trust can be established. Charlie outlines that, the main person I’ve seen so far is Crowley [HP], he’s sort of been really helpful, and he’s even given me sort of a mobile contact for him and said “if there’s anything you ever need, just give me a call and ask me anything”. So that sort of made me a lot more comfortable with him and I literally will just give him a call or things like that,
so that’s sort of been helpful, but with everything else I’m still a little bit lost.

(Charlie).

Charlie was in the process of transfer, with a few aspects of his care still situated in child services while most had transferred to adult services. As he notes, he is ‘still a little bit lost’.

Yet, the person he sees as most useful and accessible, emerges from his brief period of consistent interactions with a specific health professional whom has been ‘really helpful’ and made themselves easily accessible to Charlie.

The centrality of relations of trust is most clear when they are absent. When asked this question about a key worker Ben and his mother, Beryl, responded

> Ben  I thought that was what me mam was doing.
> Int  Yeah, yeah.
> Beryl  I think it’s difficult, because I think, not sounding too defeatist, I think the damage has been done and we’ve just got no faith, well little to no faith, and little to no trust in them. Have we? [Int: Mm] I think they’ve, they’ve let us down so many times that we just, we don’t trust them. Which is an awful thing to say if you’re a health service, but speaking generally again I suppose, but I just don’t think we trust them do we? We don’t trust them to follow through what they say, they say that they’ll do.

In this case the young person and family view of being offered sub-optimal care, in part stemmed from the lack of someone offering ‘consistent support’ (Beryl) in adult services and being an accessible source of knowledge and supportive over time. Ben had a large number of different people he would see and different services he would visit. The family members went onto outline the need for someone taking on the role of a key worker in one of their own interviews.

> Bob  Yeah, ‘cause they always fob you off onto somebody else when you ring up, “Oh, I don’t deal with that. You have to speak to this one.” Speak to them and they go, “Speak...” There’s no direct person you can deal with.
> Beryl  It’s passed round, mm. …
> Bob  They should just have one person you can get in touch with and can sort it out for you. You know, one or two, not ten other people.

The service themselves noted that such support was absent, that it was only offered by ‘whoever’s working on at the time or with them at the time’ (Bow, HP). Whatever the context, whether services are seen as effective or not, mothers are often also understood as another informal key worker. As a health professional commented
She often said she can’t remember who her key worker is. She would call her Mum and her mum would then ring the … nurses up the way er so I think at the moment Angela wouldn’t call one of our team, she’d call her Mum (Ardo, HP)

Mothers, or whomever takes on the primary carer role, are central to supporting the young person’s interaction with services. As such, they are the central consistent, trusted, knowledgeable resource for the young person. They then often liaise directly with someone whom they feel is a key worker within the service.

As noted above, very few services reported offering a formally designated key worker. Those that did were aware of a range of practical problems they could face. For example, staff turnover could mean that for some young people ‘the nurses change several times in the time’ (Ardo, HP) they are with the service. Another, when asked if they provide key workers ‘Uh, well yes and no’. They noted that:

We have a named key worker who, for every person under 19, who is one of the specialist nurses. But because there are [X] of them and they all work different hours there can’t be just one person they will always speak to [Int: Yeah]. So, um, and some of the nurses have embraced the key worker concept to different degrees. So [Nurse X] … I mean he makes a real effort to work individually with patients of his, whereas some of the others, sort of, like to leave it as a, sort of, more generic role. (Redgrave, HP)

Clearly, this echoes the families’ narratives of problems of not being able to contact a specific person given the differing work schedules. It also highlights the awareness of different ways that staff can decide to enact such a formal role, some can ‘embrace … the concept’, and others may not be so enthusiastic. A service outlined that

Well, we do in theory, erm [Int: Okay ((laughs))]) and we – we should do. And I really, really, really feel, you know, that we’ve gotta have more attention given to proper key working. I feel that this is one of my regular beefs really. … it’s also a problem that er, sometimes people get referred on to [Department X] [Int: Yeah] and then we see the [results] and then the key workers kind of – because they know that they’re going to be followed up regularly, the key worker kind of, goes out of the picture a bit but then, the other aspects aren’t properly addressed then. (Delia, HP)

As they note, again, the ‘theory’ is often not enacted in a coherent way. All the services are trying to attend to a large workload, with competing demands for their time and resources.

We’re really just um, ((laughs)), just about manage to get, um, haven’t quite got enough clinical staff to do what we’re doing , you know, but of course it’s a good idea. (Brown, HP)
For those services not providing a key worker, this is not about a lack of being ‘committed’ to such idea, but often more about ‘what they are resourced to do’ (Lucy, HP), what is practically possible given the constraints they work within.

**Coordinated team: coordination and consistency?**

Some services did try to formally coordinate appointments through offering a clinic where different members of a multi-disciplinary team attend, either in separate consulting rooms, or at time, with different members of the MDT in the same room.

> it’s very flexible, yeah. I mean we, we, essentially we’ve got three pr-professionals there in three rooms, and, er, er, we’ve got two patients coming every half an hour. So there’s, there’s opportunity for, for – although, if we haven’t got the time for each of them to see every member of the team, there’s time for some of them to see more than one member of the team. (Jones, HP)

When this can be organised, this clearly enables young people to gain a range of support at single time point, to see ‘a selection of people’ (Amy, Family). In some services, this is ‘not a formal thing, but I try to arrange it that way. (Delia, HP). This is at times positioned as something services informally try to do ‘despite all the obstacles managers put in our place we still work as a multi-disciplinary team’ (Peters, HP).

For those young people whom have been attending such a service, they see this as the norm, as unremarkable. However, for some, when they experienced a large number of coordinated appointments this was remarkable

> We’ve been up there sort of a good three quarters of a day cos I’ve had one appointment, then another appointment, so they’ve just all seem to have fallen on the same day (Charlie)

They would have preferred them spread over weeks, in part, as this impacted on college. For others, this was never an option, sometimes due to the service structure, or sometimes, as they see ‘usually just the one person’ (Sarah). Also, different services were at different stages of taking on such a model, some had historically not offered such a coordinated clinic. Some were not as coordinated in terms of information sharing between people or services – ‘I know they didn’t work as a team very well then, or you’d say one thing and people just didn’t know (Judy, Family). Others were attempting to develop this aspect more.
However, at times, potential key figures are missing from these coordinated appointments. Within some services, psychological support can be available at the same time.

Sometimes the psychologist comes as well but usually she’s not at the clinic now because she’s running her own clinics erm but there’s an option to refer to the psychologist (Ardo, HP).

Often such psychological support is offered at separate appointments, at different times, often at different days. It was noted that some services have focused on getting good access to psychological support. However, for others, the psychological support was presented as noticeably absent ‘we always talk about the fact that we don’t have good access to clinical psychology’ (Brown, HP). They noted that

It really, I mean that’s a massive problem in paediatric services and services in transition services: being able to access psychological input, because the funding’s just not there. Yeah, so you sort of beg, borrow and steal (Brown, HP).

Alongside this, physiotherapy and occupational therapy was seen as missing, as such services were already seen as ‘under resourced’ (Brown, HP). However, one offered a service that included a clinic with ‘an OT or a physiotherapist in with the doctor as well, [Int: Okay] erm, and we can call a nurse in if nursing issues come up’ (Bow, HP).

Such coordination can also be problematic given the range of services sometimes needed by young people. Going through transition and transfer can offer an additional layer of complexity. An interviewer tried to summarise the range of services one young person, Brian, was working with

Int: so, right, and so some of the people you see at the minute sit in paediatrics, some of them sit in adult care, [Brian: Yeah] some of them sit in adolescent care? Bit of pick ‘n mix [Brian: Yeah], pick ‘n mix healthcare ((Laughter)).

Distribution of services, especially across different organisational boundaries, can raise practical problems. The distribution can often mean a lack of communication between health professionals. As one family member noted, ‘you find going from appointment to appointment you just keep repeating yourself don’t you? They’re asking the same questions at each appointment’ (Cilla, Family). Another noted how
Well half your appointments wasted because you’re going over the same old ground. … Just getting the basics. [Int: Yeah] Instead of concentrating on why you’re actually there.[Int: Yeah, yeah] People need, obviously you need a background to be able to treat somebody but you’re wasting half your appointment [Int: Mm hm] going through the questions, whereas if they already know about it, they’ve been introduced to you [Int: Yeah] then you don’t have to go over that. (Beth. Family)

Relatedly, such distribution can mean, potentially, a lack of coordination and consistency in information and advice that young people can receive. Even within services that offers an MDT within a single clinic, ‘the bigger the team the harder it is to be consistent, and the harder it is to appear to be saying the same things.’ (Redgrave, HP). A missing figure, especially for those who will be transferred to primary care for all or part of their care, was the general practitioner. As one service noted

But we do try to encourage, erm, sort of firming up the relationship with the GP [Int: Yes]. Because for many of these families, the GP hasn’t played a very big part (Carlos, HP)

As noted above, the general practitioner is often someone whom the young people had often had little interaction with over the years, yet is meant to be a central figure in coordinating their health care and access to health services

**Holistic life-skills training: another service’s work?**

Very few services within our data-set actually provided any form of holistic life-skill training. One did provide specific elements of Holistic life-skill training, often in the form of talks or group meetings.

So we normally do an education session in the summer holidays for university leavers. But we need to do more of that. Obviously those staying locally stay under us [Int: Yeah] for a bit longer. Um, and so it’s an easier transition and their mums and dads help them do things and navigate, you know, how to change general practitioner and get your repeat prescriptions and things like that. But there are those practical skills they need to learn, actually, just how do you do things? And, um, so for jobs we do talk, if, you know, if they have specific career aspirations (Redgrave, HP)

This service provides some focused support around key issues – going to University, jobs and careers - they feel that the young people face. This service, and some of the others, were aware they could and needed to do more around such issues. One health professional was
interested in extending their service to offer a broader range of support through a series of talks, albeit focused around ‘self-efficacy’, but including aspects around ‘managing money, er, about jobs, about managing my time’ (Bow, HP)

Yeah. Well, it’s part of what we see as [core] which is trying to help people, [Int: Yeah] er, achieve [the] maximum [Int: Yeah, yeah] You know, and thinking of … in terms of biopsychosocial. (Bow, HP)

Given the context of a focus on the broader young person, they were currently working on a longer term plan to introduce and implement a formalised Holistic life-skills training. A few parents also felt that such work was going in with health services, albeit in an informal way.

I think this team have, have been doing those kind of issues informally [Int: Yeah, yeah] i- but in a structured manner, in their heads already, without [young people] realising that they’ve gone … Well, you see, they knew they were going to this. They were invited to attend this driving, [Int: Yeah] erm, seminar and so they met other teenagers the same - a couple of boys the same age as themselves there [Yeah] when they went. (Amy, Family)

Within this service, they had no formal courses or resources which they drew on to support such Holistic life-skills training. Instead, topics, like sex, may emerge or be prompted within the space of consultations. However, the focus appeared to be on the implications of the long-term condition and its potential impact on these topics, over a broader more holistic focus. Health professionals were aware that such services could be offered and some felt it could be ‘really helpful’ (Lucy, HP) albeit given the caveats of more time and resources. However, they were aware that other non-health services are already offering this: ‘I think it would be something for another service. … they can go to places like [Charity A] and that and, and they’ll do social skills there’ (Pete, HP). As such, this style of work is not always seen as a core responsibility.

I think it’s a bit over the top to be honest, you know, I think, but, you know, w- there are, there are aspects of what they need to do that’s a bit different to the next young person who doesn’t have [long-term condition], but that sort of stuff is the same for every [Int: Yeah] young person.(Jones, HP)

Holistic life skills are, given their nature, positioned as something that all young people need to acquire albeit that condition-specific issues will impact in specific ways on elements of their engagement with the world. Rendering this as something tied to health and health services per se can be seen as problematic.
No, I don’t think that should be part of … health [Int: Yeah]. I think it’s more social services domain [Int: Okay]. That’s just my personal view point. (Peter, HP)

Clearly, there is an element of resistance from some professionals to realign the scope of their work in such a way. This is in part driven by the knowledge that other services the young people encounter are potentially offering such support already and may be better resourced and skilled to provide such training. However, as another health professional noted:

I think it’s one of those, this is one of those areas that sort of falls between the agencies; so you could argue that that kind of input could be, erm, part of an education remit; part of a health remit; part of a, you know, social care remit (Delia, HP)

In this way, given the broad focus of such work, a range of service providers could, in theory, offer such support. However, in practice, only some young people are actively engaged with social and educational providers, from across the state, private and charitable sectors.

Echoing the health professionals, young people and families, were aware that such work was already going on through other providers. Some of this work occurred within the school or college environment. This was especially so when the young person was attending college courses tailored to offering such support around topics like ‘independent living’ or was involved in specialist schooling.

They had a little flat and it was a little flat where they would teach them how to budget money and day to day sort of living and how to cope and that sort of thing. I thought it was absolutely fantastic. But it came from the school. It came from nowhere else and it was never sort of kept up anywhere else and I really do think that helps to keep him on the right track but I suppose unless you are in a special school you don’t get that. (Daisy, Family)

Some young people also were provided with such training and support through groups, events or trips provided by the third sector: ‘well I’ve done sort of similar things but through maybe private charities, things like that’ (Charlie). Such charity run specialist groups, sometimes long term condition-specific, or more general, offered as part of their services elements of Holistic life-skills. In some cases, third-sector partners already had good links with the services.
It should be noted that, this work was also seen as something that families are already providing and should be central in. As one young person noted, when asked about such provision, the only person she has received support from is ‘My mam, it’s only me mam helps us with everything and all that sort of stuff.’ (Penelope). Again, echoing some health professionals, a family member also felt that such work should not be tied to health services

I think probably health departments, they’ve got enough to do really haven’t they? I think that should be down to the, you know, the, the individuals and their families. You know, to sort of sort out. I, I, I mean, I mean if there’s any advice there to be given, obviously, or, or asked for it might be handy. But, uh, but I really think, you know, health departments are for the health really aren’t they? (Ralph, Family)

The social institution of the family was often seen as a central resource – and note that all these young people had at least one family member closely involved in their healthcare. In this context, a core responsibility of health services was to signpost young people to relevant services outside of the NHS.

Beryl  Um, yeah certainly signpost to, they’d probably dismiss it as not being their responsibility I would imagine, but

Bob  I think they probably do a lot more things before they’d start doing this [Int: Okay], you know, they need to get other things put right [Int: Yeah] before they thing about [Int: Yeah] taking on more things they cannot do.

Beryl  Yeah, I think so. … I think that’s very fair point to raise [Int: Yeah], that they need, they need to do what they’re supposed to do best first and foremost [Int: Yeah] before they look at, at taking on more

For those families who felt aspects of the child or adult services were in some way sub-optimal, a focus into other domains of work, beyond a focus on supporting the core medical issues was clearly problematic.

Coordinator at managerial level: an absent idea(l)?

Only one service reported that they had introduced such a coordinator role as they realised the need. However, this was role was newly created

We have identified one of the nurses as taking a lead for transition and she’s the person who’s going to be looking at the pathway and the overall thing but they haven’t done anything much yet cos they’ve only been in post a month. So we we’ve
sort of thought about having a person and erm but we haven’t got very far with what
they’re actually doing in that post yet (Ardo, HP)

Other services were also aware of the opportunities that such a role could provide. One
health professional noted that ‘I would like one. I think that’s a really important role’
(Redgrave, HP) and discussed a range of evidence they were aware of that demonstrates how
it could benefit their service. It was clearly seen as ‘useful’ (Bow, HP), and offering a range
of potential benefits

Ideas about how to organise these clinics, you know, disseminating ideas, um,
information sources – all that sort of thing and I mean, if all the various facets were all
given the same message saying the same thing, directing to the same services then
yeah, of course. That would be, that would possibly be the single most useful thing to
do … if somebody could kind of co-ordinate and pull together what, what is going on
across the board, service wide, then that would make that sort of planning easier as
well, I think. (Brown, HP)

Despite such enthusiasm, the practical realities of limited resources, managing increasing
workloads and competing demands mean that such an ideal seems far from being
implemented. For example, in one service, they noted that, they are a ‘relatively small area’,
with few young people transferring, ‘So whether that’s enough to justify an individual’s
work’ (Barbara, HP). In this way, such innovations will depend on such factors as clinician
enthusiasm alongside, more external, policy drivers like developments in guidelines, tariffs
and quality standards.

Strengths and Limitations
Conducting serial and triangulated interviews enabled us to confirm stories and capture
evolving perspectives. Observing consultations enabled us to compare what people do,
against what they said they did in these contexts. Whilst both the form and content of
healthcare that is received may differ between the three exemplar groups, the organisation
and experiences of the transition and transfer process showed many more similarities than
differences. The findings have face validity as they relate well to the findings in other WPs and other
studies in the literature, especially how transition and transfer can be disorientating for young
people and their families.44, 50, 82 This study strongly echoes work on how young people build
relations of trust with health professionals and services,44, 50 especially where those relations
are consistent and supportive;\textsuperscript{58} as well as work on how the family, especially the mother, have built relations of trust with health professionals and services.\textsuperscript{82}

In its nature, qualitative work is in-depth but small-scale; a consequent strength being the richness of data and a weakness being the low number of case examples. We aimed to recruit fifteen families and achieved thirteen. We had difficulties in recruiting young people, with many seeing the breadth and depth of data-collection as an additional burden whilst already taking part in WP 2.1. Retention of young people for follow-up and/or post-transfer interviews was poor, so learning about the adult context was limited. We were unable to contact some young people and some of those we did contact declined follow-up interviews. They either withdrew from this aspect of the study, or suggested we speak to their parents or health professionals. Thus, our findings are valid in relation to the data we collected; however, it is possible we did not identify key messages that would have been relevant after transfer to adult services.

Additionally, all the young people had at least one family member closely involved in their healthcare. We therefore lack the perspective of young people with less input from families, including looked-after young people.

Discussion

Our work echoes the reviews of Lugasi, Fegran and Heath\textsuperscript{44, 50, 82} that transition and transfer is disorientating for young people and their families. The young person has usually been in a specific child health service for some time, generally since early childhood. They have, over time, built relations of trust with health professionals and services, especially where those relations are consistent and supportive.\textsuperscript{58, 144} They have, over time, learnt to make sense of how best to integrate the practical, cognitive and emotional work it takes to be a patient with a long term condition within a specific paediatric health service system. Similarly, the family, especially the mother, have built relations of trust with health professionals and services.\textsuperscript{82} They have, over time learnt how best to support their child, how best to support the management of their child’s health condition(s) and importantly, how to effectively navigate, manage and engage with the child health service system.

The process of transition breaches\textsuperscript{88} the relations of trust. It breaches the relations of trust they have developed with others, with a range of health professionals, services and organisations. It also breaches the relations of trust they have developed with themselves. They no longer know what to practically do, how best to navigate consultations and services, whom best to contact. In this way, it breaches their taken-for-granted expectations,
knowledge and relationships. The event of transfer is central to enacting this disruption for young people and their families.

Allen, following and developing the work of Forbes, has focused on how continuity of care be effectively enabled, so as to reduce disruption for young people and so enact a ‘smooth transition’. They discuss seven different forms of continuity: relational, longitudinal continuity, managerial, cultural, informational, flexible, and developmental. Importantly, they note that

Relational and longitudinal continuities are the mechanisms central to transition because they also facilitate management and flexible continuity. They also provide a sense of safety at times of change, obviating the need for informational continuity interventions. Flexible and cultural continuities also emerge as important.

Relational and longitudinal continuities refer to an ‘ongoing therapeutic relationship’ and ‘uninterrupted relationships with service providers over time’. However as we saw above, for these young people and families, relational and longitudinal continuity are breached. In all the services we focused on, the young people moved to a separate adult service provider with a different set of health professionals offering them care. In such a context, Allen highlights that informational continuity – ‘the provision of information in order that young people and their families are prepared for transition and understand the new arrangements for their care’ – can become central.

We have seen that systems, processes and practices that work to help people make sense of and minimise these disruptions are more likely to be effective for young people and their families. In Allen’s terms, informational continuity is a central resource through which effective transfer takes place within our data set. Quite simple and mundane practices, like being very clear about the processes in discussions and documents, are key, as is exploring how child and adult practices and procedures actually differ, exploring the new norms and routines. When there is informational discontinuity, young people and families can become lost, abandoned and feel there is no one to turn to. Similarly, organisational turbulence, through things like staff or services changes, prior to transfer, can led to informational discontinuity and so create confusion and uncertainty. As young people are transferred to a new clinical and organisational environment with a new set of health professionals, norms and routines, the core focus they need is support and confidence in the practicalities of managing the adult healthcare system itself. We have also seen how, undertaking joint clinics
and meetings with members of the adult team which the young person will actually be seeing, can be central. Following Allen, this enables the possibility of the initial steps towards ‘relational continuity’.

Finally, we have seen that systems, processes and practices that work to recognise, enable, support and accommodate interdependence and relational autonomy are more likely to be effective for young people and their families. Interestingly, in the reviews, and in nearly all the papers they worked with, the figure of the parent is cast as, albeit for good reasons, in some ways holding back the young person’s move from dependence to independence. Allen’s work is a notable exception, in that they problematize the myth of independence, highlighting how ‘the individualized focus of adult services does not reflect the realities of young people’s lives, which are characterized by interdependencies’. As ethics of care work has repeatedly outlined, interdependence, or rather ‘relational autonomy’, is a routine feature of everyday life. The involvement of others is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members should be supported in shifting roles to a more ‘partnership’, ‘shared care’ or ‘consulting’ role.

May et al argue that, over time, patients with long term conditions, especially those with multiple morbidities, have increasing ‘workloads’, a burden of treatment. The everyday work of living with a long term condition includes work that is delegated from health professionals to patients. This includes managing and coordinating multiple appointments, treatment regimes, self-care and self-monitoring. This work disrupts everyday life. Through the process of transition, and especially the process of transfer, we are increasing that burden for young people and their families. Following May et al, we need to support and enable a minimally disruptive transition.

**Conclusion**

Transition and transfer is disorienting for young people and their families. It has practical, cognitive and emotional impacts. Importantly, it disrupts their often hard-earned knowledge of how best to navigate the child healthcare system effectively. Health professionals need to focus on helping young people and their families make sense of these disruptions. They can minimise them through actions like: being very clear about the process in discussions and documents; exploring how child and adult practices and procedures actually differ; undertaking joint clinics and meetings with members of the adult team the young person will actually be seeing; and including family members in the process. Transition is about
supporting and enabling young people to become responsible for their own healthcare. However, family members remain crucially important in this process. The involvement of others is normal, not dysfunctional, and for people in other age groups is largely accepted. Family members should be supported to shift roles to be more ‘partnership’, ‘shared care’ or ‘consulting’.
Interview schedule: Young person

Schedules for parents and health professional are similar – not reproduced here

Young Person Interview Schedule – Time 1

Note: The interview schedule is developmental. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.

Plan of interview

1. Introduction
2. About you
   - Education; Employment; Leisure/hobbies; Health/Mental Health
3. Proposed Beneficial Features/Things that might be part of your transition
4. Transition/discharge plan
5. Becoming an adult
6. Feedback

Setting

- Young people will choose setting – mainly their home, could be their school/workplace/college etc
- Time 1 interviews to take place in 2012/2013
- Newcastle University lone worker policies will be followed

Introduction

- Explain purpose of the study and this interview and that it is the first of two:
  - Won’t affect the care you receive whether you take part or not
  - What you tell me will not be discussed with your health professionals/parents/carers or anyone else outside of the research team without your permission. (Unless you tell me that someone is hurting or harming you, in which case I will have to tell someone to make sure that you are safe)
  - We’re looking at the experiences of young people with complex health needs as they move from child to adult health services
  - No right or wrong answers – not a test of your knowledge
- Consent – written.
- Explain interview recorded but details will be confidential I am not a clinician, but [appropriate clinician] who is involved in the study can speak with you or facilitate an appointment with your general practitioner
- Questions or concerns?
About you

Firstly can you tell me about yourself (things like how old you are and who you live with)?

Points they might cover:

❖ Age
❖ Current living arrangements
❖ With who?
❖ Plans to move?
❖ If yes – When?
❖ Where?
❖ Who with?

About your health/mental health care

Can you give me a brief description of your current health/mental health care (things like who you see and if they are helpful etc.)?

Have any plans been made about what might happen after you leave children’s services?

Have you met anyone to talk about what might happen after you leave children’s services?

Do you know if you will need to be followed up in adult services?

Have you talked to anyone about adult services and what might happen there?

Tell me about your current health/mental health appointments

Points they might discuss:

❖ Helping to make decisions about your care?
❖ Attending appointments (or part of your appointments) by yourself?

Do you think there is anything that could be changed about your health/mental health appointments to make them work better for you? (The things you like and the things you would like to improve)

Points they might discuss:

❖ Timing
❖ Location
❖ Professionals talking to you more
❖ Professionals talking to your parents more
❖ Language used

Education

Tell me about your education/school/college

❖ Where
❖ Subject(s) and level(s)
❖ Continue on to sixth form/college/university?
❖ Future studies?

Have you discussed education with your health/mental health professional(s)?
- If no – do you think this would be helpful?
- If yes – Tell me about it
- Helpful/useful to you?

**Employment**

*Have you thought about what you might like to do for work/career?*
- Specific career plans?
- How to do that

*Have you had any support/advice about planning for your future career?*

Points they might discuss:
- Who (Connexions/school careers advisor/transition employment support officer/similar)
- Tell me about this
- What did they say
- Helpful/useful to you?
- How could it be more helpful/useful to you?

*Have you discussed this with your health/mental health professional?*
- If yes – Tell me about it
- Was this helpful?
- How could it be more helpful/useful to you?

**Leisure/hobbies**

*What do you like to do in your spare time?*

*Do you need any support with this/these?*

Points they might discuss:
- Get any support?
- Tell me about your support
- Who
- Is it helpful/useful to you
- How could it be more helpful/useful to you

*Have you discussed this with your health/mental health professional?*
- If yes – Tell me about it
- Was this helpful/useful for you?
- How could it be more helpful/useful?
Proposed Beneficial Features/Things that might be part of your Transition

Here are some things that some people have said might be useful to help them move from children’s health services to adult health/mental health services. You will have this list in your health contacts diary from the other research assistant who is working with you.

What would work for you, why, what would not work for you?

Go through each of the 11 features and find out if they have experienced them (in conjunction with health diary and information from clinical notes obtained from relevant local RAs) (See also Health Diary Piloting)

Things that might be part of your transition:

<table>
<thead>
<tr>
<th>Number</th>
<th>Questions to think about</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Was the clinic you attended separate from the children’s clinic; therefore just for young people or young adults?</td>
</tr>
<tr>
<td>2</td>
<td>Have you been introduced to people in the adult team who will take on your care in due course?</td>
</tr>
<tr>
<td>3a</td>
<td>Did anybody ask you formal questions or ask you to complete a questionnaire about whether you are a confident type of person. This does not mean how you appear to other people; rather whether inside you appreciate yourself, can deal calmly with difficulties or unexpected events etc</td>
</tr>
<tr>
<td>3b</td>
<td>Did anybody in the clinic team work with you to become more confident in looking after your health condition and your health generally?</td>
</tr>
<tr>
<td>4</td>
<td>Did anybody ask you formal questions or ask you to complete a questionnaire about whether you felt ready to move to adult services?</td>
</tr>
<tr>
<td>5</td>
<td>Do you have any document completed by you and the clinic team with information about you and your condition; a document you can share with any new health staff you meet? This might be a health passport or a transition plan.</td>
</tr>
<tr>
<td>6</td>
<td>Did you think your parents were involved and consulted to the right amount about your healthcare?</td>
</tr>
<tr>
<td>7</td>
<td>Is there one person in the clinic or team working with you who you feel knows you well and is identified as your “key” worker?</td>
</tr>
<tr>
<td>8</td>
<td>Do you know if there is a person (a co-ordinator) whose job is to make sure services are well co-ordinated as you move from child to adult services (you may not know the individual personally)?</td>
</tr>
<tr>
<td>9</td>
<td>Did you think the doctor, nurses and other healthcare staff involved in your care work together as a team?</td>
</tr>
<tr>
<td>10</td>
<td>Do you or your parents receive an “individualised budget”? This is a sum of money you or your parents receive to buy your health care which previously was</td>
</tr>
</tbody>
</table>
Did you receive from staff in the clinic any **training such as watching a video or attending a course** on preparing for your future? So it would cover such things as:

- Planning for training or work or more education
- Looking after your health
- Making good and happy relationships
- Looking after you finances

For each of those they have experienced:

*Tell me about it*

Potential prompts/areas they might discuss:

- What happened?
- What was discussed?
- What was done well?
- What could have been done better?
- What could have been done differently
- Do they think this was helpful?

If they do not think they have experienced them discuss the idea:

- Do they think it could be helpful/why

*Ask them about any other ideas they have which might be helpful and use prompts if needed:*

- Other ways to organise your health care
- Other training that might be useful to you

**Transition/discharge plan**

*What do you think should be on a transition/discharge plan?*

- Education
- Employment
- Leisure/hobbies/spare time
- Independent living skills
- Condition related needs
- Health/Mental health

*Do/did you have a written transition/discharge plan?*

If yes, tell me about it

Points they might discuss:

- helping to write it
- Anything extra should be on
- Anything should be taken off
- Do you have a copy?
- Was/is it helpful/useful to you?
- How could it have been more helpful/useful to you?
**Who was involved?**

Potential people involved:

- You
- Education
- Health
- social services
- parents/carers
- other family members
- friends
- Anyone else

**What was on your plan?**

Potential areas covered:

- Education
- Employment
- Leisure/hobbies/spare time
- Independent living skills
- Condition related needs
- Health/Mental health

**If no do you think it would be/have been useful?**

**Becoming an adult**

*Do you feel like a ‘grown up’ or an ‘adult’?*

*What do you think will make you feel like a ‘grown up’ or an ‘adult’?*

*When do you think someone becomes a ‘grown up’ or an ‘adult’?*

Discuss, then show them the list adapted from Arnett\(^{204}\) and discuss whether or not they think each item contributes to being an adult. Can be simple yes/no.

**Finally, we need to understand whether the kinds of questions we are asking actually relate to the issues that you think are important?**

- Are we asking the right questions?
- Did these questions allow you to talk about what was important for you?
- Is there anything else you would like to tell me?

**Thank you for taking part**

Remind them that you will be contacting them about the arrangements for the diary exercise in 2-3 months’ time.
Appendix 8a: Discrete Choice Experiment

This appendix contains the questionnaire used in the DCE, followed by a draft paper that provides further details about the DCE Questionnaire.

DCE Questionnaire

Preferences for a transition service

All information will be kept strictly confidential.

Dear Participant

We are interested in your views on the best way to organise NHS services for young people with long term health conditions. We want to hear from young people who are or will soon be making the transition from children’s health services to adult health services.

You kindly agreed to participate in this study.

In this document, there is:

Section 1 This helps you to think about what the questionnaire will ask about

Section 2 This asks you about your current situation

Section 3 This is an example question

Section 4 This is the questionnaire itself

Please follow carefully the guidance about how to answer the questionnaire. There are no right or wrong answers; we are interested in your opinions. Don’t spend too much time answering each question, as your first impression is likely to be the most accurate.

Please ask me if there is something you don’t understand or find difficult to answer.

We will only use your answers for research purposes, and we will keep your answers private. No-one from outside the study team will see your answers, and you will not be identifiable when we report the results.

Thank you for taking the time to answer this questionnaire.
Yours sincerely, Jenni Hislop, on behalf of the Transition Collaborative Group
SECTION ONE

This section is to help you get used to the ideas we want to ask you about later on
Below are some aspects of transition that we want you to think about. Please read the
descriptions and think about what you would prefer. We are not asking you to answer
anything here; this comes later in Sections 2 and 4.

Appointment flexibility

<table>
<thead>
<tr>
<th>Would you like the service to offer you an appointment:</th>
<th>During office hours only</th>
<th>OR</th>
<th>During and outside office hours</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The service is open from 9am to 5pm during weekdays only.</td>
<td></td>
<td>The service is open at various times throughout the week and may be able to offer you an appointment outside the hours of 9am to 5pm during weekdays.</td>
</tr>
</tbody>
</table>

Staff consistency

<table>
<thead>
<tr>
<th>Would you like to see the same team of staff regularly?</th>
<th>Yes</th>
<th>OR</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>You would like to see the same staff members on each of your visits to the service.</td>
<td></td>
<td>You don’t mind seeing a team that is different from the team you saw at your previous appointment.</td>
</tr>
</tbody>
</table>

A key worker

<table>
<thead>
<tr>
<th>Would you like to have a named “key worker”?</th>
<th>Yes</th>
<th>OR</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>You would like there to always be one staff member you know who takes responsibility for sorting out any problems regarding your healthcare.</td>
<td></td>
<td>You don’t mind which staff member(s) take responsibility for sorting out any problems regarding your healthcare – it doesn’t need to be done by one specific person.</td>
</tr>
</tbody>
</table>
## Communication between staff members

<table>
<thead>
<tr>
<th>Is it important to you that staff communicate well with each other to pass on relevant information about your care?</th>
<th>Yes</th>
<th>OR</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>You would like information about your care to always be passed on to the right people straight away</td>
<td></td>
<td></td>
<td>You don’t mind if information about your care isn’t passed on to the right people straight away.</td>
</tr>
</tbody>
</table>

## Parental/carer involvement

<table>
<thead>
<tr>
<th>At your appointments, how do you think staff should involve your parents?</th>
<th>Welcomed</th>
<th>OR</th>
<th>Discouraged</th>
</tr>
</thead>
<tbody>
<tr>
<td>You would like staff at the service to welcome your parents’ involvement in your treatment.</td>
<td></td>
<td></td>
<td>You would like staff at the service to discourage the involvement of your parents in your treatment as you get older.</td>
</tr>
</tbody>
</table>

## My autonomy in decisions

<table>
<thead>
<tr>
<th>When there are decisions to make about your care, what would you like to happen?</th>
<th>My treatment is discussed but staff make the decisions</th>
<th>OR</th>
<th>I am given choices and I make the decisions</th>
</tr>
</thead>
<tbody>
<tr>
<td>You would like the staff to talk to you about how your care could be managed, but then the staff decide on the best way forward.</td>
<td></td>
<td></td>
<td>You would like the staff talk to you about how your care could be managed, but you will decide on the best way forward.</td>
</tr>
</tbody>
</table>

## Support

<table>
<thead>
<tr>
<th>Would you like the service to offer extra support to help prepare you for everyday living with your condition in the future (e.g. for financial help, equipment, advice about life changes)?</th>
<th>Yes</th>
<th>OR</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>You would like to be offered support to help prepare you for the future.</td>
<td></td>
<td></td>
<td>You would not like to be offered extra support to help prepare you for the future.</td>
</tr>
</tbody>
</table>
SECTION TWO: YOUR CURRENT SITUATION

We would like to know some details about the care that you currently receive. This will help us better understand the choices you make.

*Please tick ONE box for each question.*

**Question 1**

Do you currently attend a special health service for your condition?

☐ Yes

☐ No - I do not attend a special health service for my condition because there is no service available.

☐ No - I do not attend a special health service for my condition because I choose not to do so.

*If you ticked “Yes” to Question 1 please move on to Question 2. If you ticked either of the “No” boxes, please just move on to Section Three on Page 6 now.*

**Question 2**

When you visit the service, are appointments available outside of office hours (i.e. 9am to 5pm on weekdays)?

☐ Yes.

☐ No.

**Question 3**

When you visit the service, do you usually see the same team of people that you’ve met before?

☐ Yes, I usually see the same team of people I’ve met before on each of my visits to the service.

☐ No, the team people are usually different.

**Question 4**

When you attend the service, how do staff involve your parent(s)/carer(s) in your treatment?
☐ Staff welcome the involvement of my parent(s)/carer(s) in my treatment.

☐ Staff discourage the involvement of my parent(s)/carer(s) in my treatment.

**Question 5**

When you talk with staff at the service about your treatment, how are decisions made?

☐ Staff discuss my treatment with me but make the decisions on my behalf.

☐ Staff give me with choices about my treatment but expect me to make the decisions.

**Question 6**

Thinking about support for your condition (e.g. financial support, getting new equipment, advice on coping etc.), is help with this provided by the service you attend?

☐ Yes, the service provides extra support to help me prepare for everyday living with my condition in the future.

☐ No, the service does not provide extra support to help me prepare for everyday living with my condition in the future.
SECTION THREE: AN EXAMPLE QUESTION

Here is an example of a question. We want you to imagine that you have the choice to attend either of two transition services for your condition. These services are described in the box below. We want you to choose which service you think would be best for you if you had to choose between those two services and there was no other option available for you. We then want you to think about which situation would be best if you could choose either of the two transition services described, or your current situation in real life.

If you have already moved to the adult service in real life, just imagine you get to do it all again and choose the option that you would prefer.

For each question we ask you to select the best for you by putting a tick in the appropriate box.

Figure 15 Example DCE question

<table>
<thead>
<tr>
<th></th>
<th>Care at Service A</th>
<th>Care at Service B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment flexibility:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The service offers</td>
<td>During and outside of office hours</td>
<td>During office hours only</td>
</tr>
<tr>
<td>appointments:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff consistency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The staff I see at the</td>
<td>Usually same staff members that I’ve met before but I do not have a key worker</td>
<td>Not usually the same staff members I’ve met before but I do have a key worker</td>
</tr>
<tr>
<td>service are:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff communication</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about my</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>care always seems to get</td>
<td></td>
<td></td>
</tr>
<tr>
<td>passed on to the right</td>
<td></td>
<td></td>
</tr>
<tr>
<td>person who can help me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My parents’ involvement</td>
<td>Welcomed</td>
<td>Discouraged</td>
</tr>
<tr>
<td>is:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My autonomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When it comes to</td>
<td>My treatment is discussed but staff make</td>
<td>I am given choices and I</td>
</tr>
<tr>
<td>decisions</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
In this example, the participant has ticked “Service A” for both parts of the question. This shows that the participant prefers what happens in Service A to what would be available in Service B, and that the participant prefers what happens in Service A to what would be available in both Service B or the service they currently receive in their life.
SECTION 4: THE ACTUAL QUESTIONNAIRE

The questionnaire sets out eight questions with the layout of the example question on the previous page.

The response options varied with each question. The full questionnaire is available on request.
DCE Report

A discrete choice experiment of the service preferences of young people with long-term conditions as they transition from paediatric to adult care.


Introduction

Young people with long-term conditions diagnosed during childhood face the prospect of having their health care transferred, at some point, from paediatric services to adult health services. This process of transfer occurs within a wider “purposeful, planned process that addresses the medical, psychosocial, educational, and vocational needs of adolescents and young adults with chronic medical and physical conditions as they move from child-centred to adult-oriented health care systems” known as ‘transition’. It is known that this period of transition can be difficult for young people, and that this can lead to poorer long-term health, social and educational outcomes. By developing a full understanding of young people’s preferences for services during this time, it may be possible to minimise withdrawal from or reduced uptake of health services during transition, thereby preventing future health risks associated with this. The Transition Research Programme aimed to establish how successful transition can be facilitated in the United Kingdom to improve health and social outcomes. Part of the work involved a longitudinal study of young people at four time points during their transition (baseline and follow-up at one, two and three years respectively). This paper reports one component of this longitudinal study which sought to quantify young people’s preferences for health services using a discrete choice experiment (DCE).

Methods

A sample of young people was drawn from the third annual visit (or fourth visit if they did not attend the third visit) of a longitudinal cohort study to identify which features of transitional healthcare are effective and efficient. These young people were aged 14-18 at the time of the baseline visit and had been in receipt of specialist paediatric services at that time point, for one of three conditions; autistic spectrum disorder (with an additional mental health need), cerebral palsy or diabetes. DCEs are well-established methodology in health economics. DCEs describe a service in terms of a number of characteristics, or ‘attributes’ (e.g. the flexibility of appointments,
parental involvement). The extent to which an individual values an intervention is expected to depend upon the ‘level’ these attributes take (e.g. can appointments be made outside office hours or not; is parental involvement encouraged or not). In other words, DCEs explore relative preferences for the different ways services can be organised where the services are defined by differing levels of their attributes.\(^{92}\)

The design and conduct of the DCE involved four steps:

**Step 1: Identification of attributes and levels**

Attributes and levels of the DCE were informed by a Q-sort\(^{51}\) From this work, the transition issues that young people had strong opinions about (regardless of their viewpoint) were selected for further consideration as attributes for the DCE and were discussed with “United Progression” (UP) a young people’s group convened specifically for the Transition Research Programme.\(^{208}\)

Other information was drawn from the findings from the literature about important features of transition.\(^{93}\) Refinements on content and layout of the DCE were undertaken in conjunction with the members of the Transition Research Programme’s Collaborative Group and the UP young people’s group. The chosen attributes and levels are shown in Table 21.

**Table 21: Description of the attributes and levels used in the DCE**

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Number of levels</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility</td>
<td>2</td>
<td>0 = Does not offer appointments outside of office hours</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Offer appointments outside of office hours</td>
</tr>
<tr>
<td>Staff at appointments</td>
<td>4</td>
<td>0 = Do not see the same staff at my appointments and do not have a key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Do not see the same staff at my appointments but have a key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2 = See the same staff at my appointments but do not have a key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 = See the same staff at my appointments and have a keyworker</td>
</tr>
<tr>
<td>Staff communication</td>
<td>2</td>
<td>0 = Yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = No</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>2</td>
<td>0 = Discouraged</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Welcomed ‘if I want it’</td>
</tr>
<tr>
<td>Decisions about care</td>
<td>2</td>
<td>0 = Staff discuss my care but make the decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 = Staff give me choices but expect me to make the</td>
</tr>
</tbody>
</table>
Step 2: Experimental design

The number of attributes and levels described in Table 21 gives 128 possible combinations. Therefore, statistical approaches were used to reduce the number of scenarios to be more manageable. N-gene software was used to identify the most statistically efficient number of questions to ask. The d-efficient design contained twenty-four discrete choice questions. The number of questions was further reduced by ‘blocking’ the design into three groups, so that each respondent in each block was asked to complete eight questions (thereby reducing response burden). Young people were also asked to answer questions about the current care they received in terms of the attributes and levels used in the DCE.

In each choice question respondents were presented with two hypothetical ways the service might be organised. Respondents were asked to consider whether they would prefer either of these two hypothetical options or their own care. Details of the service the respondent was receiving were collected in a separate part of the questionnaire. Figure 16 gives an example of a choice question.
Figure 16: **Illustrative example of a choice question presented in the DCE**

We want you to imagine that you have care of the type at Clinic A or Clinic B.

We then want you to choose which would be best for you between those two imaginary situations and your current situation.

If you have already moved to the adult service in real life, just imagine you get to do it all again and choose the option that you would prefer.

For each question we ask you to select the **best** by putting a **tick** in the appropriate box.

Please tick just **one** box for every question. Here is an example question:

<table>
<thead>
<tr>
<th></th>
<th>Care at Clinic A</th>
<th>Care at Clinic B</th>
<th>My current care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Appointment flexibility</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The service offers appointments:</td>
<td>During and outside of office hours</td>
<td>During office hours only</td>
<td></td>
</tr>
<tr>
<td><strong>Staff at my appointments</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The staff I see at the service are:</td>
<td>Usually same staff members that I’ve met before but I do not have a key worker</td>
<td>Not usually the same staff members I’ve met before but I do have a key-worker</td>
<td></td>
</tr>
<tr>
<td><strong>Staff communication</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about my care always seems to get passed on to the right person who can help me</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>Parental involvement</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My parents’ involvement is:</td>
<td>Welcomed</td>
<td>Discouraged</td>
<td></td>
</tr>
<tr>
<td><strong>Decisions about my care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When it comes to decisions about my care:</td>
<td>My treatment is discussed but staff make the decisions</td>
<td>I am given choices and I make the decisions</td>
<td></td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The clinic provides extra support to help me prepare for everyday life with my condition</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td><strong>I would choose</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(please tick <strong>one</strong> box)</td>
<td>Clinic A</td>
<td>Clinic B</td>
<td>My current care</td>
</tr>
<tr>
<td></td>
<td>✓</td>
<td>❑</td>
<td></td>
</tr>
</tbody>
</table>

In this example, the participant has ticked ‘Clinic A’. This shows that the participant prefers what happens in Clinic A to what would be available in Clinic B or their current care.
Refinements on content and layout of the questionnaire developed following discussion and feedback with the UP group. Further advice was provided by members of the Transition Research Programme’s Collaborative Group on how best to help facilitate completion by the programme’s longitudinal cohort with autistic spectrum disorder (ASD).

**Step 3: Data collection**

Following completion of the design work for the DCE and receipt of ethics approval the DCE was completed during visit 3 or 4 of the longitudinal study. The paper-based DCE was administered in a face to face setting by researchers, trained to facilitate completion of this particular DCE. To further minimise non-response, a range of additional tools were created to aid completion (Table 22). The final DCE questionnaire therefore contained five parts: the reference guide describing each of the attributes, questions about the service they currently received, the discrete choice experiment questions, the ranking exercise and an office-use only section allowing the researcher to document use of additional tools.

**Table 22: Description of tools developed to aid completion of the DCE**

<table>
<thead>
<tr>
<th>Additional tool</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attribute ticking</td>
<td>For each attribute, if the respondent was struggling to choose they were permitted to tick, for each attribute within the question, their preferred alternative.</td>
</tr>
<tr>
<td>Current practice grid</td>
<td>Paper grid showing respondent’s own levels of ‘current care’ being received. The grid can then be placed alongside the two hypothetical alternatives in each question to readily show how the respondents own care corresponds to each alternative.</td>
</tr>
<tr>
<td>Scenario grid</td>
<td>Empty paper grid version of the hypothetical alternatives. The researcher made up the grid using cut-out pieces of paper printed with the levels for each attribute. They could then move the pieces of paper as the respondent progressed from one question to the next, to show that each question was different to the previous one.</td>
</tr>
<tr>
<td>Skip to ranking exercise</td>
<td>If the respondent was struggling, the researcher had the option of asking them if they would prefer to skip to the ranking exercise and omit the remaining choice questions.</td>
</tr>
<tr>
<td>Tear off reference guide</td>
<td>The first section of the DCE questionnaire described each of the attributes and what they meant. If the respondent was struggling to recall what these meant at any point during the DCE, this reference guide could be torn out of the DCE questionnaire so that the respondent could re-read these definitions without having to turn pages back and forth.</td>
</tr>
<tr>
<td>Researcher</td>
<td>If the researcher was concerned that the respondent was struggling, or not considering the options before answering, they could ask the</td>
</tr>
</tbody>
</table>
prompting respondent to articulate their thinking behind their choice. This would enable the researcher to either verify that they respondent understood the exercise, or help facilitate completion using any of the other tools if the respondent was struggling.

**Step 4: Data analysis and interpretation**

Data were analysed within a random utility model framework using logistic regression techniques to predict the value that young people placed on the different attributes and levels of the DCE.

DCE analysis can provide estimates of the predicted uptake of the service. This can illustrate the relative importance of attributes and their associated level – the more an attribute is preferred by young people, then the higher the predicted uptake.

**Results**

**Response rates and participants characteristics**

Of the 375 participants who commenced the longitudinal study, by the time of the DCE 101 participants had left the study or could not be contacted. Of the remaining 274 participants, 247 had completed at least one DCE question (238 completed it at visit 3 and 9 completed it during visit 4). Of those completing the questionnaire it was fully completed by 223 participants and partially completed by 24 participants. All data collected between September 2014 and December 2016. Demographic details for study participants are provided in Table 23.
Table 23: Characteristics of participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Responders (Partial and complete)</th>
<th>Non-responders (Did not complete any DCE question)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample</td>
<td>247</td>
<td>27</td>
<td>274</td>
</tr>
<tr>
<td>Gender: Female</td>
<td>109</td>
<td>8</td>
<td>117</td>
</tr>
<tr>
<td>Gender: Male</td>
<td>138</td>
<td>19</td>
<td>157</td>
</tr>
<tr>
<td>Mean (SD) age at time of data collection</td>
<td>17.92(1.28)</td>
<td>18.11 (1.53)</td>
<td>17.94 (1.31)</td>
</tr>
<tr>
<td>Condition: ASD</td>
<td>71</td>
<td>16</td>
<td>87</td>
</tr>
<tr>
<td>Condition: Cerebral palsy</td>
<td>71</td>
<td>4</td>
<td>75</td>
</tr>
<tr>
<td>Condition: Diabetes</td>
<td>105</td>
<td>7</td>
<td>112</td>
</tr>
<tr>
<td>Block: A</td>
<td>76</td>
<td>13</td>
<td>89</td>
</tr>
<tr>
<td>Block: B</td>
<td>90</td>
<td>6</td>
<td>96</td>
</tr>
<tr>
<td>Block: C</td>
<td>81</td>
<td>7</td>
<td>88</td>
</tr>
<tr>
<td>Block: Missing</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Additional tools used: Y</td>
<td>85</td>
<td>12</td>
<td>97</td>
</tr>
<tr>
<td>Additional tools used: N</td>
<td>162</td>
<td>7</td>
<td>169</td>
</tr>
<tr>
<td>Additional tools used: Missing</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Attends specialist service: Y</td>
<td>196</td>
<td>13</td>
<td>209</td>
</tr>
<tr>
<td>Attends specialist service: N</td>
<td>50</td>
<td>6</td>
<td>56</td>
</tr>
<tr>
<td>Attends specialist service: Missing</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Transfer status at time of data collection: Transferred</td>
<td>162</td>
<td>18</td>
<td>180</td>
</tr>
<tr>
<td>Transfer status at time of data collection: Not transferred</td>
<td>85</td>
<td>8</td>
<td>93</td>
</tr>
<tr>
<td>Transfer status: Missing</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
In terms of these characteristics there were no statistically significant (0.05 level) differences, except that compared to participants with diabetes, young people with ASD were less likely to be respondents (p=≤0.001). Also when comparing complete and partial responders (data not shown), partial responders were less likely to be attending a service (p=0.0032).

With respect to the ranking exercise complete rankings data were available from 259 respondents, including 16 of the 27 who did not complete the DCE, and 243 of those who did. Whilst not formally tested there appeared to a high priority given to “Decisions about care” whilst “Extra support” is consistently given a low priority (Table 24). Although not shown in Table 21 those with ASD and those who had not yet transferred, may prioritise flexible clinics compared with those with other long-term conditions. Those with ASD, those with cerebral palsy may give less priority to which staff they see at their appointments compared to those with diabetes. Likewise those with ASD and those with cerebral palsy. Compared to those who had transferred those who had transferred also may give less priority to who they see at their appointment and to staff communication.

Table 24: Result of ranking exercise

<table>
<thead>
<tr>
<th></th>
<th>Respondents</th>
<th>Median (IQR)</th>
<th>Mean (SD)</th>
<th>Estimated rank based on scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility of clinics</td>
<td>260</td>
<td>5 (3)</td>
<td>3.4 (1.7)</td>
<td>4</td>
</tr>
<tr>
<td>Staff coordination</td>
<td>260</td>
<td>3 (2)</td>
<td>3.3 (1.6)</td>
<td>3</td>
</tr>
<tr>
<td>Staff communication</td>
<td>261</td>
<td>3 (2)</td>
<td>3.1 (1.4)</td>
<td>2</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>260</td>
<td>4 (3)</td>
<td>4.0 (1.7)</td>
<td>6</td>
</tr>
<tr>
<td>Decisions about care</td>
<td>261</td>
<td>2 (3)</td>
<td>2.6 (1.5)</td>
<td>1</td>
</tr>
<tr>
<td>Extra support</td>
<td>259</td>
<td>4 (3)</td>
<td>3.8 (1.7)</td>
<td>5</td>
</tr>
</tbody>
</table>

Results of DCE

Table 25 reports the result of the DCE analysis. There were 43 respondents who always chose their current care and 60 who never chose it. Those not currently receiving a service were significantly less likely to choose current care (p<0.001).

In the analysis the attributes levels are compared to the situation where the attribute is absent. For example, the base level for flexibility of clinics attributes is that clinics are only available
The model results reported in Table 25 do not take into account respondent characteristics including these showed that preferring current care itself (ASC) more pronounced amongst men than women and less pronounced among those who had transferred compared with those yet to transfer. Those with ASD compared with those with cerebral palsy had less pronounced preferences for parental involvement and for being the ones to make decisions about their treatment. Appointment flexibility was the only attribute no longer statistically significant once demographics were taken into consideration, but men had a significantly more pronounced preference for out-of-hours clinics than women, and less pronounced preference for making decisions about treatment.

Table 26 shows that in a service where none of the attributes were present the uptake of the service would be 78% (95% CI: 75% to 81%). This is as would be expected given the chronic
nature of the young people’s conditions. So as an example, adding a new service with flexible appointments would result in predicted uptake by young people of 81% (95% CI: 78% to 84%).

**Table 26: Predicted probabilities of uptake of services as attributes are added**

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Probability of uptake</th>
<th>Lower 95% CI</th>
<th>Upper 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current service (none of the attributes)</td>
<td>0.78</td>
<td>0.75</td>
<td>0.81</td>
</tr>
<tr>
<td>New service with flexible appointments</td>
<td>0.81</td>
<td>0.78</td>
<td>0.84</td>
</tr>
<tr>
<td>New service with a keyworker</td>
<td>0.79</td>
<td>0.74</td>
<td>0.85</td>
</tr>
<tr>
<td>New service seeing the same staff at each appointment</td>
<td>0.90</td>
<td>0.85</td>
<td>0.94</td>
</tr>
<tr>
<td>New service seeing the same staff and having a keyworker</td>
<td>0.88</td>
<td>0.84</td>
<td>0.92</td>
</tr>
<tr>
<td>New service with good staff communication</td>
<td>0.93</td>
<td>0.91</td>
<td>0.95</td>
</tr>
<tr>
<td>New service with parental involvement</td>
<td>0.93</td>
<td>0.90</td>
<td>0.95</td>
</tr>
<tr>
<td>New service offering young people decisions about treatment</td>
<td>0.91</td>
<td>0.88</td>
<td>0.93</td>
</tr>
<tr>
<td>New service offering extra support to young people for their future</td>
<td>0.86</td>
<td>0.83</td>
<td>0.89</td>
</tr>
</tbody>
</table>

**Comparison of Ranking and DCE results**

Using the results of the DCE it is possible to indicate the relative importance respondents gave to each attribute (Table 27). The initial model showed that staff communication was on the most important attribute and use of a keyworker the least. However once we controlled for demographic characteristics and condition, decisions about care was the attribute shown to be most important to young people and clinic flexibility was least important. A direct comparison with the ranking exercise was only possible when the attribute around which staff the young person saw at an appointment (which has 4 levels – see Table 27) was collapsed into a 2 level.
Table 27: The relative importance respondents gave to each attribute

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Initial model</th>
<th>With interactions</th>
<th>Initial model</th>
<th>With interactions</th>
<th>Ranking exercise</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexibility of clinics</td>
<td>7</td>
<td>8</td>
<td>6</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Keyworker only</td>
<td>8</td>
<td>7</td>
<td>5*</td>
<td>5*</td>
<td>3</td>
</tr>
<tr>
<td>Same staff only</td>
<td>4</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both same staff and keyworker</td>
<td>5</td>
<td>6</td>
<td>5*</td>
<td>5*</td>
<td>3</td>
</tr>
<tr>
<td>Staff communication</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Parental involvement</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Decisions about care</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Extra support</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

*staff attribute averaged to compare with ranking exercise

When comparing the DCE results and the ranking exercise it is clear that young people have consistent and well-formed preferences around how much they value making decisions about their care and staff having good communication with each other. This is consistent with the model findings, once we have accounted for demographics. However, the most striking differences between the DCE and ranking are that young people may consciously underestimate the importance they place on parental involvement in their care, and overestimate the value of having clinics with flexible hours.

**Discussion**

The purpose of the DCE was to explore the importance that young people with complex health needs place on different ways their care can be organised. It was anticipated at the outset that some of the young people may struggle with this completing the DCE because it is considered demanding and it does require that respondents choose between different hypothetical ways a service can be organised. It was for this reason a number of aids to help the young people complete the task were devised and that a simpler ranking of the attributes and levels was also used.

Of those young people who had not withdrawn from the longitudinal study (n=274) over 90% were able to compete at least one DCE question. Those participants with ASD were more likely to be non-responders to the DCE but a significant proportion of those with ASD were able to complete the DCE and ranking exercise.

The results of the DCE suggest that the features of care a priori considered potentially important to young people were found to be valued with the exception of flexibility of appointments. As might be expected preference for the way care was currently provided was
strong and this preference was more pronounced amongst young men than young women. It was also stronger for those who had not transferred. Most young people (and especially women) least valued being able to have appointments outside of office hours. Clinics that welcomed parental involvement were highly valued by the young people, but this appeared more important in the DCE results than the ranking exercise. This may indicate that young people might underestimate how important this involvement is to them and the DCE by presenting a more complex set of choices allows this to be teased out. The young people also placed a high value on clinics in which: information is passed on to the right person. Young people also valued when staff give them choices and allowed them to make decisions about their care; and that those staff provide extra support to help young people prepare for everyday life with their condition in future. Notably, young people valued seeing the same staff at each clinic appointment more than having a keyworker.

**Strengths and limitations**

A major strength of the DCE was that it was embedded with a rigorous longitudinal study. Within this study extensive and exhaustive efforts were made to recruit, engage and retain a large cohort of young people throughout a period of major change in their lives. Whilst potentially framing the responses the various aids to completing the DCE were arrived at using the study team’s considerable experience of working with these groups and following advice and piloting with the young people themselves. The aids to completion of the DCE might have infringed strict DCE methodology but they enabled young people, with a wide range of confidence, intellectual ability and flexibility of thinking, to complete it. Indeed the use of aids has been advocated.97-99

The results of the DCE suggest that the condition itself was not of central importance in preferences, this is not to say that the condition the young person had did not have an effect. The number of withdrawals and dropouts from the longitudinal study limited the ability to detect differences in preferences when they existed. A DCE can be demanding to complete. Whilst most young people were able to respond, proportionately fewer with ASD responded. It is possible that these young people may have different preferences to those that did complete the DCE. Furthermore, it is possible that the DCE failed to accurately capture the preferences of those young people who did complete the DCE. For this latter issue some reassurance was provided by the broad similarities between the DCE findings and the ranking
exercise. The advantage of the DCE over the ranking exercise was that the DCE provided an indication of the relative importance of each attribute.

As a methodological approach DCEs are widely accepted and are a tool preferred by many organisations. For example, they form the basis of eliciting EQ-5D-5L population tariffs throughout the world and Center for Devices and Radiological Health, part of the Federal Food and Drug Administration have stated that DCEs are a suitable method for eliciting patient preferences. The approach adopted is consistent with best practice with respect to design and conduct of the DCE.

With respect to analysis, a fixed-effects modelling assumed respondents were consistent in their choices over time. Whilst the approaches adopted are not incorrect, more sophisticated econometric modelling approaches could be used to explore heterogeneity and whether participants considered only a subset of attributes when choosing among alternatives. This might help explain why an appreciable proportion of respondents always chose current care. Further interrogation of the data set might help but there is a limit to how complex an analysis can be within the confines of the sample size.

**Conclusions**

These finding from the DCE may help those tasked with designing services in deciding how services might be redesigned. The study has shown that tall the different aspects of organising a service are wanted, except flexibility in clinic appointments. Most young people prefer clinics where staff give them choices and allow them make decisions about their care. They also place a high value on clinics where staff communication is good and information about them always seems to get passed on to the right person. Young people may also underestimate how much they would like clinics that welcome parental involvement. Young people generally liked there current care although this was less marked for those who had made the transfer to adult services.
Appendix 8b: Economic analysis

Report WP 2.3.2 Economic analysis

1. Introduction
This appendix focuses on the economic analysis conducted as part of the second work package. The main quantitative empirical part of the second work package is a four year longitudinal study of young people with diabetes, cerebral palsy or autistic spectrum disorder (ASD), who are aged 14-18 at baseline. These people are followed up three times, on a roughly annual basis, after being recruited at baseline. During each of these visits, the young people complete a battery of outcome measures. There are three sets of outcome measures that are most relevant to the economic component of the work:

1) The EQ-5D-Y. This is a generic health status measure developed for completion of people aged between 7+ and is an adaptation of the EQ-5D measure which is primarily aimed at adults. Since the programme has started the EQ-5D has been validated for people aged 12+. We have continued to you the EQ-5D-Y to remain consistent and the main difference between the two versions is how the EQ-5D-Y describes one aspect of daily living. Within the cohort study the EQ-5D-Y is completed at baseline and each of the 3 subsequent visits.

2) Health and social service contacts. At each visit a form was completed, describing the nature, type and number of contacts is collected. The young person also kept a diary of all the contacts they had had with the NHS since their previous visit. Further, data was obtained from the young person’s medical notes and this was reviewed prior to the young person’s visit. The resulting data (called the ‘Final Account of Consultations) provides details of the use of services for each young person over the follow-up visit.

3) Stated preference exercise. The young people complete once during the third or fourth visit (depending upon whether they met the third scheduled visit) a discrete choice experiment (DCE) questionnaire.

These data were also collected to inform a proposed economic evaluation model. The design conduct and analysis of the discrete choice experiment are covered in the preceding appendix (Appendix 8a). The remainder of this Appendix 8b covers the analysis of: (1) the longitudinal data quality of life data; (2) the longitudinal cost data; and (3) the proposed economic model.
2. Methods

2.1. Longitudinal data analysis

The analysis of the ‘economic’ data as part of the longitudinal cohort followed similar principles to those used for the statistical analysis of outcome data reported for WP2.1. The dependent variables are health related quality of life as measured by the EQ-5D-Y and costs.

2.1.1 EQ-5D-Y

As noted already the EQ-5D-Y was collected 4 times within the longitudinal data set. The responses to the EQ-5D-Y were considered in two ways. First EQ-5D-Y data were converted into a utility score using the value set for adults. Second they were summed with equal weighting to each of the five component questions. In this simple scoring system each of the five domains of the EQ-5D-Y was given equal weighting, and each level of each domain was scored 1, 2, or 3 depending on severity. This meant that each individual’s response to the EQ-5D-Y could be scored between 5 and 15. This is defined hereafter as the sumscore. Lower scores by domain and sumscore indicate better health related quality of life.

These two approaches were adopted because there are known difficulties with applying the adult EQ-5D value set to the EQ-5D-Y, which does not have its own value set. However, it should also be noted that the study population was, on average, aged 16 or over at baseline and the adult EQ-5D questionnaire can be used with such a population. So, while the EuroQol Foundation note the EQ-5D-Y is a separate instrument, we expect that most of our study population would have been able to complete the adult version and, had they done so, it would be possible to apply utility values to such results without question.

Coupled with data on the young person’s last date in paediatrics (considered the date of transfer), and also the visit (two, three or four) by which the young person had transferred, we calculated two definitions for their average pre- and post-transfer utility and their average pre- and post-transfer sumscore.

The plan was to assess the impact of the proposed beneficial features as well as demographic features of condition (diabetes, cerebral palsy or ASD), age at baseline, gender and transfer status (child services, adult services or general practice) using generalised linear modelling (GLM). This approach was adopted because of the highly skewed nature of sumscore, utility data. To conduct GLM fitting we utilised STATA and additional 'glimdiag' code [http://www.uphs.upenn.edu/dgimhsr/stat-cstanal.htm; accessed August 2017] and methods

For utilities, there were no appropriate distributions (from either Gaussian, Inverse Gaussian, Gamma or Poisson) combined with tried link functions (cube root, square root, reciprocal, identity, log, squared, cubed) that could successfully model results. For sumscore the inverse Gaussian distribution with a log link and the gamma distribution with a log link were also considered plausible. Nevertheless, results from these analyses did not appear robust.

As a consequence an exploratory analysis estimating the median scores when a specific proposed beneficial feature was present were estimated.

2.1.2 NHS, social service and costs to young people and their families

The use of services all elicited as part of the longitudinal study were used in the estimation of costs. The costs data were then used as dependent variables in a set of regression analyses similar to those outlined above for the EQ-5D-Y data.

The perspective for the estimation of costs is the NHS/social services. Thus, it covers use of primary and secondary NHS care services, personal and social services and out-of-pocket expenses for the costs of accessing care (time and travel).

NHS and personal social service costs

Use of NHS, personal and social services based upon each young person’s Final Account of Consultations obtained at each visit. A unit cost was be assigned to each item of resource use. These unit costs were sought from standard data sources such as the PSSRU Unit Costs of Care for, for example, general practitioner visits. The unit cost of medications was taken from the British National Formulary (BNF) and unit cost of inpatient and/or day case stays was derived from NHS reference costs. As insulin prescriptions were not consistently mentioned in the data, these were costed separately according to existing literature sources inflated to the current price year (2016) and whether or not the young person was documented as receiving an insulin pump in the Final Account notes. Visits that were cancelled in advance did not incur costs, but those where either the respondent or the staff member did not attend, incurred 50% of the cost of a typical visit of that type.
Once all documented resource use items received a unit cost, data were combined with information on each participant’s transfer status to calculate average pre- and post-transfer costs across all participants.

The plan was to assess the impact on cost of the proposed beneficial features as well as demographic features of condition (diabetes, cerebral palsy or ASD), age at baseline, gender and transfer status (child services, adult services or general practice) using generalised linear modelling (GLM). A similar problem to that described above was encountered and hence an exploratory analysis estimating the median scores when a specific proposed beneficial feature was present were estimated.

2.2. Economic evaluation modelling
The purpose of the economic modelling was to compare the costs and effects of alternative hypothetical ways (termed interventions in the economic model) of delivering care during transition. The different transitions interventions were to be defined in terms of the presence or absence of the potential beneficial features. Data on the impact of the potential beneficial features was to come from the longitudinal analysis described in WPs 2.1 and 2.2. A model such as this however has limited value unless it is plausible that the potentially beneficial features could influence costs and effects. Therefore, its conduct was conditional on the findings of WPs 2.1 and 2.2.

Figure 17 gives the structure of the model. In the model all young people start in child services and are aged 14 years old and are followed for 10 years; the time over which a young person would be expected to be undergoing transition. The model considers a hypothetical cohort of 1,000 young people. Each year they have a probability of transferring out of child services and being discharged into primary care or moving into adults services. If in any given year they do not make the transfer then they remain in child services indicated by the ellipse connected to the Child Services state. In each state an annual cost, utility or sumscore value was assigned. The values used for this were derived from the work conducted under WPs 2.1 and 2.2. By combining these values with the chance of being in a state in give year it was possible to estimate cumulative costs, cumulative utilities (which because they are estimated over time provide an estimate of quality adjusted life years – QALYs) and sumscore.
The chance of being in a given state in a given year was given by the rate of transfer. The rate of transfer was calculated by considering the number of people who transferred from child services each year, and the ratio of transferred young people who were transferred to adult services compared with PRIMARY CARE services. This decline in the proportion of young people in child services is modelled by the exponential distribution whereby $y = n(e^{-0.498t})$, where $n$ is the baseline sample size and $t$ is the number of years since baseline. Of those who transfer, approximately 55% go to adult services, with the remainder of those who transferred going to primary care.

The cumulative effects were estimated for hypothetical transition services. The first of these was a service that did not contain any of the proposed beneficial features. Alternative services were defined in terms of the presence of a single proposed beneficial feature, thus there was an alternative service was defined for each of the nine proposed beneficial features.

The difference in cost and QALYs and sumscore between each alternative service and a service containing no proposed beneficial features. These data were then used to estimate the extra cost required to produce one more unit of effect – the incremental cost-effectiveness ratio (ICER). All costs are presented in terms of a common price year (2016) and all costs and consequences are discounted at 3.5%.

(Discounting is used because the when a cost and benefit occurs is believed to be important. It reflects the fact that costs and benefits that occur in the future are given less weight than costs and benefits that occur now. This ‘time preference’ for when costs and benefits might
occur is captured by the use of a discount rate, which reduces the importance of future costs and benefit in an analysis.)

The presence or absence of the proposed beneficial features was elicited in two ways. A form was completed each year by the research associate from data in the medical notes. It consisted of details of clinic visits, professionals in attendance, medical tests undertaken and whether PBFs had been experienced. This was called the ‘Final Account of Consultations’. Following the home visits with further discussion of appointments and PBFs and completion with the young person of a questionnaire, it became clear that the Final Account was incomplete for some young people. Therefore analysis was also undertaken with data combined from both sources.

2.3. Balance sheet analysis

The results of the model were combined with finding from other areas of the report in a balance sheet analysis. In this analysis we have presented those outcomes that could favour a hypothetical transition intervention compared to a situation where there is no support during the transition from child to adult services. The approach can incorporate quantitative data such as that produced from the statistical analysis of the longitudinal study, evidence from the broader literature and evidence from the other work conducted within the programme.

3. Results

3.1. Longitudinal data analysis

3.1.1. EQ-5D results

Of the 375 participants in the Transition Research Programme, 66 left the study. EQ-5D-Y data were available for 373 respondents at baseline, and 244 respondents by visit 4.

Summary response data for the EQ-5D-Y

For each of the five domains, the minimum and maximum scores were the extremes of the 3-levels (1 and 3 respectively, and the median score was consistently 1, meaning that for every domain at every time point, at least half the respondents reported "no problems". The number and proportion of respondents responding at each of the three levels for each of the five domains is provided in Table 28. For most domains the proportion of respondents report some or lots of problems (scores 2 and 3) increase over time. The mean score also suggest that health may have declined over time (score look to have increased on average for all domains except self-care).
Table 28: Responses by each of the domains of the EQ-5D-Y over the follow-up

<table>
<thead>
<tr>
<th>Domain</th>
<th>Scoring 1</th>
<th>Scoring 2</th>
<th>Scoring 3</th>
<th>Missing</th>
<th>Mean Score</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>Baseline</td>
<td>298</td>
<td>79.5%</td>
<td>63</td>
<td>16.8%</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>239</td>
<td>63.7%</td>
<td>59</td>
<td>15.7%</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>190</td>
<td>50.7%</td>
<td>52</td>
<td>13.9%</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>189</td>
<td>50.4%</td>
<td>44</td>
<td>11.7%</td>
<td>11</td>
</tr>
<tr>
<td>Self-care</td>
<td>Baseline</td>
<td>311</td>
<td>82.9%</td>
<td>50</td>
<td>13.3%</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>258</td>
<td>68.8%</td>
<td>35</td>
<td>9.3%</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>214</td>
<td>57.1%</td>
<td>30</td>
<td>8.0%</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>204</td>
<td>54.4%</td>
<td>30</td>
<td>8.0%</td>
<td>10</td>
</tr>
<tr>
<td>Usual Activities</td>
<td>Baseline</td>
<td>273</td>
<td>72.8%</td>
<td>96</td>
<td>25.6%</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>226</td>
<td>60.3%</td>
<td>73</td>
<td>19.5%</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>163</td>
<td>43.5%</td>
<td>90</td>
<td>24.0%</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>170</td>
<td>45.3%</td>
<td>70</td>
<td>18.7%</td>
<td>4</td>
</tr>
<tr>
<td>Pain</td>
<td>Baseline</td>
<td>245</td>
<td>65.3%</td>
<td>122</td>
<td>32.5%</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>200</td>
<td>53.3%</td>
<td>95</td>
<td>25.3%</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>163</td>
<td>43.5%</td>
<td>88</td>
<td>23.5%</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>154</td>
<td>41.1%</td>
<td>78</td>
<td>20.8%</td>
<td>12</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Baseline</td>
<td>236</td>
<td>62.9%</td>
<td>117</td>
<td>31.2%</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>177</td>
<td>47.2%</td>
<td>106</td>
<td>28.3%</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>142</td>
<td>37.9%</td>
<td>95</td>
<td>25.3%</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>125</td>
<td>33.3%</td>
<td>102</td>
<td>27.2%</td>
<td>17</td>
</tr>
</tbody>
</table>

The variations in EQ-5D-Y responses by the three conditions is reported in Table 29. As this table show that young people with diabetes consistently experienced fewest problems in any domain. Those with cerebral palsy were more likely to experience problems in the mobility
and self-care domains than young people with diabetes or ASD. The proportion of respondents with ASD reporting problems in the anxiety domain was consistently higher than for the other two conditions. As these differences were present at baseline, they may simply reflect the nature of the conditions under consideration.

Table 29: Summary of EQ-5D-Y responses by condition

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Time point</th>
<th>% experiencing problems (score 2 or 3) including missing</th>
<th>% experiencing problems (score 2 or 3) excluding missing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>ASD</td>
<td>CP</td>
</tr>
<tr>
<td>Mobility</td>
<td>Baseline</td>
<td>16.1%</td>
<td>47.7%</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>11.9%</td>
<td>40.2%</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>14.4%</td>
<td>43.0%</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>10.2%</td>
<td>36.4%</td>
</tr>
<tr>
<td>Self-care</td>
<td>Baseline</td>
<td>15.3%</td>
<td>40.2%</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>8.5%</td>
<td>31.8%</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>11.9%</td>
<td>24.3%</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>10.2%</td>
<td>26.2%</td>
</tr>
<tr>
<td>Usual activities</td>
<td>Baseline</td>
<td>36.4%</td>
<td>37.4%</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>24.6%</td>
<td>29.0%</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>35.6%</td>
<td>32.7%</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>26.3%</td>
<td>25.2%</td>
</tr>
<tr>
<td>Pain</td>
<td>Baseline</td>
<td>38.1%</td>
<td>51.4%</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>27.1%</td>
<td>42.1%</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>29.7%</td>
<td>37.4%</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>25.4%</td>
<td>34.6%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Baseline</td>
<td>65.3%</td>
<td>28.0%</td>
</tr>
<tr>
<td></td>
<td>Visit 2</td>
<td>50.8%</td>
<td>29.9%</td>
</tr>
<tr>
<td></td>
<td>Visit 3</td>
<td>46.6%</td>
<td>27.1%</td>
</tr>
<tr>
<td></td>
<td>Visit 4</td>
<td>46.6%</td>
<td>27.1%</td>
</tr>
</tbody>
</table>

ASD = Autism spectrum disorder; CP = cerebral palsy

**EQ-5D Sumscore**

The higher the sumscore the worse health is reported to be. The median sum score for all participants across all time points was 6 (IQR: 2.8), which indicates at least at least half of participants did not experience "no problems" across all domains (a score of 5 is required).
Average sumscores were not associated with gender, nor were pre or post transfer scores. In addition, there were significant differences in both sumscores by condition, as diabetes participants had significantly lower scores (i.e. better health) (p<0.001) at all time points (Table 30).

**EQ-5D-Y Utilities**

The median utility score across all participants was 0.83 (IQR: 0.304). Average utility scores were not associated with gender nor were pre or post transfer scores. However, among those who transferred, scores were significantly higher (Wilcoxon Signed Rank test 7465.5, p<0.001) for those doing so to adult services (median 0.86, IQR: 0.37) compared to Primary Care services (median 0.78, IQR: 0.38). As was found for the sumscore participants with diabetes had a higher significantly higher scores (p<0.001) at all time points (Table 30).

**Table 30: Summary Sumscore and Utility score by condition pre- and post-transfer**

<table>
<thead>
<tr>
<th></th>
<th>All (IQR)</th>
<th>ASD (IQR)</th>
<th>Cerebral palsy (IQR)</th>
<th>Diabetes (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>301</td>
<td>96</td>
<td>83</td>
<td>122</td>
</tr>
<tr>
<td>Median sum score</td>
<td>6 (2.79)</td>
<td>7 (2)</td>
<td>7 (2.98)</td>
<td>5.2 (1)</td>
</tr>
<tr>
<td>Median utility score</td>
<td>0.83 (0.30)</td>
<td>0.75 (0.27)</td>
<td>0.70 (0.43)</td>
<td>0.94 (0.14)</td>
</tr>
<tr>
<td>n</td>
<td>269</td>
<td>86</td>
<td>70</td>
<td>113</td>
</tr>
<tr>
<td>Median pre-transfer sumscore</td>
<td>6 (2)</td>
<td>7 (2)</td>
<td>7 (3)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Median pre-transfer utility score</td>
<td>0.85 (0.27)</td>
<td>0.75 (0.26)</td>
<td>0.72 (0.43)</td>
<td>0.95 (0.13)</td>
</tr>
<tr>
<td>n</td>
<td>230</td>
<td>68</td>
<td>66</td>
<td>96</td>
</tr>
<tr>
<td>Median post-transfer sumscore</td>
<td>6 (3)</td>
<td>7 (2)</td>
<td>7 (2.75)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>Median post transfer utility score</td>
<td>0.82 (0.29)</td>
<td>0.76 (0.24)</td>
<td>0.70 (0.33)</td>
<td>0.95 (0.16)</td>
</tr>
</tbody>
</table>

IQR = Interquartile range; ASD = Autism spectrum disorder
3.1.2 Use of services and costs

Use of services overall and by condition

The number of participants providing data was 286 at visit 2, 249 at visit 3 and 216 at visit 4, representing 76.2%, 66.4% and 57.6% of the total sample respectively. The young people in the sample recorded a total of 8383 visits over the course of the follow-up. Of these 7755 (92.5%) occurred, with others either being cancelled in advance or without sufficient prior notification (i.e. "did-not-attend" or "DNA'd"). Corresponding to the fall in the sample contributing data the number of visits occurring at each time point declined from 3293 (42.5% of all visits) at visit 2, to 2476 (31.9% of all visits) at visit 3 and 1986 visits (25.6% of all visits) at visit 4.

The average number of visits experienced by the participants declined from a median of 7 (IQR 8) at visit 2, to a median of 6 (IQR 9) at visit 3 and 4 (IQR 9) at visit 4. The median number of visits across the whole duration of follow-up was 19 (IQR 20), but this varied depending on condition, ranging from 14 (IQR: 27.8) for those with cerebral palsy to 23 visits for those with diabetes (IQR: 13.8). Those participants with ASD had an average of 16 visits (IQR: 23).

Over time, the median number of visits, among participants who experienced visits over the time period decreased for those with cerebral palsy and diabetes (from 7 and 8 at visit 2 respectively to 5 and 7 at visit 4), whereas for those with ASD the median number of visits increased from 5 to 6 over the same time period. If we include those who had no visits here, this trend is lost (cerebral palsy goes from 6.5 to 1 and Diabetes goes from 8 to 6, ASD goes from 4 to 3). The composition of visits also varied in terms of venue and staffing, both across time and for each of the three conditions (Table 31).

As Table 31 illustrates for those with ASD, visits were typically held in community/high street venues (this includes CAMHS) or home/school visits. Whereas for those with cerebral palsy visits typically took place at either home/school or outpatient clinics. Over half of contacts for those with diabetes took place in outpatient settings at each visit, and the majority of "other" types of contact were comprised of telephone conversations with clinicians.

Table 32 illustrates the type of staff seen and as this table shows there was a very small number of multidisciplinary contacts. Compared to participants with diabetes, participants with ASD and cerebral palsy were less likely to have multidisciplinary visits, although the
proportion of visits that were multi-disciplinary for those with ASD increased over time, whereas for those with diabetes they decreased. The proportion of visits involving doctors increased over time for those with diabetes, whereas it declined for those with ASD. Visits involving other care providers (typically social care staff or volunteers working with the young person) increased in those with ASD as did nursing visits, whereas the latter decreased for those with diabetes.
<table>
<thead>
<tr>
<th>All</th>
<th>% of all visits of this type at visit 2</th>
<th>% of all visits of this type at visit 3</th>
<th>% of all visits of this type at visit 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>17.5%</td>
<td>16.8%</td>
<td>12.6%</td>
</tr>
<tr>
<td>Primary care</td>
<td>7.0%</td>
<td>8.9%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Home visit</td>
<td>34.5%</td>
<td>29.7%</td>
<td>26.0%</td>
</tr>
<tr>
<td>Inpatients (elective)</td>
<td>0.6%</td>
<td>0.6%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Inpatients (emergency)</td>
<td>0.9%</td>
<td>1.2%</td>
<td>1.3%</td>
</tr>
<tr>
<td>Outpatients</td>
<td>30.2%</td>
<td>33.9%</td>
<td>39.1%</td>
</tr>
<tr>
<td>Other</td>
<td>9.5%</td>
<td>8.8%</td>
<td>7.9%</td>
</tr>
<tr>
<td>ASD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>53.1%</td>
<td>29.2%</td>
<td>22.3%</td>
</tr>
<tr>
<td>Primary care</td>
<td>5.6%</td>
<td>11.2%</td>
<td>17.6%</td>
</tr>
<tr>
<td>Home visit</td>
<td>25.7%</td>
<td>43.9%</td>
<td>41.7%</td>
</tr>
<tr>
<td>Inpatients (elective)</td>
<td>0.0%</td>
<td>0.1%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Inpatients (emergency)</td>
<td>0.3%</td>
<td>1.5%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Outpatients</td>
<td>3.4%</td>
<td>7.7%</td>
<td>10.4%</td>
</tr>
<tr>
<td>Other</td>
<td>11.8%</td>
<td>6.4%</td>
<td>6.3%</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>6.5%</td>
<td>17.4%</td>
<td>15.5%</td>
</tr>
<tr>
<td>Primary care</td>
<td>4.5%</td>
<td>4.0%</td>
<td>4.7%</td>
</tr>
<tr>
<td>Home visit</td>
<td>63.1%</td>
<td>46.8%</td>
<td>39.9%</td>
</tr>
<tr>
<td>Inpatients (elective)</td>
<td>0.5%</td>
<td>0.8%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Inpatients (emergency)</td>
<td>1.0%</td>
<td>0.5%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Outpatients</td>
<td>23.6%</td>
<td>28.9%</td>
<td>34.8%</td>
</tr>
<tr>
<td>Other</td>
<td>0.8%</td>
<td>1.5%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>2.0%</td>
<td>4.5%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Primary care</td>
<td>10.6%</td>
<td>10.4%</td>
<td>14.3%</td>
</tr>
<tr>
<td>Home visit</td>
<td>10.5%</td>
<td>3.8%</td>
<td>1.3%</td>
</tr>
<tr>
<td>Inpatients (elective)</td>
<td>1.1%</td>
<td>0.9%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Inpatients (emergency)</td>
<td>1.4%</td>
<td>1.5%</td>
<td>1.6%</td>
</tr>
<tr>
<td>Outpatients</td>
<td>57.8%</td>
<td>62.4%</td>
<td>67.2%</td>
</tr>
<tr>
<td>Other</td>
<td>16.5%</td>
<td>16.6%</td>
<td>13.1%</td>
</tr>
</tbody>
</table>

ASD = autism spectrum disorder
Table 32: Descriptive statistics on use of health services

<table>
<thead>
<tr>
<th>All</th>
<th>From baseline to visit 2</th>
<th>From visit 2 to visit 3</th>
<th>From visit 3 to visit 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>% healthcare contacts with doctor(s) present</td>
<td>31.9%</td>
<td>33.4%</td>
<td>32.6%</td>
</tr>
<tr>
<td>% healthcare contacts with nurse(s) present</td>
<td>28.3%</td>
<td>26.4%</td>
<td>26.1%</td>
</tr>
<tr>
<td>% healthcare contacts with AHP*(s) present</td>
<td>38.2%</td>
<td>34.2%</td>
<td>28.6%</td>
</tr>
<tr>
<td>% healthcare contacts with others present</td>
<td>16.4%</td>
<td>18.8%</td>
<td>24.7%</td>
</tr>
<tr>
<td>% of healthcare contacts: multidisciplinary</td>
<td>13.1%</td>
<td>13.0%</td>
<td>11.5%</td>
</tr>
<tr>
<td><strong>Diabetes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% healthcare contacts with doctor(s) present</td>
<td>39.4%</td>
<td>41.6%</td>
<td>43.6%</td>
</tr>
<tr>
<td>% healthcare contacts with nurse(s) present</td>
<td>66.3%</td>
<td>56.6%</td>
<td>51.7%</td>
</tr>
<tr>
<td>% healthcare contacts with AHP(s) present</td>
<td>29.2%</td>
<td>29.7%</td>
<td>29.2%</td>
</tr>
<tr>
<td>% healthcare contacts with others present</td>
<td>2.1%</td>
<td>1.9%</td>
<td>1.7%</td>
</tr>
<tr>
<td>% of healthcare contacts : multidisciplinary</td>
<td>32.0%</td>
<td>29.2%</td>
<td>24.4%</td>
</tr>
<tr>
<td><strong>Cerebral palsy</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% healthcare contacts with doctor(s) present</td>
<td>18.6%</td>
<td>23.1%</td>
<td>20.1%</td>
</tr>
<tr>
<td>% healthcare contacts with nurse(s) present</td>
<td>3.8%</td>
<td>2.6%</td>
<td>2.9%</td>
</tr>
<tr>
<td>% healthcare contacts with AHP(s) present</td>
<td>56.6%</td>
<td>36.5%</td>
<td>41.2%</td>
</tr>
<tr>
<td>% healthcare contacts with others present</td>
<td>23.4%</td>
<td>39.5%</td>
<td>38.0%</td>
</tr>
<tr>
<td>% of healthcare contacts: multidisciplinary</td>
<td>2.6%</td>
<td>2.0%</td>
<td>2.7%</td>
</tr>
<tr>
<td><strong>Autism spectrum disorder</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% healthcare contacts with doctor(s) present</td>
<td>40.6%</td>
<td>32.9%</td>
<td>31.3%</td>
</tr>
<tr>
<td>% healthcare contacts with nurse(s) present</td>
<td>13.0%</td>
<td>12.9%</td>
<td>18.0%</td>
</tr>
<tr>
<td>% healthcare contacts with AHP(s) present</td>
<td>23.9%</td>
<td>37.1%</td>
<td>16.1%</td>
</tr>
<tr>
<td>% healthcare contacts with others present</td>
<td>25.4%</td>
<td>20.6%</td>
<td>39.0%</td>
</tr>
<tr>
<td>% of healthcare contacts: multidisciplinary</td>
<td>3.0%</td>
<td>4.4%</td>
<td>4.6%</td>
</tr>
</tbody>
</table>

*AHP Allied Health Professional*
Combining data from Table 31 with unit cost data allowed a cost of care for each young person to be estimated. Data were available on 301 young people (78.6%). The overall median cost per participant was £4954 (IQR: £6103). Diabetes was the most costly condition, and cerebral palsy was the least costly although there was considerable variation between individuals. The difference between the cost of those with diabetes and those with ASD was statistically significant (p<0.001). The difference in pre and post transfer costs was not statistically significant at the 0.05 level although there was a trend both overall and by each condition (Table 33).
Table 33: Estimated median costs, by condition both overall and pre and post transfer

<table>
<thead>
<tr>
<th></th>
<th>All (IQR)</th>
<th>ASD (IQR)</th>
<th>Cerebral palsy (IQR)</th>
<th>Diabetes (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>301</td>
<td>96</td>
<td>77</td>
<td>125</td>
</tr>
<tr>
<td>Median total costs</td>
<td>£4954 (£6103)</td>
<td>£2351 (£4211)</td>
<td>£2394 (£5606)</td>
<td>£7003 (£3667)</td>
</tr>
<tr>
<td>Median total costs per annum</td>
<td>£2307 (£2705)</td>
<td>£1659 (£2573)</td>
<td>£1447 (£2725)</td>
<td>£2915 (£2422)</td>
</tr>
<tr>
<td>N</td>
<td>279</td>
<td>88</td>
<td>67</td>
<td>121</td>
</tr>
<tr>
<td>Median pre-transfer costs</td>
<td>£2420 (£4506)</td>
<td>£1694 (£2454)</td>
<td>£1370 (£4215)</td>
<td>£4434 (£5136)</td>
</tr>
<tr>
<td>Median pre-transfer costs per annum</td>
<td>£1673 (£2242)</td>
<td>£915 (£1277)</td>
<td>£949 (£1974)</td>
<td>£2410 (£1587)</td>
</tr>
<tr>
<td>N</td>
<td>194</td>
<td>56</td>
<td>48</td>
<td>87</td>
</tr>
<tr>
<td>Median post-transfer costs</td>
<td>£2080 (£3470)</td>
<td>£1262 (£2540)</td>
<td>£1395 (£3015)</td>
<td>£3114 (£3440)</td>
</tr>
<tr>
<td>Median post-transfer costs per annum</td>
<td>£1371 (£1862)</td>
<td>£645 (£1883)</td>
<td>£707. (£1673)</td>
<td>£1849 (£1193)</td>
</tr>
</tbody>
</table>

**Presence of proposed beneficial features**

The presence or absence of the proposed beneficial features was elicited in two ways.

A form was completed each year by the research associate from data in the medical notes. It consisted of details of clinic visits, professionals in attendance, medical tests undertaken and whether PBFs had been experienced. This was called the ‘Final Account of Consultations’.

Following the home visits with further discussion of appointments and PBFs and completion with the young person of a questionnaire, it became clear that the Final Account was incomplete for some young people. Therefore analysis is also undertaken with data combined from both sources.

Sensitivity analyses were carried using these alternative definitions.

Details regarding the nine criteria used to define the amount of PBF required to be 'satisfactory' is defined elsewhere. When this was applied to the data, the following numbers of young people met the criteria for receiving each PBF – Table 34. This has been shown by the two data sources. These young people did not always also have available cost data, but where they did have cost data this is reported in Table 34 in parenthesis.
3.2 Economic evaluation model

Using the data reported above in the proposed economic model an attempt was made to estimate the impact of the proposed beneficial features on sumscores, utility score, QALYs and costs. The model sought to reflect the fact that the young person’s place of care would change over time as they leave child services. On leaving child services the young person would be either receive care in primary care or secondary care.

Table 35 shows the input parameters for costs, utilities and sumscore. The data reported in Table 35 are point estimates and whilst there may be apparent trend in the data it is important to remember that confidence intervals around these values would be very wide. Therefore, for the purposes of making decisions about care their quality would be judged as low. However, when interpreted with other findings they may help highlight areas for further research.

Table 34: Number of young people experiencing the proposed beneficial features when experience is captured in different ways

<table>
<thead>
<tr>
<th></th>
<th>All (for whom cost data are available)</th>
<th>Child services (for whom cost data are available)</th>
<th>Transferred to adults services (for whom cost data are available)</th>
<th>Transferred to primary care (for whom cost data are available)</th>
<th>Left study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>As captured from Final Account</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No PBFs</td>
<td>35 (33)</td>
<td>9 (9)</td>
<td>11 (11)</td>
<td>15 (13)</td>
<td>0</td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>66 (60)</td>
<td>3 (3)</td>
<td>57 (52)</td>
<td>5 (5)</td>
<td>1</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>141 (129)</td>
<td>25 (25)</td>
<td>108 (97)</td>
<td>8 (7)</td>
<td>0</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>128 (114)</td>
<td>29 (29)</td>
<td>80 (73)</td>
<td>18 (12)</td>
<td>1</td>
</tr>
<tr>
<td>Key worker</td>
<td>58 (50)</td>
<td>12 (12)</td>
<td>37 (32)</td>
<td>9 (6)</td>
<td>0</td>
</tr>
<tr>
<td>Transition manager for clinical team</td>
<td>23 (21)</td>
<td>3 (3)</td>
<td>17 (16)</td>
<td>2 (2)</td>
<td>1</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>11 (11)</td>
<td>3 (3)</td>
<td>8 (8)</td>
<td>0 (0)</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>All (for whom cost data are available)</td>
<td>Child services (for whom cost data are available)</td>
<td>Transferred to adults services (for whom cost data are available)</td>
<td>Transferred to primary care (for whom cost data are available)</td>
<td>Left study</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>----------------------------------------</td>
<td>-------------------------------------------------</td>
<td>----------------------------------------------------------------</td>
<td>----------------------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>30 (27)</td>
<td>4 (4)</td>
<td>26 (23)</td>
<td>0 (0)</td>
<td>0</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>95 (84)</td>
<td>27 (27)</td>
<td>53 (48)</td>
<td>14 (9)</td>
<td>1</td>
</tr>
<tr>
<td>Transition plan</td>
<td>26 (24)</td>
<td>5 (5)</td>
<td>20 (19)</td>
<td>0 (0)</td>
<td>1</td>
</tr>
<tr>
<td>All PBFs</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0</td>
</tr>
</tbody>
</table>

**As captured from both sources (face-to-face contacts and Final Account)**

<table>
<thead>
<tr>
<th></th>
<th>All (for whom cost data are available)</th>
<th>Child services (for whom cost data are available)</th>
<th>Transferred to adults services (for whom cost data are available)</th>
<th>Transferred to primary care (for whom cost data are available)</th>
<th>Left study</th>
</tr>
</thead>
<tbody>
<tr>
<td>No PBFs</td>
<td>7 (7)</td>
<td>1 (1)</td>
<td>2 (2)</td>
<td>4 (4)</td>
<td>0</td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>121 (108)</td>
<td>12 (12)</td>
<td>91 (84)</td>
<td>15 (12)</td>
<td>3</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>163 (142)</td>
<td>26 (26)</td>
<td>119 (107)</td>
<td>13 (9)</td>
<td>5</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>149 (129)</td>
<td>31 (31)</td>
<td>91 (83)</td>
<td>23 (15)</td>
<td>4</td>
</tr>
<tr>
<td>Key worker</td>
<td>78 (66)</td>
<td>17 (17)</td>
<td>54 (45)</td>
<td>7 (4)</td>
<td>0</td>
</tr>
<tr>
<td>Transition manager for clinical team</td>
<td>70 (61)</td>
<td>13 (13)</td>
<td>45 (44)</td>
<td>7 (4)</td>
<td>5</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>121 (108)</td>
<td>18 (18)</td>
<td>73 (69)</td>
<td>30 (21)</td>
<td>0</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>100 (90)</td>
<td>19 (19)</td>
<td>70 (63)</td>
<td>11 (8)</td>
<td>0</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>195 (170)</td>
<td>45 (45)</td>
<td>122 (111)</td>
<td>21 (14)</td>
<td>7</td>
</tr>
<tr>
<td>Transition plan</td>
<td>56 (50)</td>
<td>9 (9)</td>
<td>41 (39)</td>
<td>2 (2)</td>
<td>4</td>
</tr>
<tr>
<td>All PBFs</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0</td>
</tr>
</tbody>
</table>
Table 35: Costs, utilities and sumscore data  Cost

<table>
<thead>
<tr>
<th>State</th>
<th>PBFs captured from final account</th>
<th>PBFs captured from final account and face-to-face</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Child services</td>
<td>Transferred adult services</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>IQR</td>
</tr>
<tr>
<td>No PBFs</td>
<td>816</td>
<td>1,162</td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>2,915</td>
<td>1,554</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>2,915</td>
<td>1,837</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>2,456</td>
<td>2,328</td>
</tr>
<tr>
<td>Key worker</td>
<td>3,233</td>
<td>2,727</td>
</tr>
<tr>
<td>Transition manager</td>
<td>2,616</td>
<td>4,777</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>1,373</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>1,616</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>2,915</td>
<td>2,712</td>
</tr>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>1,258</td>
</tr>
<tr>
<td>All PBFs</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>State</td>
<td>PBFs captured from final account</td>
<td>PBFs captured from final account and face-to-face</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>---------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Child services</td>
<td>Transferred adult services</td>
</tr>
<tr>
<td></td>
<td>Median</td>
<td>IQR</td>
</tr>
<tr>
<td>No PBFs</td>
<td>0.90</td>
<td>0.19</td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>0.36</td>
<td>0.44</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>0.88</td>
<td>0.16</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>0.83</td>
<td>0.40</td>
</tr>
<tr>
<td>Key worker</td>
<td>0.87</td>
<td>0.19</td>
</tr>
<tr>
<td>Transition manager</td>
<td>0.73</td>
<td>0.28</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>0.30</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>0.06</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>0.87</td>
<td>0.52</td>
</tr>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>0.12</td>
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<tr>
<td>All PBFs</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td></td>
<td>PBFs captured from final account</td>
<td>PBFs captured from final account and face-to-face</td>
</tr>
<tr>
<td>---------------</td>
<td>---------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td></td>
<td>Procuring</td>
<td>Child services</td>
</tr>
<tr>
<td></td>
<td>State</td>
<td>Median</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No PBFs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Meet adult team before transfer</td>
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<td></td>
<td></td>
<td>Age-banded clinic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Holistic life-skills training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Key worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Transition manager</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Appropriate parent involvement</td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>Transition plan</td>
</tr>
<tr>
<td></td>
<td></td>
<td>All PBFs</td>
</tr>
</tbody>
</table>
Using these data within the economic model described in Section 2.2 and modelling over a 10 year time horizon it is possible to estimate how costs, sumscore and QALYs vary by presence or absence of proposed beneficial feature. This analysis considers each proposed beneficial feature separately and given the limited data available as reported in Table 34 should be considered as exploratory only. Given the exploratory nature probabilistic sensitivity analysis has not been conducted as there is considerable imprecision in result. The results are best considered as either illustrative of the approach take or hypothesis generating about possible proposed beneficial features to consider when developing an intervention to improve transition.

Table 36 shows estimated costs, effects (sumscore and QALY) and Table 37 the incremental cost-effectiveness for the comparison of a service incorporating each proposed beneficial feature alone a service where no features were present. All outcomes are discounted (each at 3.5%) It was not possible to compare individual PBFs against a situation where all PBFs were provided, as only one young person experienced all PBFs in the study. As the presence of the proposed beneficial features is based on reports during face to face contacts a sensitivity analysis has been performed using these data.

The data reported in Tables 36 and 37 illustrate that the results are sensitive to the methods used to define whether a proposed beneficial feature was present. In general there were more reports of the PBFs being present. The higher the incremental cost-effectiveness ratio the less likely an intervention would be considered value for money.

In relative terms there were several PBFs that seemed to perform better regardless of whether the definition of 'satisfactory' PBF exposure is based on final account or face-to-face data. These were the provision of holistic care; having a key worker, and, (where the sample was sufficient to quantify it) promotion of health self-efficacy.

Meeting the adult team was sensitive to the source of data and was considerably better when estimates were based on face to face data. Having a written transition plan was one of the poorer performing proposed beneficial features as was having a Transition manager for clinical team.
Table 36: Estimated costs and effects for each intervention

<table>
<thead>
<tr>
<th>PBFs captured from Final Account of Consultations</th>
<th>Mean costs of strategy over model time horizon</th>
<th>Mean QALYs for strategy over time horizon</th>
<th>Mean sumscore for strategy over model time horizon</th>
</tr>
</thead>
<tbody>
<tr>
<td>No PBFs</td>
<td>£6552</td>
<td>6.65</td>
<td>8</td>
</tr>
<tr>
<td>Meet adult team before transfer</td>
<td>£15726</td>
<td>6.48</td>
<td>8</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>£20018</td>
<td>7.02</td>
<td>8</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>£13406</td>
<td>7.28</td>
<td>7</td>
</tr>
<tr>
<td>Key worker</td>
<td>£19922</td>
<td>7.53</td>
<td>7</td>
</tr>
<tr>
<td>Transition manager</td>
<td>£26134</td>
<td>6.96</td>
<td>8</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>£14116</td>
<td>6.80</td>
<td>8</td>
</tr>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>All PBFs</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
</tbody>
</table>

PBFs captured using responses to Final Account and face to face questionnaire

| No PBFs                                         | 6415                                        | 6.02                                   | 9                                                |
| Meet adult team before transfer                 | 15941                                       | 7.36                                   | 7                                                |
| Age-banded clinic                               | 18396                                       | 6.93                                   | 8                                                |
| Holistic life-skills training                   | 13519                                       | 7.28                                   | 7                                                |
| Key worker                                      | 13592                                       | 7.51                                   | 7                                                |
| Transition manager                              | 16042                                       | 6.78                                   | 7                                                |
| Appropriate parent involvement                  | 12912                                       | 6.94                                   | 8                                                |
| Promotion of health self-efficacy               | 13644                                       | 7.43                                   | 7                                                |
| Coordinated team                                | 15268                                       | 7.05                                   | 8                                                |
| Transition plan                                 | 18523                                       | 7.09                                   | 7                                                |
| All PBFs                                        | NA                                          | NA                                     | NA                                               |
Table 37: Incremental cost effectiveness

<table>
<thead>
<tr>
<th>Cost per QALY gained</th>
<th>ICER using PBFs captured from final account</th>
<th>ICER using PBFs captured from final account and face to face questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet adult team before transfer</td>
<td>Dominated*</td>
<td>7121</td>
</tr>
<tr>
<td>Age-banded clinic</td>
<td>36487</td>
<td>13176</td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>10991</td>
<td>5618</td>
</tr>
<tr>
<td>Key worker</td>
<td>15259</td>
<td>4811</td>
</tr>
<tr>
<td>Transition manager</td>
<td>64359</td>
<td>12592</td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>7070</td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>5127</td>
</tr>
<tr>
<td>Coordinated team</td>
<td>52100</td>
<td>8596</td>
</tr>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>11259</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cost per 1 unit change in sumscore</th>
<th>Meet adult team before transfer</th>
<th>15092</th>
<th>7011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age-banded clinic</td>
<td>22693</td>
<td>12662</td>
<td></td>
</tr>
<tr>
<td>Holistic life-skills training</td>
<td>5692</td>
<td>4563</td>
<td></td>
</tr>
<tr>
<td>Key worker</td>
<td>13363</td>
<td>3878</td>
<td></td>
</tr>
<tr>
<td>Transition manager</td>
<td>23364</td>
<td>7114</td>
<td></td>
</tr>
<tr>
<td>Appropriate parent involvement</td>
<td>NA</td>
<td>5345</td>
<td></td>
</tr>
<tr>
<td>Promotion of health self-efficacy</td>
<td>NA</td>
<td>5341</td>
<td></td>
</tr>
<tr>
<td>Coordinated team</td>
<td>12746</td>
<td>7700</td>
<td></td>
</tr>
<tr>
<td>Transition plan</td>
<td>NA</td>
<td>8947</td>
<td></td>
</tr>
</tbody>
</table>

* PBF on average more costly and less effective. Therefore it is dominated by a service without that PBF

ICER Incremental cost effectiveness ratio
QALY Quality adjusted life year
PBF Proposed beneficial feature
3.3 Balance sheet

Taking the data from the all the economic analyses and elsewhere within the programme a balance sheet summarising the pros and cons of developing a service which has some of the proposed beneficial features compared to a service without these features can be developed (Table 38). The purpose of Table 38 is to inform a decision about whether the cost of implementing a new service would be offset by any reductions in cost in the future and improvements in health.

The development and implementation of a service containing one or more proposed beneficial features would incur a cost, the magnitude of that cost will be determined by how that proposed beneficial feature is delivered.

The limited data available from the economic model suggests that the implementation of a new service will increase the use of NHS services at least over a 10 year time horizon for a young person aged 14 entering a ‘transition’ service but there are no obvious harms to the young person of any of the proposed beneficial features.

The question for the decision-maker is whether the development of a flexible service capable of meeting the changing needs of young people, allowing appropriate parental involvement, promoting self-efficacy and more general independence of the young person would be worth these extra costs given that they may increase engagement with health services and prevent deterioration/exacerbation in health in the long-term.
Table 38: Pros and cons of a transition service containing some of the proposed beneficial features

<table>
<thead>
<tr>
<th>Favours service containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.</th>
<th>Favours service not containing the adaptability needed from the findings of the Q-sort, the preferences in the DCE and the proposed beneficial features in the prospective study.</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>A service should be flexible enough to meet the need of individuals – one size does not fit all and needs may change over time. Service needs to consider the condition, the stage of development, and the young person’s personality.</td>
<td>Avoided the currently unknown costs of providing beneficial features. Costs of some may be modest e.g. a ‘written transition plan’ whilst others are substantial e.g. adoption of a multi-disciplinary team.</td>
<td>Costs not estimated</td>
</tr>
<tr>
<td>Predicted uptake of a service higher when the service included parent involvement; a service where the same staff are seen at each clinic appointment; where the young receive good communication and are offered the opportunity to make decisions.</td>
<td>DCE (WP 2.3.1)</td>
<td>DCE (WP 2.3.1)</td>
</tr>
<tr>
<td>‘Appropriate parent involvement’, ‘Promotion of health self-efficacy’, ‘Meeting the adult team’ improved outcomes.</td>
<td>From the DCE a strong preference for current care; no strong preference for a ‘key worker’ or flexibility of appointments</td>
<td>Anticipated impact not measured in study</td>
</tr>
<tr>
<td>Estimated additional benefit to health service of adopting any of the above features, except care by a co-ordinated team</td>
<td>Estimated additional cost to health services of adopting any of the proposed beneficial features</td>
<td>Economic model analysis (WP 2.3.2)</td>
</tr>
<tr>
<td>Longer term model cautiously suggests ‘holistic life-skills training’; ‘having a key worker’, and ‘promotion of health self-efficacy’ might be value for money.</td>
<td>Longer term model cautiously suggests that a ‘transition manager for clinical team’, ‘age-banded clinic’ or ‘meeting the adult team before transfer’ might not be value for money.</td>
<td>Economic model analysis (WP 2.3.2)</td>
</tr>
<tr>
<td>No evidence of a difference</td>
<td>Lack of clarity over what was meant by a health passport, which might be valued but rarely used</td>
<td>Works conducted by UP (WP 1.2)</td>
</tr>
<tr>
<td>During transition, no evidence of any effect on outcomes of ‘having a transition plan’, ‘attending an age-banded clinic’, ‘being cared for by a coordinated team’; ‘being part of a service with a transition manager for clinical team’; ‘having access to holistic life-skills training’</td>
<td>Analysis of longitudinal data (WP 2.1)</td>
<td></td>
</tr>
<tr>
<td>Over the duration of the longitudinal study, no evidence of any effect on costs or health related quality of life of ‘having a transition plan’, ‘attending an age-banded clinic’, ‘being cared for by a coordinated team’; ‘being part of a service with a Transition manager for clinical team’; ‘having access to holistic life-skills training’.</td>
<td>Analysis of costs and EQ-5D data in the economic analysis (WP 2.3.2)</td>
<td></td>
</tr>
</tbody>
</table>
4 Limitations and strengths

Loss to follow-up may have led to biased estimates if those lost to follow-up differed systematically from those who were not. For this reason, we did not conduct an analysis of completers only (i.e. those for whom data at all four time points was available). On the factors for which we had data, there was no selective attrition except for a suggestion in those with cerebral palsy that more socio-economically deprived young people were likely to drop out.

A second concern was whether the HRQoL instrument was sufficiently sensitive to capture an influence of PBFs. The study was not powered on the EQ-5D-Y but rather on the outcomes used in WP 2.1. We did have sufficient power to identify clinically significant changes in the EQ-5D-Y but, for analysis by condition, sample size meant that some real effects of difference may not have been detectable. In relation to the PBFs, power was limited if a feature was often absent.

Alternatively, the HRQoL instrument might have been sufficiently sensitive but follow-up time was too short to capture any influence of PBFs.

The DCE suggested that experiencing some of the PBFs might increase young people’s engagement with health services, which in turn might alleviate longer term harms (and costs) due to inadequate healthcare. The economic evaluation was exploratory and only compared services with individual PBFs to a service with no PBFs. Therefore, no probabilistic sensitivity analysis was conducted as is normally recommended for health technology assessment type economic evaluations and a quantified estimate of the effect associated with various combinations of PBFs was not possible. Therefore the economic conclusions should be interpreted with care.

It was necessary to annuitise the cost data for participants to compare with the EQ-5D-Y data. Thus, certain costs for participants for items mentioned occasionally but likely to apply over the course of the study were calculated as a daily rate following aggregation of the visit data. For example, as insulin prescriptions were not consistently reported in the data, these were costed separately according to existing literature and then inflated to the current price year. We think this made best use of the available data and is unlikely to have distorted the results.

The data collected on outcomes, costs and health service use were complex to interpret because there was loss to follow up, differing healthcare transfer arrangements and the intervals between the annual visits by the research assistants were not always one year (young people have a lot going on in their lives and often visits had to be rescheduled). Strict
econometric modelling, despite considerable efforts, proved intractable to undertake. A less robust exploratory analysis was adopted. This drew out some key implications and generated a balance sheet. This was not wholly in concordance with some conclusions from other parts of the Programme, but triangulation of findings allowed key consistent conclusions and implications to be identified and reported.
Appendix 9: Introduction of Developmentally Appropriate Healthcare

In this appendix we list the URLs of the papers we refer to in the synopsis.

Then we present a draft of a paper submitted for publication.

URL Toolkit for introducing Developmentally Appropriate Healthcare

URL is:

https://www.northumbria.nhs.uk/dahtoolkit

URL Scoping paper, Developmentally Appropriate Healthcare

Developmentally appropriate healthcare for young people: a scoping study.

Green Open Access

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4912032/

https://doi.org/10.1136/archdischild-2014-306749

URL Concepts paper, Developmentally Appropriate Healthcare

Health professionals’ and managers’ definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies

Green Open Access

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5245734/

https://doi.org/10.1136/archdischild-2015-309473
Normalising Developmentally Appropriate Healthcare for young people in hospitals: commitment, practice and inequity

Introduction

Adolescent health is a neglected yet pressing global issue\textsuperscript{211} affecting the largest generation in human history.\textsuperscript{212} Internationally, and in the UK, there is now increasing recognition of the importance of providing quality healthcare for the specific biopsychosocial needs of adolescents and young adults. One key challenge to addressing and researching this issue is the variable status of adolescent medicine across countries. Within the UK adolescent medicine is not a recognised medical speciality.

Youth-friendly health care\textsuperscript{104} has been promoted as a way to enable improvement of health services for young people. This concept has been used to underpin quality of care\textsuperscript{105} and policy\textsuperscript{93, 213} frameworks. However, as highlighted by the World Health Organisation (WHO), there is the need to move from the ad hoc provision of adolescent-friendly projects and services into adolescent-responsive health systems that can respond to the priority health and development needs of all young people.\textsuperscript{106} Health care needs to respond to adolescents’ and young adults’ changing developmental needs. This provision needs to be consistent and universal, provided across all areas of the health care system. Such youth-responsive health systems need to focus on how health care professionals engage and communicate with young people in the consultation through to how services are planned, organised, delivered and commissioned. Developmentally appropriate healthcare (DAH) for young people\textsuperscript{3, 4} is one concept that could underpin a youth-responsive health systems.

DAH has been described as a key principle underpinning the practice of adolescent medicine.\textsuperscript{214} It is about making health care work for young people by recognising their changing developmental needs and the role of health care in addressing and supporting these through adolescence and young adulthood. It focuses on biopsychosocial development rather than chronological age. Each young person will make this journey to adulthood in a way that is unique to them and young people’s development does not have a fixed time frame attached to it. Many of these developmental milestones will be met after reaching the legal age of adulthood.
DAH services with particular reference to adolescents and young adults have been reported nationally and internationally as a key mechanism to improve health outcomes for young people and national guidance in the UK now specifically refers to the need for provision of DAH for young people. Alongside this, the increasing knowledge surrounding adolescents’ and young adults’ development offers unprecedented opportunities for service improvement. Existing approaches that draw on the concept of youth-friendly health care need to be reframed and extended. DAH offers an opportunity to transform traditional models of healthcare delivery, to create youth-responsive health systems.

However, in spite of the existing evidence base and guidance, sub-optimal provision of health care for adolescents and young adults continues.

There has been a range of ways that the concept of DAH has been operationalized in the medical literature. We have shown that clinicians and managers directly involved in the provision of health care for adolescents and young adults in three UK hospitals have different ways of making sense of the concept. In this paper, we focus on the normalization of DAH for young people within three UK hospitals. We explore the ways that people and services attempted to implement a more youth-responsive healthcare delivery.

Methods

Initially a scoping review was conducted to explore the use and meanings attributed to the concept of DAH for young people. Articles were subjected to manifest and latent content analysis in order to identify preliminary patterns and to explore the core ideas attached to concept.

A qualitative multi-site ethnographic study was then conducted across three hospitals in England: a district general hospital, a paediatric tertiary hospital and an adult tertiary hospital. Health professionals (HP) were recruited through six medical and surgical specialties chosen to represent the heterogeneous services found in UK National Health Service hospitals: Diabetes; Emergency Care; General Paediatrics; Outpatients; Rheumatology; and Trauma and Orthopaedics. In addition, some HP were recruited during the course of the study through other specialties (Endocrinology, Cardiology, Oncology and Respiratory), departments (Chaplaincy, Psychology, Radiology, and Youth Work) and settings (training sessions). Managers (MA) were recruited at each site when their roles were relevant to the provision of services for young people in paediatrics and/or adult care.
The Interview guide is at the end of this report.

Data collection took place over three phases, between June 2013 and January 2015. Recruitment was initially mediated through gatekeepers, then a mixture of snowball, criterion and theoretical sampling was used to recruit further staff. 192 participants were recruited. Approximately 1600 hours of non-participant observations were conducted, alongside 65 formal qualitative interviews (See Table 39). Observations where recorded in contemporaneous field notes. Formal interviews were audio-recorded, transcribed, edited to ensure respondents anonymity and then analysed alongside anonymised field notes.

Table 39: Participants recruited for the study by site, type of staff and method of data collection

<table>
<thead>
<tr>
<th></th>
<th>District general hospital</th>
<th>Paediatric tertiary hospital</th>
<th>Adult tertiary hospital</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Participants observed</strong></td>
<td>Health professionals</td>
<td>65</td>
<td>27</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Managers</td>
<td>57</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td>122</td>
<td>27</td>
<td>26</td>
</tr>
<tr>
<td><strong>Participants interviewed</strong></td>
<td>Health professionals</td>
<td>13</td>
<td>18</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Managers</td>
<td>13</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td>26</td>
<td>24</td>
<td>15</td>
</tr>
<tr>
<td><strong>Overall participants</strong></td>
<td>Health professionals</td>
<td>78</td>
<td>45</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Managers</td>
<td>70</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td>148</td>
<td>51</td>
<td>41</td>
</tr>
<tr>
<td><strong>Number of participants who were both interviewed and observed</strong></td>
<td>39</td>
<td>5</td>
<td>4</td>
<td>48</td>
</tr>
<tr>
<td><strong>Total number of participants</strong></td>
<td>109</td>
<td>46</td>
<td>37</td>
<td>192</td>
</tr>
</tbody>
</table>

All analysis was conducted according to the standard procedures of rigorous qualitative analysis. We used procedures from first-generation grounded theory - coding, constant comparison, memoing - and from analytic induction, deviant case analysis. Data collection and analysis occurred concurrently, so that issues raised in earlier phases of fieldwork were explored in subsequent ones. We undertook independent coding and cross checking, team data sessions and member validation with some of the participants in the fieldwork. The analysis was theoretically-informed by Normalization Process Theory.

**Findings**

Diverse values and commitment
As we have outlined elsewhere,\textsuperscript{4} there was a wide variety of definitions of DAH across clinical and managerial staff in all the sites. Some did not recognise it as a concept, for some it made little sense and for others it was difficult to conceptualise, it is ‘a bit amorphous’.

Many focused more on the need to create a more age appropriate environment, in terms of the physical space, the visual and material culture of waiting room and wards (e.g. age appropriate leaflets and computer games). Others, especially those who did some work with young people, often discussed ‘the medical bit plus all the extras’, outlining a wide array of features, including aspects like developmentally appropriate communication, norms around confidentiality and a more holistic focus. As one manager noted:

the young people have told us that, um, we need, they’re not bothered about where they are seen so, as in, what the building’s look like or what the clinic room looks like. They want to make sure that they see somebody who’s interested and who knows what their disease is like, but also has an awareness of all the other stuff that’s going on when they’re 16 to 18, as in their, the, sort of, the physiological bit of just being a normal teenager and what happens. (MA, General)

This manager’s view is intimately informed by working closely with and listening to the experience of young people. At this site, there were a variety of ways in which young people were involved in the provision of services for other young people as well as research. Recruitment of young people was often done through various channels within the hospital, for instance via the posters and leaflets which adorn the walls. Centrally, involvement at this hospital was considered to be part of patient experience, and it was mentioned that young people were involved in doing things such as helping to design books about the patients’ journey, as well as sitting in on governance meetings and helping with the training of staff. In this way, young people’s experiences were a central resource in helping to shape their understanding of appropriate service provision.

Alongside the different understandings of the purpose of DAH, there were conflicting views on the value and worth of enacting it across the organisations. The numbers of young people accessing health services were often portrayed as quite small, so in organisational terms they can become ‘just below the radar’. In contrast to older, and especially elderly, patients, they were also positioned to often be ‘very rarely unwell’. For some, this raised questions about whether a focus on young people is legitimate.
the trouble that we still have is that it’s seen as a paediatric problem. It’s not recognised as an adult medical issue, uh, because it’s a small number I think. … [for example] when you’ve got 10, at most, per year coming through with complex health problems. Why do they have to set up a separate service for them? Or why do they have to change the way that they work? Um … because they don’t come into contact with them that, very often (HP, General)

In this way, the ‘small number’ argument, in both paediatric and adult contexts, led some to question whether they, or others, should be adjusting their practices or offering distinct, more tailored, services. Relatedly, there are always competing demands for resources, time and expertise.

It's small enough [numbers] that if you don’t, if you don't buy into it, there's plenty to be getting on with the other 90%. And everybody's jobs are so frantic that you could easily do a very good job with that 90% who are 25, 26 plus. You wouldn't be short of things to do, do you see what I mean? So, you could actually ignore these young people completely. (MA, Adult)

Individuals can, at times, choose not to buy into such work. Questions of legitimacy and buy-in, or rather, enrolment, are central to individual, team and organisational change.

In part, this lack of capacity and willingness seems to be compounded by the liminal status of young people within the organisational and professional culture of the UK healthcare system: ‘adults don’t really want them because they are too young and the paediatricians don’t really want them because they are too old’ (HP, General). Adolescent medicine is not a distinct profession, ‘still considered as somewhat of an add-on’. Albeit with the exception of charity-supported oncology wards, adolescent only wards, or spaces within wards, were rare and often temporary affairs subject to dissolution given competing demands across all three sites. This is also reflected in management terms.

there isn’t a designated clinical lead for adolescents or a designated board member for adolescence. … you know, who’s flying the flag high up for adolescents? I don’t know. (MA, Paediatric)

None of the sites had a senior clinical or management lead for young people. However, across all the sites we did observe a complex network of adolescent minded practitioners. We frequently either meet with, or heard about, people acting as adolescent or young people
‘enthusiasts’, or ‘champions’, within specific clinical or management teams in either a formal or informal capacity. In this way, specific services and practices were organised around the care of young people. However, relying on the enthusiasm and willingness of specific individuals can become problematic.

Several people have left, who have been very senior members and very adolescent minded and have been replaced by either rotational posts or part-time posts, so that continuity within our team and the wealth of expertise has been impacted on significantly. (HP, Paediatric).

In this way, a focus on champions raises key questions for people about the sustainability of services for young people over time.

Across all three sites, we found a variety of definitions of DAH, alongside conflicting views on the value and worth of enacting youth orientated care across the organisations. For some, a focus on young people is questioned, given the contexts of small numbers and competing demands. Such a view is compounded by the liminal status of young people, given the lack of professional and managerial roles focusing solely on young people. Across all the sites, young people’s champions, be they working in a formal or informal capacity, were key in getting people involved in the care of young people. However, people were aware of the practical problem of relying on key individuals. For them, it should be ‘about consistency of approach, not a person’, about developing local cultures of good practice within and across teams and clinical spaces, that can withstand changes in specific personnel.

Informal cultures of good practice

As one manager, with clinical experience outlined ‘Transitions, probably, um, suggest a process where Developmentally Appropriate Healthcare suggests a philosophy’ (MA, General). Across all three sites, we observed local cultures – in teams, clinics, wards and meetings - where they attempted to enact both a set of processes and philosophy of care towards young people. They were driven by an awareness of how approaching young people in a different way can mean that they ‘might take the right messages away, might not end up neglecting their health needs, damaging themselves’ (MA, General). For these professionals working with young people required a specific mind-set and skill-set.

At its simplest level this often involved the ability of the professional, or professional across an MDT, to communicate effectively, listening carefully to young people about their health
needs and asking them questions, often tied to the dimension of the HEEADSSS assessment tool,\(^{216}\) about their broader social situation in order to determine how these fitted together. It was an approach that centred on going beyond strict medical issues or focusing solely on chronological age, to consider a range of psychosocial issues impacting the young person given their stage of development. As such, care is contextualised with a wide variety of information surrounding the patient’s life, including educational, vocational, social, and friendship and family issues, exploring the normal ‘risks’ a young person faces. Such information is used by teams to generate an appropriate context for effective communication or to organise consultations in a particular way, including appropriate health education and support for self-management.

Providing an appropriate service for young people is often a deeply rooted value for these individuals and groups. The ‘You're Welcome Quality Criteria’\(^{93}\) were generally well known, including core issues such confidentiality and consent, joined-up working, transition and accessibility. So, for example, some schedule some of the clinics to start in the afternoon and extend them into the evening to enable young adults to arrange their appointments to suit their college or work schedule. Within the context of adult care, DNA was a prevalent issue in some of the clinics. Ways of dealing with this seemed to vary from clinic to clinic and across organisations, as policies regarding DNA may vary. However, we were told about what was referred to as, ‘a softer approach to the DNAs’

> The Trust ruling of one strike and you’re out, we don’t adhere to, so we will give them multiple attempts to come into clinic … since as we don’t actually put them as a DNA, because they just booked in [the consultants] calendar but we don’t actually book it on the system so they don’t officially come as a DNA … So I’ll make informal appointments with the young people and then, when they arrive we book them into clinic, so that way they don’t DNA (HP, Adult).

Working creatively with the existing norms, rules and resources was typical of individuals and groups that had bought into the idea that young people need to be recognized as a group with specific needs and approaches.

What we observed across all the organisations was ‘lots of great pockets of work’ as some specialties, teams, people or spaces seemed to offer very strong young person orientated care. However, not all people or services felt it relevant to make ‘special arrangements’, but choose
instead to treat them like ‘an ordinary patient’. Alongside this, the uneven distribution of resources within and across specialties can create inequities of care.

There are … areas in the hospital who, because they have more funding or they’re funded in a different way, they might have a youth worker because it’s part of their team and just for their team. They might have a psychologist who is just part of their team, social worker. … it very much depends on what speciality you’re unfortunate to fall into, depending on what illness you’ve got as to what service you then get. … So, if you were a liver patient, you’ve got access to more services that if you were a medical patient. That’s not appropriate. … We should be offering the same service to everybody that comes through the doors. (HP, Paediatric)

However, resources are not the only source of inequities. In part the inequities in skills and experience across the organisations seem to be self-sustaining within organisations. Centrally, those with an interest, the ‘enthusiasts’, are embedded in an informal network of care.

we’ve now got a group of interested people across the Trust. So if a young person comes to me and they’ve got a, a joint problem, but they’ve also got a bowel problem, I know which bowel consultant and which bowel nurse will be the most appropriate to send them to, which chest doctor, which chest nurse will be the appropriate. Um, so we’ve got a good group of people across the Trust that we can actually send these youngsters to who’ve got more awareness of the issues that they could have (HP, General)

In this way, an informal knowledge economy of young person friendly practitioners and practices exists within the organisations. These are networks of trust. These referrals help to create, sustain and reinforce the network over time. This practice also exists across organisations, as practitioners, especially in terms of the transfer of young people to adult services, will seek to refer the young person to specific organisations, clinical teams or individuals over others – as this early field note illustrates:

they refer to known doctors from this or that hospital as being more “appropriate” or “adolescent friendly” for the patient being discussed, it’s as if they are able to assess the suitability of a professional based on some not evident informal knowledge that I am not aware of at this point. (Paediatric)
Adolescent-minded practitioners refer to other adolescent-minded practitioners – in this way, they work to actively avoid referring young people to those less adolescent minded practitioners. As such these people then gain less practical experience with managing these patients, and so less chance to reappraise there values and commitment to working with young people in new ways, as well as to develop the right mix of skills.

We also see an informal network in terms of spaces, as well as, people. At each site, at least one specific ward was known to offer more young person friendly care. They are seen as repositories of key knowledge and skills, able to manage the potentially unruly, undisciplined, teenage other.

We were getting so much inquiries regarding adolescents from the other wards, even just for the basics. So, they would ring us and say, “We can’t get them out of bed in the morning”. You know, “they just want to stay in bed all the time and they don’t want to interact with anything”. So we would say, “Well then you have to be stern, you know, you have to tell them, ‘This is the plan,’ you have to do a contract with them and agree with them that if they get over this time, then they can do this at this time” (HP, Paediatrics).

Such wards were not only required to offer basic advice to teams on other wards, but were also called onto to manage more complex issues. For example, when a young patient was self-cutting, the ward staff panicked and sought to move the patient to the more youth-friendly, or rather youth-experienced, ward.

instead of sort of accepting that everybody has these patients throughout the hospital because this is just another component of young people’s care, they are not just a regular like thing, they’ve got other parts to them as well and about holistic approach. There was quite a bit of panic and, “This patient needs to get off our ward immediately,” (HP, Paediatrics)

The immediate reaction was to move the teenager. It is not only that ‘just different wards have a different tolerance’, but rather that different wards and teams, develop, over time, different young-person orientated understandings and different sense of what is legitimate work, as well as young-person friendly skills, competencies and routines.

in some situations, we've had patients on our general wards where the parent has wanted to stay. And we, my nurses, would find that very strange. But actually, in
oconomy, that would not be strange at all. Because … [they] would be used to that, even a patient could be 22, 23 and still may want their mum. But they’re not exposed to that in the main wards because they only see bits of the journey as well. (HP, Adult)

Centrally, exposure to working with young people was a central resource to enable them to become seen as just another young patient, over a set of unknown and unexpected concerns. Exposure offers a chance to adjust expectations and develop new skills.

Across all three sites, local networks of people, teams and spaces, work to enact services tailored to the specific needs of young people. They work to integrate biological, psychological, social and vocational issues across MDT and offer specific services and spaces for young people. Developmental assessment is used to inform aspects of service delivery and they seek to offer appropriate and timely health education and support for self-management. However, in all the sites, such DAH is unevenly distributed. Some people or services feel no ‘special arrangements’ are required. Some services are perceived as being overly- or under-invested. In this way, inequities of care for young people exist within each organisation. Informal networks of trust existed within each site, where certain people, teams or spaces were understood as having the right skill-mix, or mind-set, or access to resources, to work effectively with young people. As a young person moves through an organisation, the preference is to direct them to those people and spaces that are known to have an interest in young people. Albeit for good clinical reasons, this can mean that some of the inequities in skills and practical experience across the organisations can be self-sustaining. A lack of meaningful exposure to the care of young people, can also mean a lack of a chance to reappraise values and reconfigure practices.

(In)formal cultures of training

Within each of the organisations there were different ways in which the young people enthusiasts or champions met and supported each other collectively. They took the form of both formal and informal groups. Essentially, these groups were a collective effort to promote initiatives to raise awareness across the organisations, create change, offer support and, importantly, learn from each other outwith their team, area or specialty.

‘I have nothing in writing in my job plan that says I specialise in young people. … The training that I've had is training that I have thought that I need. Nobody said, “If you want to be a young adult person, you need to go on this”. It's just something that I
became aware of through organisations or talking to people. So, it's all quite ad-hoc rather than really, really planned. And it's just really by hearsay and talking to people and networking throughout [this organisation] over many years.’ (HP, Paediatrics)

Without any formalised professional routes available to people, the local, regional and national special interests groups became a central resource in supporting young people focused training across the organisations. Training in how to communicate effectively and around the needs of young people was seen to be an important component of effectively delivering DAH as well as an important driver to raise awareness and create change across the organisations.

In two of the sites, the only initiatives involving training around young people that we were aware of originated from their respective special interest groups in the form of yearly organised study days. At one of these sites, there was a policy initiative explicitly around transition, yet no specific training had been organised. It is worth noting that, focusing on young people in relation to transition means a focus on young people with long-term conditions, over a broader focus on the experience of all young people that enter the organisation. At the other, development of a formal policy was said to be ‘not a priority for the trust’.

Priorities are the front door, A&E, CDU, waiting times and, it’s those things that they are being judged on.

Interviewer: Why do you think this is not a priority at all?

Just because they’ve got bigger fish to fry … I mean if you sat them down individually and talk about it they would be very, they are, very supportive. But it’s not a priority for the [organization] because of all the other things by which they are measured. And young people’s care isn’t on that list. (MA, Adult)

In the current context of the factors that drive organisational change at this site, creating further engagement and buy-in from senior management was not seen as a practical solution to enable change. As such, issues about the care of young people remained focused in the informal, organisation-wide group, of young people’s champions. As we discovered during our fieldwork, not everyone interested in the care of young people in that organisation was aware of the existence and work of that group. Even within the group, they were often
surprised by the number and range of young person-orientated initiatives that were occurring within the organisation.

However, at one site we did observe specific training around the topic of DAH being planned and delivered. A DAH strategy emerged as the result of the work of a number of key people who sat on a transition strategy group. The group comprised of managers, clinicians and allied healthcare professionals who meet every couple of months and who all had a particular interest in the healthcare of young people and transition. There was strong cross over between managerial and clinical levels and they worked to actively foster communication and create connections across services in order to highlight the issue. In this way, the ideas emerged from the local special interest group, but centrally the dissemination was targeted well beyond the special interest group. Part of this involved looking where change was currently occurring within the organisation and ‘where the energy within the Trust at the moment is’, alongside the broader national, governmental, agendas on young people’s health, in order to harness that momentum and get people involved.

Training at this site was very much linked to the development of a DAH strategy and consisted of ‘delivering key messages’ from various government policy initiatives, especially the ‘You’re Welcome Criteria’. It was positioned both in management meetings and in training sessions as ‘just … good holistic healthcare’.

The focus of the strategy, and concomitant training, was on organisational level factors (e.g. staff appraisal includes training goals around young people; provision of age-banded clinics) clinic and consultation level factors (e.g. signpost sexual health, drug and alcohol services; copying letters to young people) and training and awareness factors (e.g. adolescent development; confidentiality). This programme of training had senior management support, albeit initially from within child health, alongside access to resources. Using money to ‘back fill’ was seen as a key component in the success of the roll-out of training, as without this, departments would not only be unwilling but also unable to release staff for training. For example, some training sessions, were focused on raising awareness of basic issues.

Last year we did, um, we did ten days, so ten individual day sessions for training in adolescent, basic adolescent health. Basically to increase awareness across the [organisation] so as to make sure it wasn’t just the, the chronic illness patients that were being looked at … but it was the patients coming through A&E, coming through X-ray. And so we had members of staff from all over the [organisation] came on these
training days. So it could’ve been a radiographer taking an X-ray, um, it could’ve been a nurse in theatre, it could’ve been a, a nurse in, um, A&E, just to get them aware of what a young person’s needs are and why they’re different to being an adult [HP, General].

In this way, central norms and practices of good, everyday care for young people were distributed well beyond the local existing networks of people, teams and spaces of young people’s champions. The initiative emerged from, and depended on, their enthusiasm and expertise. The network of trust of young person friendly practitioners was then supported by key actors within wider management. This led to an on-going programme that sought to make the young people’s healthcare visible across the organization, to begin to get to people to reappraise values and commitment.

**Discussion**

Our findings reveal the everyday working practices of something like a discipline of adolescent medicine-in-action without a formal professional or organisational status as a ‘Discipline’. Across each organisation a complex distributed network of young people minded practitioners understood the potential value and worth of practices and services for young people, such as DAH. These were people committed to working with and for young people, to enacting adolescent medicine, to enacting DAH, within consultations, clinics and wards. Within and across organisations, an informal knowledge economy of young people friendly practitioners, practices and spaces exists. People have a preference for referring to other young people friendly practitioners or spaces, to others within the networks of trust. Such referrals help to create, sustain and reinforce the network over time. Such networks also support and provide, through formal and informal means, the training and development around young people’s health.

In this way the concept of DAH is being normalised as networks of people within each hospital make sense, buy-into, enact and reflect on and adapt it. Clearly, the enactment of DAH is fluid - both present and not, both excellent and not - within and across professional, organisational, ward and team boundaries. It is largely sustained and (re)enacted by a distributed network of informal ties, knowledge and practices. However, the very definition of DAH, its organisational and policy relevance and its resource and spatial allocation, are contested issues within and across hospital settings. To move beyond normalisation of DAH for a few, to normalisation for an organisation, we need to move beyond the informal cultures
of training and good practice. At one site, providing a trust-wide strategy and training on organisational, team, clinic and consultation level factors as well as training and awareness factors offered such an opportunity. It relied on buy-in and formal support from senior managers in both child and adult services to initiate and sustain it over time. The WHO recommendations to achieve adolescent-responsive health systems, highlight the centrality of service delivery and workforce capacity issues to achieve successful integration and consistency of health services for all young people within and across organisations and levels of care.

There is also a need for strong and clear guidelines, strategies and policies on the practical implementation of DAH. At the end of the fieldwork, guidance appeared in the UK around the need to implement DAH in relation to transitional healthcare. However, such a focus on transition and transfer has important limitations. Currently, the guidelines are concerned with young people with long term conditions whose care is planned at the clinic and team levels within a specific speciality. However, not all young people attending hospital services will have a long term condition. Some will follow acute, emergency or surgical pathways. Young people with long term conditions will often experience care in various settings within an organisation, whether that be as an in-patient, out-patient, day-case or in other departments such as radiology, pharmacy or investigation suites. As we saw, normalisation of DAH for a few, introduces inequities. The potential normalisation of DAH around transition and transfer may reduce some inequities, but may sustain inequities in the access and provision of DAH care across an organisation.

Limitations

The selection of ethnographic methodology is a major strength of the study as it facilitated the immersion of the researchers into the organizational culture of each hospital, enabling them to observe and examine the process and practices in context. A limitation was that only three sites in two UK regions were studied. However, a significant number of staff participated and a wide range of settings were encompassed including outpatient, inpatient and emergency care. Furthermore, although the hospitals involved had a history of championing research and innovative service provision for young people, this did not include a defined adolescent medicine service and participating areas and/or specialties were at different stages of familiarisation with providing DAH, thus providing the study with breadth and depth of experience. We think, therefore, that we captured a broad range of relevant
views but it is likely that not all were covered. Similar work in a comparator group of hospitals who did not have the same history would be of interest. Other limitations, such as the UK scope of the study and the hospital-based (non-community) sampling of professionals, should be addressed in future research.

Conclusion

Currently there are a wide variety of definitions of DAH within the literature and across clinical and managerial staff. There are conflicting views on the value and worth of DAH. Youth-friendly practitioners and managers, be they working in a formal or informal capacity, are initially key to raising the profile DAH. To move beyond pockets of good practice to services responsive to young people buy-in and formal support from senior managers in both child and adult services is central. Providing a trust-wide strategy and training on organisational, team, clinic and consultation level factors is key.
WP 3.1 Interview schedule: clinician manager

Interviews
Implementation of Developmentally Appropriate Healthcare in an Organisation (IDAHO)

Note: The interview schedule is developmental. The questions will be developed from the findings of the observations. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.

Plan of interview
Setting
Staff member will choose setting – mainly hospital room

Introduction
Explain purpose of the study and this interview and that it is the first of two or three.
Explain interview recorded but details will be confidential.
Explore any questions or concerns?

About you
Can you just explain what your role is?
How long have you been working in this role?
What where you doing prior to this?

Definitions
The WHO defines ‘young people’ as those aged 10 to 24 years old, ‘youth’ as those aged 15-24 and adolescents as those aged 10 to 19
What types of distinctions do you make?

How would you define ‘developmentally appropriate services’?
And specifically in relation to young people?
What do you think are the key aspects of developmentally appropriate services for young people?
How would you define Transition?
What do you feel are the key aspects for a successful transition?

*Trusts wide issues*
Do you feel that the Trust as a whole is particularly young people friendly?
Are young people are priority for the trust?

Are you aware of any Trust wide strategies promoting developmentally health care for young people?
Where did you first hear about them?

Have you heard of the ‘Trust Transition Strategy’?
Has this been discussed in your governance meetings?

*Your service*
Roughly what percentage of your service provision (in patient /clinic) do young people make up?
Those aged 10–19?
Those aged 16-24?

Do you feel that the in your service is particularly young people friendly?
Are young people are priority for your service?
Is there a ‘young person’s champion’ in the speciality?
Are they formally recognised (i.e. in job description/within Trust?)
Or are they only internally recognised?

Does your service offer specific services for young people?
What are they?
Which of these focus on transition?
How developmentally appropriate do you think they are?
Are you considering developing them?
In what ways?
What’s been successful/unsuccessful?
What do you feel are the key barriers?
What are the key drivers?
Are staff supportive?

What steps have been taken to introduce/further develop services in line with the Trust Transition Strategy?
What’s been successful/unsuccessful?
What do you feel are the key barriers?
What are the key drivers?

Do you think the roll out of developmentally appropriate services should be a priority for your service?
What priority should be given to those focused on transition?

Are you aware of the Department of Health ‘You’re Welcome’ accreditation and are you considering using this?

Feedback
Have you had concerns / complaints / compliments about your services for young people?
From young people themselves?
What issues did they raise?
How where they managed?
Did any change happen as a result of this?

Are young people involved in the design and evaluation of your services?
What issues did they raise?
What impact have they had on your service provision?

Training and support
Have your staff had any specific training/CPD about working with young people (as distinct from the care of children)?
How useful did you find it?
Is training ongoing?
What, if any, further training do you feel they need?
Have your staff undertaken the Trust in house awareness raising programme on the needs of adolescents?
How useful did they find it?
Do you know if they apply it in their day-to-day practice?

Finally, we need to understand whether the kinds of questions we are asking actually relate to the issues that you think are important?
Are we asking the right questions?
Did these questions allow you to talk about what was important for you?
Is there anything else you would like to tell me?

Thank you for taking part
Remind them that you will be contacting them about the arrangements for a follow-up interview at some point in the future.
Appendix 10: Commissioning

In this appendix we list the URLs of the papers we refer to in the synopsis.

Then we present the draft of a paper submitted for publication.

**URL Commissioning interviews paper**
What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview study.

Gold Open Access


[https://doi.org/10.1136/bmjpo-2017-000085](https://doi.org/10.1136/bmjpo-2017-000085)

**URL Integrated commissioning paper**
Falling through the gaps: exploring the role of integrated commissioning in improving transition from children's to adults' services for young people with long-term health conditions in England.

Gold Open Access


[https://doi.org/10.1177/1355819617752744](https://doi.org/10.1177/1355819617752744)
Report WP 3.2

Authors: Maniatopoulos G, McCafferty S, Bate A, Vale L, Colver A, Kolehmainen N.

BACKGROUND

Work package (WP) 3.2 aimed to contribute to the third objective of the Transition programme by investigating how transitional healthcare should be commissioned.

‘Commissioning’ is the process by which public services are organised and contracted to meet population needs. Commissioners follow a generally cyclical process of: assessment of population needs, setting priorities, developing strategies in line with objective outcomes, procuring services and measuring outcomes. The commissioning landscape for health and social care has recently been subject to substantial change. Specifically, changes in policy set out in the Health and Social Care Act which came into force April 2013 and resulted from the White Paper ‘Equity and Excellence: Liberating the NHS’. Under the reformed system, the NHS Commissioning Board (now called NHS England) was established within the Department of Health to provide national leadership for commissioning healthcare, to allocate budgets to clinical commissioning groups and to commission specialist services (with the abolition of incumbent PCT commissioners and SHAs).

Commissioning has a pivotal role in ensuring the successful transition of young people with CHN from child-centred to adult-oriented healthcare systems. The need for better discharge of this role was highlighted in the Kennedy report, recommendation 32 which stated: ‘Ensuring a smooth transfer between children’s and adults’ services should be a priority for local commissioners’. Further, the Green Paper highlighted the importance of successful transitional healthcare and proposed that PRIMARY CARE Consortia and Health and Wellbeing Boards should be supported in their commissioning for young people with disability.

Further the complexity of transitional healthcare overall, due to its multidisciplinary, interagency nature, is a particular challenge for NHS Trusts, even when the organisation has the strategic will and resources to develop services. User-friendly, effective and efficient health and social care protocols may have little impact on health outcomes of the young people with long term conditions if the service providers are unable to implement the protocols and/or services in other agencies are absent or inadequate. The Government’s proposal that more public health and social care service commissioning should be undertaken
by Local Authorities is a significant opportunity to ensure services for more comprehensive transitional healthcare are not commissioned in isolation from services in other sectors.

NHS England’s Draft Research and Development Strategy 2013-2018 has as its first Objective ‘To identify and prioritise commissioning health services research topics and co-ordinate this work with the Department of Health, NIHR, ……………’ Research is needed to explore and understand the challenges of commissioning for transitional healthcare, and identify successful commissioning practice and guidance within the context of a restructured combined health and social care service.

**AIMS AND OBJECTIVES**

Aims:

1. To explore and understand the challenges of commissioning for transitional healthcare, focussing on the explicit and implicit organisational structures, processes and relationships which drive commissioning decisions around transition.
2. To explore and understand what constitutes successful commissioning practice for transitional healthcare and identify lessons to inform guidance on commissioning for transition across the NHS, including CCG’s; Local Authorities and Health and Wellbeing Boards.

These Aims were addressed in two stages:

Stage 1: Literature review

Stage 2: Semi-structured in-depth interviews with key stakeholders

Stage 3: Case studies
STAGE 1: Literature review of academic, peer-reviewed papers

A systematic review of academic, peer-reviewed literature relevant to commissioning for transition was conducted. The core bibliographic databases used were: Medline (1996 -), Web of Knowledge (WOK) (1996 - ) and Scopus (1996 - ). A structured search strategy was formulated using controlled search terms, including free text terms and MESH headings were available. Given the complexity and ambiguity of the terms ‘commissioning’ and ‘transition’, all alternative terms were used in order to be as thorough as possible. Search terms (Box 3) were applied across databases. To ensure that the literature review remained up to date, searches were conducted regularly over the duration of the review from September 2013 to July 2014. The identified papers were reviewed using explicit exclusion criteria (Box 4).

**Box 3. Academic literature search**

<table>
<thead>
<tr>
<th>Commissioning search terms</th>
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<tbody>
<tr>
<td>“Delivery of Health Care” OR [(Contract Services OR Contract* OR Commission* OR fund* OR purchase* OR budget* OR plan* OR provide* OR manage* OR procurement* OR assess*NEAR/1needs) AND healthcare]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transition search terms</th>
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<tbody>
<tr>
<td>Transition to Adult Care OR Health Transition OR transition* OR continuity* OR pathway OR &quot;service mapping&quot; OR transfer*</td>
</tr>
</tbody>
</table>

AND healthcare AND (‘to adult OR ‘from paediatric’) AND (young person* OR young adult* OR adolescent* OR youth OR child*)

**Box 4. Academic literature exclusion criteria**

**Title and abstract criteria**

1. Non-English Language
2. Transitions other than from children’s services to adult services
3. Populations other than young people with ‘complex health needs’ as defined for the research programme
4. Only identify current problems to transition, no mention of approaches to improve transition or barriers to successful transition

**Full text criteria**

1. It was a book
2. Not an academic or peer reviewed research study
3. Transition papers with no focus on commissioning (or related) processes
4. Focus of the paper not on commissioning or transition processes in the NHS
The PRISMA diagram (Figure 18) shows how the searches of Medline and WOK databases were structured. Separate searches for papers on commissioning and transition identified 302 papers relevant to both topics, which were then screened and assessed for eligibility according to the exclusion criteria. The most common reason for exclusion was that the paper focused only on transition, with no content about commissioning. No academic publications on commissioning for transition were identified. Of the 66 whose full-text was reviewed, 17 were identified as potentially informative for the wider work of the NIHR Programme.
**Figure 18:** Academic literature PRISMA diagram

**Identification**

- **Medline & Web of Knowledge (1996 - )**
  - Commissioning $n = 121,211$
  - Transition $n = 1351$

**Screening**

- Commissioning AND transition $n = 302$
  - Excluded non-English language records $n = 12$
  - Records excluded for: not NHS, not transition of adolescents, not complex health needs, and/or no focus on improving transition, implementing successful transition or barriers to successful transition $n = 224$

- Titles and abstracts screened $n = 290$
  - Records excluded for: only book availability, US papers with insurance focus, not academic or peer-reviewed research study, not specific, no focus on improving transition, implementing successful transition or barriers to successful transition, and/or no focus on commissioning $n = 66$

**Eligibility**

- Full text articles assessed for eligibility (after duplicates removed) $n = 66$

**Included**

- Academic, peer reviewed literature about commissioning for transition $n = 0$
  - Publications not specific to commissioning but potentially informative for programme $n = 17$
Results from the academic literature

Our failure to identify any papers about commissioning for transition led us to undertake a grey literature search which will be presented in the next section. However, review of the 17 papers in the academic literature identified three key themes about barriers to and suggestions for successful transition:

1 Consequences of poor transition
2 Barriers to successful transition
3 Components of successful transition

1 Consequences of poor transition

Two key long term consequences from problems in transition were disengagement of young people from adult services and poor health outcomes.\(^{219, 37, 154, 220, 221}\) Patients often experienced a gap in care which led to disengagement from adult services due to limited accessibility, non-familiarity and non-adherence to follow-up appointments. Poor health outcomes were both physical and psychological, including: patient non-adherence to post-transition medication and increased anxiety described by parents, carers and paediatricians.

2 Barriers to successful transition

The literature outlines structural and process barriers to successful transition, some of which are likely to have implications for commissioners. Barriers were related to challenges in ‘communication’ and ‘implementation/management’.\(^{154, 222}\) Inadequate patient-provider communication and lack of information sharing between providers proved problematic.\(^{221, 223}\) Communication barriers also involved lack of appropriate education (between providers)\(^{37, 219, 221, 223, 224}\) and lack of cooperation between providers.\(^{26}\) Patients lacked knowledge of self-management and decision-making skills and about how to navigate transition; paediatric providers lacked training in adolescent development and management of transition; adult providers lacked training in paediatric diseases, adolescent development and management of transition. Disagreements and lack of consensus on transition between providers and NHS Trusts led to further complications for management of transition.\(^{154}\)

Challenges for implementation included process barriers, paucity of resources and insufficient evidence.\(^{37, 221}\) The challenge of providing a holistic transition process and
meeting the needs of a wide spectrum of types of disability were described. Another barrier was the difficulty in obtaining sufficient funding to allocate resources efficiently for a variety of populations and purposes, such as planning, staffing, infrastructure and training. Further research on testing and evaluation of models is needed to support the development of a generalised transitional plan, skill-assessment techniques and appropriate outcome measurement tools.\textsuperscript{154, 219, 223, 224}

3 Components of successful transition
The majority of key issues highlighted in theme 2 are very relevant and addressed by this third theme. Indeed the literature reviewed provided a number of recommendations that might lead to an improvement of current transition standards, including examples of transition plans and components of successful transitional healthcare. These were related to two key areas: communication/education and planning/processes.

Communication/education
Provider communication barriers may be addressed by increased cooperation between all professionals involved in a holistic transition process and information sharing through written medical summaries.\textsuperscript{154, 219, 223, 224} Patient communication barriers may be resolved by peer support groups or use of new IT opportunities such as texting and social media;\textsuperscript{222, 52, 219, 220} Provider educational barriers could be resolved by development of training curricula.\textsuperscript{222} Patient and carer educational barriers could be addressed by the development of multi-faceted education programmes and provision of appropriate resources materials; including: written checklists, health passports, e-learning and skills assessment. This will further enable the development of required self-advocacy skills as more independent patients are noted to be associated with higher transition success.\textsuperscript{52, 154, 221-223}

Planning/processes
Joint transition clinics.\textsuperscript{52, 154, 221-224}
Successful transition plans included ongoing preparedness assessments\textsuperscript{52, 219, 224} and early meetings with adult clinicians.\textsuperscript{52, 154, 219} Successful plans were flexible, personal, appropriately timed and holistic.\textsuperscript{52, 154, 219, 224} The planning and other processes were often enabled by a trained and dedicated professional, variously described as a nominated key worker, transition care coordinator or specialist nurse.\textsuperscript{158, 220}
STAGE 1 (cont’d): Review of grey literature

Grey literature is defined as “information which is produced on all levels of government, academics, business and industry..., but which is not controlled by commercial publishers”. It is more broadly described as material not published commercially or indexed by major databases, e.g. policy papers, discussion papers, briefings not covered in the bibliographic search. The same search terms used for the academic literature were applied wherever possible (Box 5). We hand-searched the following sources: Social Care Institute for Excellence (SCIE), Health Management Information Consortium (HMIC) (Department of Health, Kings Fund), Nuffield Trust, Public Health England (PHE), NHS Evidence (NICE), NHS Institute for Innovation and Improvement, NHS Improving Quality, Health Services Management Centre (HSMC), National Research Register Archive, UK Clinical Research Network, and Google Scholar. These searches were further supplemented using the ‘360 Review’ technique on any key literature, looking at its references, citations and other papers written by same authors. ‘Snowball’ referencing was used to retrieve references cited in key primary research texts. Papers were also retrieved from email subscription, discussion listings, and supplemented by literature obtained within the wider programme of research. The identified literature was screened for inclusion using exclusion criteria (Box 6). The search of grey literature was completed in June 2014; we decided to keep the search open and update it throughout WP3.2 up to July 2016.

**Box 5. Grey literature search strategy**

<table>
<thead>
<tr>
<th><strong>SCIE search terms</strong></th>
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<tbody>
<tr>
<td>‘Commissioning for Transition’ – simple search box didn’t permit combining terms with ‘AND’ / ‘OR’ in same manner as Academic database search.</td>
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</table>

<table>
<thead>
<tr>
<th><strong>HMIC search terms</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Commissioning’ control vocabulary selected:</td>
</tr>
<tr>
<td>Locality Commissioning OR General Practice Commissioning Groups OR Practice Based Commissioning OR Commissioning Agencies OR Hospital Commissioning OR Lead Commissioning OR Commissioning AND</td>
</tr>
<tr>
<td>‘Transition’ control vocabulary selected:</td>
</tr>
</tbody>
</table>
Palliative care OR "Quality of patient care" OR Patient transfer OR transition to adult services OR Mental health services OR Learning disabilities
AND
Management practice OR Primary Care Trusts OR Healthcare OR Primary care OR Organisational culture
AND
‘Adults’ or ‘Young People’
*Nuffield Trust and PHE search terms*

Hand searched publications on website under Commissioning topic where possible

**Box 6. Grey literature exclusion criteria**

1. Non-English Language
2. Non-comparative health care system – developing countries
3. Older populations
4. Lower grade cases, or non-disability cases e.g. dentistry
5. Lack of commissioning or lack of transition content
6. Only book availability
7. Focus of the paper not on commissioning or transition processes in the NHS
8. Lack of focus on health care (purely social or educational services)
Figure 19: Grey literature PRISMA Diagram

Social Care Institute for Excellence SCIE (1996 - )

Commissioning and transition
SCIE: n = 125
HMIC: n = 46

Records excluded for: transition of commissioning practice/structure, not healthcare (social or educational focus), developing country, not transitioning adolescents with disability, lack of content in either transition or commission (or equivalent) n = 144

Titles and abstracts screened n = 171

Full text articles assessed for eligibility
SCIE: n = 13 (and 7 unavailable)
HMIC: n= 14 (5 unavailable)

Records excluded due to lack of content or focus on specifically commissioning for transition in health care
SCIE: n = 6, HMIC: n = 7

Literature included narrative synthesis
SCIE: n = 7
HMIC: n = 7

‘Useful’ publications identified
SCIE: n = 4, HMIC: n = ?
Partial relevance / not commissioning

Health Management Information Consortium HMIC
Results of grey literature review

This review identified two main areas with evidence:

1 Commissioning

2 Organisation and delivery of care

1 Commissioning

Within the grey literature, no specific policies relating to commissioning for transition were identified. However we identified some key themes from policies with a focus on improving outcomes for children and young people, key delivery plans with a focus on personalisation of care, and some commissioning guidelines. Together these themes may provide useful insight into some of the issues which may be relevant for commissioning for transition. The four themes related to commissioning were:

Transition protocols
Clinic structure
Funding
Co-ordination

1.1 Transition protocols

A number of recommendations were made by the Department of Health for robust or a ‘successful and consistent’ transition protocol. There is currently a lack of joint planning and commissioning and the need to improve this, specifically between children and adult services, was recognised. In order to facilitate this the key responsibilities of commissioners were described as: (i) developing service specifications based on local needs assessments; (ii) stimulating the market place to fill identified gaps in service provision and (iii) stimulating providers to provide best practice services based on research evidence. CQUIN (Commissioning for Quality and Innovation) was suggested as a mechanism to aid effective commissioning practice. Further the need for a transition protocol to embed the principles of personalised planning as part of the personalisation agenda was highlighted. Finally, there was a practical suggestion that the management of transition in hospitals, primary care and community care should be factored into the overall rating which
is calculated as part of CQC inspection models, in order to incentivise improved performance.

1.2 Clinic structure

The ‘age conundrum’ was identified as a barrier to successful transition.\textsuperscript{225} This means that at age 18 a young person is treated in adult services but for children and young people with complex health needs, including learning difficulties and mental health difficulties, this is not necessarily the most developmentally appropriate age to transfer to adult health care providers. Further, age boundaries were perceived to be set arbitrarily and as such considerable variety and inconsistencies existed between different services. There was a variety of suggestions about how this ‘age boundary’ challenge might be addressed. Some suggested a distinct young person’s service, e.g. spanning age 14-25; whilst others suggested a flexible approach to managing transition within the existing structures.\textsuperscript{13} Development of young person focused services in the community were also suggested to provide additional support for children from 11-25.\textsuperscript{228}

1.3 Funding

With respect to transition funding, resources were noted to be lacking, funding arrangements complex. There was at least one suggestion that early investment now would release resources in future.

Funding for transition was noted to be complex, fragmented and often not clear. In order to improve this it was suggested that funding responsibilities for equipment and short-term breaks should be agreed earlier between commissioners and providers in order to avoid delays during transition.\textsuperscript{13}

Current funding for adolescent health and social care was deemed insufficient, particularly with respect to developmental disorders and mental health, where workloads were perceived to be rising amidst inadequate staffing and resources.\textsuperscript{225}

Upstream investment, in terms of commissioning of evidence based preventative measures, and early stage intervention in children and young people services were advocated. This shift
in investment was cited as having the potential to enable the child or young person to receive appropriate services more swiftly and for a shorter time and as a means to future savings.\textsuperscript{225}

There may be few services suitable for young adults (e.g. a lack of age appropriate short break facilities, few chances of meaningful employment, few residential places that can take young people with very complex health needs and few health specialists with a holistic approach to a young person’s care.\textsuperscript{227}

Requires joint planning and funding by child and adult commissioners “work in collaboration to build local capacity to meet the distinct needs of this age group”

1.4 Co-ordination

Appleton (pages 11, 18-23)\textsuperscript{225} argues that effective commissioning practice: depends on important relationships between key groups. “Engagement between commissioners and local clinicians, as well as with young people and their families will be increasingly important in the new commissioning environment. Building relationships has been highlighted in a number of reports as a critical factor in successful transition planning. Commissioner’s interest and support for CAMHS and AMHS working together and in partnership with other services are essential”. “Commissioners can help services to join up by facilitating a local Transitions Forum, including representatives from CAMHS, AMHS, the voluntary sector and service user groups to review and monitor transition protocols, and provide an arena for debate and service development”.

“Current commissioning models often place CAMHS commissioning and AMHS within different frameworks, structures and organisations. Not facilitated joint working across the two sectors and has not enabled a sharing of ideas and solutions. As a result, separate service development has taken place that has not properly addressed the issues relating to transition” (Appleton\textsuperscript{225} Pages 10 & 11. “Commissioners should ensure that joint agency planning and commissioning takes place to enable the development of person centred, co-ordinated and integrated packages of care and support for children and young people, to enable smooth transition to adult services and avoid crises”.\textsuperscript{229}

2 Organisation and delivery of care
2.1 Transition plan (TP)

Transition planning, stated and updated in a document shared with the young person, was recommended by the Department of Health and the Care Quality Commission, Department of Health, the Care Qual, to start early and continue if necessary into adult care. It will be tailored to the needs of young person and family and be age and developmentally appropriate. It was advised that TP should also include education, social services and voluntary agencies as active partners.13, 227, 229

Transition planning is not happening everywhere and opportunities are being missed to focus on employment and housing options at an early stage, for example by embedding career planning in person-centred transition pathways.226

There is debate about whether a health passport is implied in a TP or whether it should be a separate document.13, 230

2.2 PRIMARY CARE involvement

PRIMARY CAREs more involved at an earlier stage.13

Future Service planning challenges: “the adult sector and adult physicians may have little experience in ‘paediatric’ diseases in adult life.

2.3 Key worker

A key worker is a person who assists an individual to negotiate transition.

A number of papers recommend that patients should have a key worker.13, 229, 230

Co-ordination of transitional healthcare is critical and, if this does not already exist, a key worker is ideally placed to oversee a young person’s transition, ensuring links with a counterpart within the receiving adult service”.227

2.4 Transition manager for clinical team

A coordinator is a person working in a service that involves Transition, who works at a managerial level to ensure effective processes such as reminding young people by text of forthcoming clinics, ensuring transition plans are drawn up etc.

Named leader to coordinate, best practice must be followed.13, 229

2.5 Holistic care
Key characteristics of an effective holistic transition process include: young person centred, wide age range, informal, flexible, voluntary, confidential, free, independent, early intervention, continuity; support of multiple needs (emotional, mental, personal, physical, social welfare, practical, safeguarding etc.), with complementary interventions delivered under one roof.

Transition is likely to include arrangements for: Independent living, employment, health and social inclusion.229

Issues considered: supported employment, housing, leisure activities. Page 7 lists of range of services commissioners might consider.230

“A comprehensive local CPC service spans health, social care and education. It is a whole-family approach and has the following characteristics: It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children’s to adult’s services. It ensures review of the care plan at key points in transition”.231

2.6 Effective coordination

The Department of Health is recommended that there be a transition lead in every region to support the delivery of a regional multi-agency transition strategy, supported by an implementation group involving all key stakeholders, in particular young people and their families.232

CCGs and Local Authorities must listen and learn from young people and their families’ experiences.13

One of the five ambitions of the NHS pledge - NHS Mandate for 2014/15 is that “services will be integrated and care will be coordinated around the individual, with an optimal experience of transition to adult services for those young people who require ongoing health and care in adult life.”228
STAGE 2: Interviews with key informants

Design

Semi-structured in-depth interviews with key stakeholders directly involved in commissioning at two sites in the North East of England. The interviews focused on informants’ views about what successful commissioning for transition should look like; how commissioning for transition is currently undertaken; and what the barriers and enabling factors to successful commissioning for transition are. NHS Research Ethics (REC) guidance deems interviews with NHS staff to be ‘service evaluation’ and therefore this part of the research did not require approval from NHS REC. The researcher, SM, obtained a research passport from a local NHS Research and Development Office, and a letter of access from each NHS Trust prior to conducting interviews. We obtained ethics approval from Newcastle University Faculty of Medical Sciences Ethics Committee (ref: 00767/2014).

Sampling and recruitment

Interviewees were selected using a mixture of purposive and snowball sampling methods. The study steering group members were asked to nominate potential interviewees according to role/involvement in commissioning for transition, including representation from CCG, Health and Wellbeing boards and Local Authorities which commission services from the lead NHS Trust, as well as with local general practitioners and the third sector. The nominated interviewees were considered for participation based on their job title. Interviewees who agreed to participate were then also invited to nominate further participants. We anticipated that around 25 completed interviews would be required to reach theoretical saturation and coverage of a range of views and perspectives at various organisational levels, but we were prepared to conduct more or fewer interviews as necessary. During recruitment, 46 potential interviewees were emailed a letter inviting them to participate. If no response was received to the initial contact then a maximum of three follow up attempts were made by telephone. Where participants declined to participate and provided a reason for declining, the reason was recorded and they were asked to nominate another potential interviewee to participate in their place. Recruitment was continued until new data no longer added content - i.e. to the point of saturation.

Participants were asked to sign a consent form giving permission for the interview to be recorded and transcribed, and confirming that they had read the information sheet. Before
asking participants to give informed consent, they were provided with the opportunity to ask
questions about the study, or seek clarification on any issue arising from the information
sheet.

**Data collection**

The interview schedule was developed using a modified critical incidence technique, and was
informed by grey literature and conversations with the research team and the WP3.2 Steering
Group. The schedule was designed to encourage the participants to reflect on successful and
unsuccessful practices for commissioning for transition, and to cover topics such as: i) interviewees’ perceptions of the organisational structures, processes, relationships, barriers
and facilitators related to commissioning for transition throughout the whole commissioning
cycle, and ii) interviewees perceptions about the relative influence of policy drivers, past
relationships with providers, and external influences on commissioning for transition. The
wider research team and Steering Group commented on the schedule. The schedule was
further refined in the course of conducting the interviews, based on preliminary analyses.

The interviews were conducted by the second author in a setting chosen by the interviewee,
either face-to-face or by telephone. They lasted from an hour to an hour and a half, were
audio-recorded verbatim and later transcribed. Data were collected from 22nd April 2014 to
28th August 2014.

**Data analysis**

The transcripts were analysed using framework analysis. In framework analysis the
researchers’ initial assumptions are articulated as an initial conceptual framework – this
includes assumptions based on any literature read by the researchers and experiential
knowledge of the topic. This framework is then expanded and modified, in iterative cycles,
throughout the data analysis using the themes emerging from the study. This cyclical process
produces a cumulative, refined framework that integrates the initial conceptual framework
and the results emerging from the study data.

Researchers from different disciplinary backgrounds and with different expertise contributed
to the data analysis. This included the researchers directly involved in the data collection and
analysis: Maniatopoulos (GM)-sociology, organisation and management; Kolehmainen (NK)-
NHS clinical practice, childhood disability, and implementation science; McCafferty (SM)-
healthcare commissioning, health economics. It also included the wider research Colver-
Paediatrics; Le Couteur-Child Psychiatry; Vale-Health Economics; Reape-Health Services Management; and the WP 3.2 Steering Group. The deliberate involvement of the diverse expertise within this wider research team allowed a nuanced, multifaceted analysis and reconciliation of any tensions in the coding and concepts. The analysis consisted of the four steps which form the framework analysis method:

1 *Familiarisation:* two researchers (GM, NK) familiarised themselves with the data by reading through a sample of transcripts until they felt they had developed an initial sense of the data.

2 *Identifying the initial coding framework:* three researchers (GMs, NK, SM,) independently recorded their initial impressions and any deductive themes. Two researchers (GM, NK) then met to discuss these initial impressions; to relate them to their previous knowledge and expertise; and to agree the initial conceptual framework. This process was subsequently repeated for six rounds, with the two researchers reading further transcripts between each discussion round. The discussions consisted of the researchers talking through the emerging issues and themes and relationships between these, and agreeing themes, codes and relationships which were added to the framework. Through this, each round resulted in a refined version of the framework, integrating and dividing themes, and clarifying the concepts in the framework.

3 *Indexing:* Once the framework became stable (i.e. few modifications were required on each round), one researcher (GM) used it to ‘index’ the remaining transcripts one by one. This involved the researcher ‘sifting and sorting’ the remaining data and allocating these data into the coding framework. The researcher took notes of any changes to the framework and issues, and these were discussed with a second researcher (NK) to agree further elaborations to the framework. This process was repeated until all data were indexed and the final framework agreed. This final framework summarises the study findings as the “conceptual model to illustrate the process of commissioning for transition” (aim 3 for the overall the work package, see above).

4 *Charting:* Data from the transcripts were summarised according to the themes and codes (i.e. categories) to reduce the data while carefully retaining the original meanings of the interviewees’ words. References to illustrative quotations were tagged and managed using Microsoft Word and NVivo10.

**Quality assurance**
A range of recommended quality assurance techniques were employed to ensure credibility, transferability, dependability and confirmability.\textsuperscript{233}

\textit{Credibility}

- During the data collection, contact was established through demonstrated interest in the responses, attentive listening, understanding and respect for what the participant says.\textsuperscript{234}
- The sequencing and posing of questions was carefully considered, and was dynamic so that the questions promoted positive interaction between the participant and the interviewer and stimulated the participant to share their experiences and points of view. All interviews included an opportunity for participants to comment on any topic covered in the interview, or any new topic which they felt was relevant.\textsuperscript{218, 234-236}
- Triangulation: accounts between participants and across two regions were compared and contrasted by the two researchers described above (GM, NK).
- Member-checking: the themes and their content were shared and discussed with the WP3.2 Steering Group.
- Frequent de-briefing: study progress, methods, emerging themes and any issues were reported to and scrutinised by the research programme senior team at regular intervals.

\textit{Transferability}

- Reporting of the sampling frame and criteria (see above), and the key population characteristics (see Results).

\textit{Dependability and confirmability}

- Involvement of several researchers helped to ensure that the framework was adapted to reflect the data rather than making the data ‘fit’ the framework.
- Involvement of new researchers (GM, NK) in the data analysis encouraged further peer examination through critical discussion.
- Audit trail: researchers kept field notes (SM) and a logbook of data analysis (GM), and established an electronic data analysis and synthesis trail of the development of the themes (GM in Word, NK in NVivo).
Results

Overall 29 interviews were conducted (see Table 40). Participants covered a range of roles relevant to commissioning for transition across CCGs, Health and Wellbeing Boards and Local Authorities, local general practitioners, and the third sector.

Table 40: Summary description of the participants

<table>
<thead>
<tr>
<th>Region</th>
<th>Participant role in commissioning process</th>
<th>Employer</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East of England</td>
<td>Commissioners at different levels of seniority, and related managers (n=4)</td>
<td>Local Authority, Commissioning Support Unit, CCG</td>
</tr>
<tr>
<td></td>
<td>NHS Directors (n=1) and senior clinicians (n=2)</td>
<td>NHS</td>
</tr>
<tr>
<td></td>
<td>General practitioners (n=2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transition planning workforce (n=2)</td>
<td>Local Authority</td>
</tr>
<tr>
<td></td>
<td>Regional Coordinator</td>
<td>North East Autism Consortium</td>
</tr>
<tr>
<td>Bradford</td>
<td>Commissioners and related managers at different levels of seniority, and related managers (n=3)</td>
<td>CCG, Commissioning Support Unit</td>
</tr>
<tr>
<td></td>
<td>NHS clinician (n=2)</td>
<td>NHS</td>
</tr>
<tr>
<td></td>
<td>General practitioner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transition managers and co-ordinators (n=4)</td>
<td>Local Authority</td>
</tr>
<tr>
<td>Other regions</td>
<td>National clinical leader (n=2)</td>
<td>NHS England</td>
</tr>
<tr>
<td></td>
<td>NHS clinical leaders (n=3)</td>
<td>Birmingham Mental Health NHS Foundation Trust, Sheffield HSCT</td>
</tr>
<tr>
<td></td>
<td>Voluntary sector leaders (n=2)</td>
<td>The J’s Hospice, SNOOP</td>
</tr>
</tbody>
</table>

Definition of successful transition

No agreed definition of successful transition care was reported in the participants’ narratives. However, some key characteristics of successful transition care emerged. These included that transition care should: (i) be personalised, (ii) be planned, co-ordinated and collaborative, (iii) focus on broad developmental and life participation outcomes, (iv) build pathways from children services to adult services, rather than just relying on individual care packages, (v) ensure co-ordination and continuity of relationships and knowledge across sectors and life
domains rather than just a simple transfer of the young person from one service to another, (vi) use universal services such as PRIMARY CAREs where possible, with tailored enhanced support where required.

**Box 7.** Selected quotes about perceived characteristics of successful transition care

**Personalised, planned, co-ordinated, collaborative and with focus on broad outcomes:**

“(...) what all the legislation is telling us, and all the national direction is about, is about personalisation. (...) if we start doing, planning for outcomes. (...) [in current practice] we keep on just focusing on the here and now. What we should be doing is (...) predict what the needs will be in the future (...)” (Commissioner/related manager 1, North East of England)

“(...) a smooth journey and needs met. (...) the much wider picture. So your health needs will impact on your employment outcomes or your education (...) and what you do with your aspirations within your community (...) there’s an introduction to that new service, there’s someone to coordinate that arrangement (...)” (Member 1 of transition planning workforce, North East of England)

“(…) I think successful transition (...) has to be addressed and introduced as a concept at the age of 14+ school review (...) then the families, and the young people, and the professionals begin, hopefully, to develop some type of joint work between them. So successful transition has to start early. (...)”. (Voluntary sector leader, Third sector, Other regions)

**Builds pathways, ensures continuity, and uses universal services:**

“(…) if the systems were right, so if you had children’s services interfaced properly into adult services there was a clear pathway (...) children would just sort of flow through (...)” (Commissioner/related manager 1, North East of England)

“(…) a successful transition is where the person undergoing transition has the change of care seamlessly, without any interruption in their therapeutic relationship, in their treatment strategy, and in their engagement. (…) the aspects of continuity, information continuity, relational continuity, therapeutic continuity.” (NHS clinical leader 1, NHS, Other region)

“(…) this concept of universal (…) you might have somebody who’s complex and needs CAMHS and learning disability team or whatever, and has some physical needs as well. But still can access the already commissioned services. And if they interfaced well then the transition could be seamless and wouldn’t need active commissioning. (…)”

(Commissioner/related manager 1, North East of England)
From the analysis, a range of issues and themes related to commissioning successful transition care emerged. These clustered around four meta-themes:

1 The broad context of commissioning for transition: legislation, policy and wider life transitions

2 Commissioning for transition: structures, processes, pathways and relationships

3 Service-level co-ordination, sign-posting, and relational support

4 Outcomes and contract evaluation

These four meta-themes, with summaries of their key content, are presented below.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews. It is available on request from the authors of the report.
5 A conceptual model to illustrate the process of commissioning for transition

From the analysis, we identified key characteristics of successful commissioning, and developed the first iteration of a conceptualisation of the process of commissioning for transition, as per objective 3 above. This is depicted, visually, in Figure 20. The figure provides a summary output of the results in terms of stakeholders’ perceptions of the organisational structures, processes and relationships that drive commissioning for transition. It illustrates the interrelated nature of the themes that emerged, and reflects the complexity of the commissioning process as described by the participants.

Figure 20: A visual summary conceptualisation of the process of commissioning for transition as it emerged from the data analysis

Implications for the next stage of WP 3.2

In the light of the qualitative analysis of WP 3.2 the following criteria (Table 41) were applied for the next stage of this study to further explore enablers of successful commissioning practice for transition and identify lessons to inform guidance on commissioning for transition across the NHS (including CCG’s, Local Authorities and Health and Wellbeing Boards).

Table 41: Criteria for site selection

<table>
<thead>
<tr>
<th>Derived from the interviews.</th>
<th>Potential exemplar sites.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential site-level sampling criteria for commissioning with particular issues relevant to transition</td>
<td>We seek sites where the criteria are being actively addressed by Commissioners.</td>
</tr>
</tbody>
</table>

| 1 Commissioning for Quality and Innovation (CQUIN) framework is implemented towards successful transition. | Site identified |
| Source theme/subtheme: | |

| 2 Commissioning for transition co-ordinators within a framework of Developmentally Appropriate Healthcare, rather than for services. e.g. Diabetes. | Site to be identified |
| Source theme/subtheme: 3.1 and 3.2/2.1 | |

| 3 Joint commissioning |
| i Cross-sectoral joint commissioning - Links to Education, Health and Social Care plans EHSCP. |
| ii Within-health joint commissioning – including with involvement of PRIMARY CARE. | |
| Source theme/subtheme: 3.2 | Site identified |

| 4 Where Commissioners and Providers effectively commission together | Site identified |
| Source theme/subtheme: 2 | |

Further, outcome based commissioning was considered desirable (mentioned often in transcripts) but no-one was clear what the outcomes should be and if and where outcome commissioning is being practiced.
Stage 3  Conducting the case studies

Using the findings of the literature review and qualitative analysis of the interviews of Stage 1 and 2, the criteria in Table 41, sites were then identified for visits.

Research Strategy

A case study approach was followed to collect empirical data from three Clinical Commissioning Groups (CCGs) in England. Yin\textsuperscript{237} defines the scope of a case study as “an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident”\textsuperscript{237}. Case studies, by their nature, are sensitive to complexity and can be used to provide in-depth insight into complex social phenomena. As a research strategy, case studies are well suited to addressing explanatory ‘how’ and ‘why’ questions.\textsuperscript{237} Robson\textsuperscript{238} suggests that the case study is an appropriate method towards the “development of detailed, intensive knowledge about a ‘case’, or a small number of related ‘cases’”. In this context, one of the most important uses of the case study is “to explain the causal links in real-life interventions that are too complex for survey or experimental strategies to elicit”.\textsuperscript{237} A case study can be single or multiple. For this study, a number of cases were studied jointly in order to explore local initiatives that address commissioning for transition.

Sampling and recruitment

Participants within selected Case Study sites, were selected using a mixture of purposive and snowball sampling methods. The WP steering group members were also asked to suggest potential sites where one of the criteria (see Table 41) was met.

Within the identified sites, participants were considered for participation based on their involvement in local initiatives that specifically addressed commissioning for transition. During recruitment, potential participants (commissioners and service providers) were invited to participate by a letter sent by e-mail. If no response was received then a maximum of three follow up attempts were made by email or telephone.

Participants were asked to sign a consent form giving permission for the interview to be digitally recorded and transcribed, and confirming that they had read the information sheet. Before asking participants to give informed consent, they were provided with the opportunity to ask questions about the study, or seek clarification on any issue arising from the information sheet.
Data collection

Data collection took place from December 2015 to March 2016 in three areas covered by three Clinical Commissioning Groups (CCGs) in the North West, South East and West Midlands. Across the three sites, a total of 11 semi-structured in-depth interviews were conducted. The interviews aimed to provide a mapping of local initiatives to address commissioning for transition. The breakdown of interviews by site and role is summarised in Table 42. Interviews typically took around one hour and were conducted face to face usually at the workplace of the interviewee.

Table 42: List of participants

<table>
<thead>
<tr>
<th>Site</th>
<th>Participants/Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>NW</td>
<td>General Manager, Child Health, Hospital Trust</td>
<td>NHS provider</td>
</tr>
<tr>
<td>NW</td>
<td>Senior Commissioning Manager for Children and Families at CCG</td>
<td>CCG</td>
</tr>
<tr>
<td>NW</td>
<td>Quality and Safety Lead, Partnership</td>
<td>CCG/LA</td>
</tr>
<tr>
<td>MID</td>
<td>Accountable Officer for the CCG</td>
<td>CCG</td>
</tr>
<tr>
<td>MID</td>
<td>Associate Director of Commissioning for Maternity and Children’s Services</td>
<td>CCG</td>
</tr>
<tr>
<td>MID</td>
<td>Project Manager for age 0 to 25 service, CCG</td>
<td>CCG</td>
</tr>
<tr>
<td>SW</td>
<td>Paediatric Liaison and Transition Nurse, Hospital Trust</td>
<td>NHS provider</td>
</tr>
<tr>
<td>SW</td>
<td>Assistant Director of Nursing for Specialist Services, Lead Children’s Nurse, Hospital Trust</td>
<td>NHS provider</td>
</tr>
<tr>
<td>SW</td>
<td>Consultant Paediatrician, Hospital Trust</td>
<td>NHS provider</td>
</tr>
<tr>
<td>SW</td>
<td>Service Design and Delivery Manager, Commissioning Department of the CCG</td>
<td>CCG</td>
</tr>
<tr>
<td>SW</td>
<td>Quality improvement lead in the Maternity and Children’s Strategic Clinical Networks</td>
<td>Strategic Clinical Network</td>
</tr>
</tbody>
</table>

The interviews focused on participants’ experiences of local initiatives to address commissioning for transition, in terms of processes relationships, barriers and facilitators, and
lessons learnt. We acknowledge that a potential limitation of our study is lack of participants from adult services and lack of voice of any service users.

Data analysis

Interviews were transcribed and analysed inductively, without the aid of a software programme. This process was structured using thematic analysis. Core categories and themes were identified for each participant and then compared within each case. One member of the research team (GM) undertook the analysis of interview data and emerging categories. The themes were then reviewed and discussed within the wider project team meetings. In this report, all participants have been anonymised.

Case Study A. North West: Financial Incentive - Commissioning for Quality and Innovation (CQUIN)

Background

The following case study explores the development and implementation of Commissioning for Quality and Innovation (CQUIN) payment framework to improve transition. In 2009 the CQUIN payment framework was introduced to make a proportion of healthcare providers’ income conditional on demonstrating improvements in quality and innovation in specified areas of patient care. This means that a proportion of income depends on achieving quality improvement and innovation goals, agreed between the Trust and the commissioners. The key aim of the CQUIN framework is to secure improvements in the quality of services and better outcomes for patients.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study A

In the North West the CQUIN was considered as a necessary first step to quality improvement as it helped to develop a culture, at least within Children’s Services, of shared purpose and values around transition. In this context, it was perceived as a useful scheme aiming to standardise the Transition process for young people with long term conditions.
through the introduction and use of the ‘Ready, Steady, Go’ forms, a recently developed programme supported by NHS England. Overall, participants reported that the implementation of the CQUIN contributed towards raising the profile and visibility of the transition process. Moreover, it also helped to raise awareness among clinicians of the move to improve transitions and it also contributed towards improved conversations between specific child and adult services.

However, a number of barriers were also reported such as a lack of general adult services’ engagement in spite of some successes. In some cases, this was compounded with a lack of specific Adult Services for children to be transferred to and the need for some young people to be transferred to other Trusts which participants reported it is more difficult to plan for. Moreover, it was reported that CQUINs focus on numerical indicators and its conceptualisation in terms of finance and targets rather than quality and innovation may actually negate quality improvement. Finally, concerns were raised about the appropriate use of the ‘Ready, Steady, Go’ programme especially as transition plans extend throughout the life course of transition beyond the timeframe of the one year CQUIN initiative.

Case Study B. South West: Commissioners and Providers working effectively together

Background

The following case study explores the facilitating role of the regional Strategic Clinical Network (SCN) in the South West towards the development and implementation of a regional CQUIN across 14 Trusts related to transitional healthcare (2014-2015). The South West case study provides a novel instance where commissioners and providers worked effectively together through the regional Strategic Clinical Network (SCN). Strategic Clinical Networks, work in partnership with commissioners (including local government/social care), to support their decision making and strategic planning. SCNs facilitate work across the various stakeholder boundaries such as commissioner, provider and voluntary organisations in order to promote improved care for patients, carers and the public. The following case study further explores the development and implementation of CQUIN in one of the provider Trusts.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations
from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

Conclusion Case Study B.

In the South West the Strategic Clinical Network (SCN) did play a central role in facilitating the development and the implementation of the regional CQUIN. The facilitative way of working across the 14 Trusts provided strategic leadership and was an important driver for reconfiguring the commissioner and provider relationships. All participants reported the network played an important role in both raising commissioners’ and providers awareness around transition and providing a space for the Trusts to share ideas, knowledge and experience in relation to best practice in transition (shared learning about good practice in terms of transitional healthcare). At a Trust level, the CQUIN contributed towards the development of a Trust wide Transition steering group which was responsible for developing the transition service, ensuring that the transition policy had been followed accurately, and that it was revised as practice evolved. It also provided the opportunity for the appointment of a Transition worker responsible for collaborating with professionals from their own and from other services and developing good working relationships to ensure co-ordination of care for the young person.

However, a number of barriers were also reported such as a lack of general adult services’ engagement in Transition steering group meetings and a lack of clarity about adult care commissioners’ roles and responsibilities. Evaluating commissioning outcomes for transition through feedback from service users was another challenge for the Trust. Patients’ participation and feedback was limited and fragmented across different services. Finally, echoing the findings of the North West case study, conceptualising CQUIN in terms of finance and targets did not necessarily translate into meaningful conversations about quality and innovation.

Case Study C. West Midlands: Joint commissioning (within health and between agencies)

Background
In the West Midlands a partnership was developed between two CCGs and a Local Authority to support the development and procurement of a fully integrated mental health service for 0-
25 year olds. This resulted in a change from the previous system through the provision of a seamless service that would include services for the full range of mental health conditions across the age range. Following a tendering process, a partnership led by a Children’s Hospital, as the preferred bidder, won a £124m five year contract to deliver mental health services for children, young people and young adults.

We have removed material here. We consider it is too long for this appendix. It consists of commentary on a large number of quotations from the audiotaped interviews from the three site visits. It is available on request from the authors of the report.

**Conclusion Case Study C.**

In the West Midlands the overall aim of the partnership was to support the development and implementation of a fully integrated mental health service for 0-25 year olds. The new service addressed problems identified by the commissioners namely disjointed provision of mental health services for individuals up to age 25 years between the different provider organisations. Overall, participants reported that key feature in the development of the new service was the enthusiasm and commitment of commissioners to improve transitional healthcare for young people with mental health problems. Further, participants emphasised the importance of health, social and third sector involvement and co-production with service users of the new service specification. As well as the enthusiasm of stakeholders at a local level, an important feature of the development of the new service was support by a National Children’ lead and the regional Collaboration for Leadership in Applied Health and Social Care (CLAHRC). Finally, another key feature was a focus on outcomes through feedback from service users.

However, a number of barriers were also reported such as uncertainty around post-25 years transition and related challenges with adult service engagement. Moreover it was reported that negotiating the decommissioning process with the outgoing provider was a very challenging process. Participants thought also that there was some reluctance to adopt the new service by some stakeholders. Finally, inadequate information sharing procedures were evident following the configuration of the new mental health service.
Interview schedule WP 3.2

Introduction

Summarise ethics considerations – and assure anonymity
Have participant complete consent form.

The purpose of this interview is to gain an in-depth understanding of the commissioning processes which underpin transition of patients from children and young people’s services into adult services. Specifically, we are interested in the transition of CYP with complex health needs.

Whilst we are aware that this transition or transfer is often creates challenges or is considered problematic for patients and practitioners alike, what is less clear is

   a) What the commissioning processes for transition currently are
   b) How the commissioning processes influence or affect transition outcomes

We are keen to gain your specific perspective as provider/ commissioner and to learn about how you have interacted with other providers/ commissioners around the area of transition.

We are also seeking to map commissioning processes and would welcome detail about key relationships, stakeholders and gatekeepers in the commissioning arena.

Interview Topic Guide

Background/ Context

1. Can you tell me what you understand about the term ‘transfer’ or transition’ in health care?
   a. How would you define a “successful transition”?

2. Can you tell me about your role and:
   a. How you are or have been involved in transition?
   b. How you are or have been involved in commissioning?

Probes: key relationships; inter/intra organisational networks; resource allocation; contracting/spending review

Successful Commissioning Outcomes

3. Can you describe an example of when transition (or commissioning) has been undertaken successfully? (Outcomes)

Probes: e.g. new relationships established, the result of the transition, positive patient feedback, quality standards (which ones?) Etc.
**Successful Commissioning activities/ actions/ and processes**

4. With respect to the example shared can you describe the activities/ actions/ or process that were undertaken to achieve this outcome?
Probes: what activities and actions were undertaken, including key elements of the commissioning process, key stakeholders and gatekeepers, barriers/ facilitators/ Relationships/ networks/ provision/ politics.

[NB. Labels of ‘successful/unsuccessful’ are used to encourage discussion on a range of aspects related to the quality of commissioning rather than to emphasise effectiveness]

**Unsuccessful Commissioning Outcomes**

5. Can you describe an example of when transition (or commissioning) has been undertaken unsuccessfully? (Outcomes)
Probes: e.g., the result of the transition, difficulties identifying/ engaging a provider?
Negative patient feedback, failure to meet quality standards (which ones?) Etc.

**Unsuccessful Commissioning activities/ actions/ and processes**

6. With respect to the example shared can you describe the activities/ actions/ or process that were undertaken which resulted in this outcome?
Probes: what activities and actions were undertaken (or neglected), including key elements of the commissioning process, key stakeholders and gatekeepers, barriers/ facilitators/ Relationships/ networks/ provision/ politics.

[NB. Labels of ‘successful/unsuccessful’ are used to encourage discussion on a range of aspects related to the quality of commissioning rather than to emphasise effectiveness]

**Any other points**

7. Are there any other issue which you consider to be relevant that you would like to discuss?
Close and thanks.
Appendix 11: Patient and public involvement

In this appendix we present the draft of a paper submitted for publication.

Then we present an example of a newsletter for participants and an example of a facilitator guide developed with the Council for Disabled Children for dissemination of our results to young people.

The burden of proof: The process of involving young people in research

Gail Doye-Pearce, Sophie Walker, Sophie Fairgrieve, Monica Parker, Tim Rapley

ABSTRACT

Background
Patient and public involvement in research includes activities from assigned and consultative tasks, to partnership working, to service-user led initiatives. It is considered as the ‘right’ thing to do and is required by funding bodies.

A debate is currently focused on a perceived lack of empirical ‘proof’ to demonstrate the impact of involvement upon the quality of research. It is also argued that the working relationships between researchers and those becoming involved need to be understood more fully.

These areas are beginning to be reported upon but there are few studies of young people involved in health research.

Aim and design
To add to the largely adult focused literature we explored reflections of stakeholders in a longitudinal, large-scale health research programme in the UK that brought young people together to work with academic researchers. Using qualitative interview and focus group methods, we aimed to define and understand factors that influenced involvement, and examine perceptions about key processes and outcomes.

Results
We suggest that stakeholder values, attitudes and practice steadily shifted through the course of the project, as working relationships between the researchers and young people developed. This appeared to rely upon the acknowledgement of intellectual and also emotional
responses, with negotiation, mediation, having a vision of ‘the art of the possible’, and centrally, the opportunity for face-to-face working, as key factors.

**Conclusions**

We agree that an improved understanding of how complex social processes enable involvement work, and not just what involvement achieves, is now needed.
INTRODUCTION

The term Patient and Public Involvement in health and social care research is an umbrella term, referring to the many potential roles for service users and members of the public in defining, delivering & disseminating research. Preceded by drivers to involve people more actively in their own healthcare, in 1996 a standing advisory group, ‘Consumers in NHS Research’, was set up in the United Kingdom by the Department of Health. In 2001 the remit was widened to include social care research. Renamed INVOLVE in 2004, it continues to actively promote and support public engagement and involvement across these domains. It offers comprehensive and practical guidance for involving all groups in research. Guidance specific to involving young people in a wide range of involvement endeavours, is also available.

Involvement includes activities on a continuum of working together, from assigned and more consultative tasks, through to partnership working with more collaborative decision-making, to service-user led initiatives. Hart outlines such approaches in relation to the meaningful involvement of children and young people. Examples exist of groups of young people being involved in tasks such as undertaking systematic reviews, expressing service views and preferences, and engaging with commissioning decisions. Whatever form the work takes, involving people who have lived experience is now perceived as the ‘right’ thing to do on moral, democratic and epistemological grounds. Systematic reviews suggest that involving people with experience of the issues being considered can influence all stages of the research and in broad terms, improves the ‘real life’ relevance of the work.

However, the PIRICOM review noted that:

The poor reporting of [involvement] impact and the limited consideration of how context and process factors affect impact makes meaningful comparison across studies difficult, and so prohibits firmer conclusions about their influence.

Further investigation to improve understanding and application is needed.

The debate is currently focused on a perceived lack of empirical data to demonstrate the impact of involvement upon research outputs. There is also a drive to model defined activities that constitute good practice. Involvement is a complex social process involving multiple actions and interactions occurring through the course of a study. This relies on the acknowledgement of intellectual and practical issues but also emotional and social
processes. What is clear is that involvement should not be viewed ‘as a mechanistic or procedural activity, rather a dynamic partnership and collaboration’. We now need an increased focus on how involvement works, as well as exploring what it achieves. Within the field, we are still attempting to define core concepts and to find the language to discuss the contribution that involvement makes to the quality of a study and what is meant by research quality.

When an established system, such as academia, meets new ways of working, as with involvement, ‘breaches’ in social norms and expectations arise, as different ideas are considered; novel approaches to task assignment are explored and; agreements about necessary skill sets and quality of outputs are negotiated. Power and decision-making are factors that have to be acknowledged and negotiated and as Cook notes:

In research, having multiple viewpoints, where each new view and theory is a springboard for further reflection, is an important way of finding new ways of seeing.

The emerging view, based on studies of adults working with academics, is that to achieve this, the working relationships developed between the academic researchers and their non-academic (adult) research partners are key.

Aim

To build on the largely adult focussed work in this area, this study explores the involvement processes that brought young people to work with academic researchers.

METHODS

The ‘(anonymised)’ study was a five year longitudinal health research programme, supported by the National Institute of Health Research, examining how health services in the UK can support young people with complex health needs in their move from childhood to adulthood. It comprised of nine work packages, with one focusing on facilitating young people’s involvement in the programme. The young people’s group formed in 2013, in the first months of the programme, and met once a month to carry out their work. They called their group (anonymised).

The (anonymised) group members, at the start of the programme, were all aged between 15 and 20. They all had experience of accessing a range of healthcare services and recruitment
occurred in a range of ways: via young people’s specific health services; local schools; local young people’s health action groups. With membership growing steadily in the early months, the group consisted of over 20 members, with active participation fluctuating over time, in line with exams, family events and other commitments. Most meetings had around eight members present. The group’s work into the ‘(anonymised)’ programme was facilitated by four (adult) Involvement Facilitators, one of whom had additional responsibilities as the Involvement Lead, and four Peer Support Workers (i.e. young people with prior experience of participation in health service user forums). The group’s role was to represent young people, with the aim of working in partnership with the adult researchers to oversee the governance and delivery of the (anonymised) programme.

Qualitative interviews with the senior academic researchers and Involvement Facilitators from the (anonymised) programme were carried out (n=10). Four iterative focus groups with (anonymised – young people’s group) members took place. Six (anonymised - young people’s group) members opted in and were available to take part. One person (the Involvement Lead) carried out the interviews. The young people acting as Peer Support Workers for their (anonymised- young people’s group) colleagues, carried out the focus groups, with guidance from the Involvement Lead. Knowing the (anonymised- young people’s group) members and their needs well (e.g. socially, emotionally, and in terms of communication and developmental needs), the Peer Support Workers developed creative and accessible focus group methods to elicit the views of all of their (anonymised- young people’s group) colleagues taking part in this study (see Box 8). Initial prompt questions for the interviews and focus groups were based on existing literature and developed through reflective discussions.
Box 8: Methods for focus groups with (anonymised) members

**Group 1 Design of the research: How did this influence involvement?**
- Super-sized board game set up on walls around the room.
- ‘Players’ divided into small groups to design a “man” as a counter.
- Rolling giant dice, player answered the question landed upon and then everyone else contributed comments.

Fun and interactive session covering many questions ‘quick-fire’ but with time for additional discussion.

**Example questions:**
- What was it about the (anon) study that interested you?
- How do you think your work in (anon–YP Group) makes a difference to the research?
- What are the main things that (anon–YP Group) has completed for the research so far?

**Group 2 Practical issues: How did these influence involvement?**
- Tabletop, paper-throwing game.
- ‘Players’ wrote out and scrunched up prompt questions provided and put them into a large bowl.
- Took turns to pick out a question and unfold it.
- After giving answer they scrunched it up again, with it thrown from person-to-person, for all players to answer.
- Boiled sweet taken for every question answered

Throwing phase was timed with an egg timer, to allow the interactive element, whilst managing the length of the session.

**Example questions:**
- Why did you develop group rules when (anon–YP Group) first started?
- How has it felt to have continuity of (anon–YP Group) members?
- When new members have joined (anon–YP Group), what has the group had to do?

**Group 3 Involvement approaches**
- Two life-sized body outlines drawn.
- Discussion prompted around the ‘voice’ that members have and the barriers/facilitators to them using their ‘voice’ or their ‘voice’ being heard.
- Prompted a for-and-against format, to ensure debate and discussion.
- Answers written onto the body outlines.

**Example questions:**
- Have (anon–YP Group) had some choice about what tasks they have taken on?
- Are your opinions listened to by the adult researchers?
- Thinking about the tasks you were doing two years ago, and the tasks you are doing now, have you needed different types of support at different times?
- Do you have an example when you have felt unsure about the decision taken by the group? – How did you make your views known and what happened in the end?

**Group 4 Values and attitudes**
- Focus Group facilitator came to the session dressed as an alien.
- Members described to the alien what (anon–YP Group) is, what it takes to be an (anon–YP Group) member.
- The alien asked questions about the differences between young researchers and adult researchers.
- (anon–YP Group) members divided into 2 teams and each drew an alien that would be the perfect young researcher.

**Example questions:**
- Who would you say is ‘in charge’ of the work that (anon–YP Group) is doing?
- What do you think about the work that the adult researchers are doing on the (anon–study)?
- What do the adult researchers think about young people’s views?
Interviews were recorded, anonymised and transcribed verbatim. Focus groups were transcribed in real time by two note-keepers working independently and the exercise outputs were captured in the written and drawn materials, with photographs being taken of larger pieces of data that were created.

The analysis was conducted according to the standard procedures of rigorous qualitative analysis. Techniques from first-generation grounded theory - coding and constant comparison were used, alongside deviant case analysis, mapping, analyst triangulation, and member checking.

Ethics approval was gained from The Proportionate Review Sub-committee of the NRES Committee Yorkshire and The Humber - Leeds East Research Ethics Committee (reference 15/YH/0098).

RESULTS

In this paper we show when academics and young people come together to forge new ways of working, how formative cycles occur, as values, attitudes and practices around involvement develop over the course of a study. These cycles have the potential to increase perceived value and decrease doubts, and take the work of involvement forward. However, there is also the potential for continuing doubt and the need for on-going work to support the process. As such, active management needs to happen, in order for the ‘work of involvement’ to progress. We consider the findings to have a broad scope, helpful for understanding all working partnerships with service users and not just those with young people in research.

Hopes and doubts

During the development phase of the research programme, the adult researchers held a set of values on the rights of young people to be involved in research and the importance of this not being tokenistic. They held general assumptions about what it might add to the research, in terms of bringing new knowledge and making the programme more accountable. As such, their hopes fitted with the broader moral, epistemological and democratic arguments for involvement. However these were often quite abstract ideals, as some people had little practical experience of involvement work with young people. Consequently, making sense of how best to involve young people was, at times, anxiety-provoking. For example, an adult researcher remembered a specific team meeting:
There were different views if I remember rightly… “would the young people be sufficiently equipped and have sufficient skills?” There was a thought that it might take the research down a different path that we didn’t particularly want. So from my memory, the discussions were quite pointed really, with a couple of people really selling the merits of involving young people and then I would say it was probably born from there and has grown ever since.(Adult Researcher [AR]4:- 27-35)

Questions and debate centred on if, when and in what ways young people could contribute within a more ‘scientific’ framework of a research programme. Following Garfinkel 30, bringing together the established demands of scientific academic work with the novel, emergent, uncertain practices of involvement, ‘breached’ the social norms and implicit background expectancies of people at the research meetings. The presence of people with prior involvement experience within the team helped mediate such uncertainty. They helped people to understand the different forms that involvement could take and to make ‘leaps of faith’, in order to make sense of the potential contributions of the young people. An early example of this emerged when (anonymised- young people’s group) members were asked to comment on and sign off the design of a certificate to be given to teenage participants. The Involvement Lead suggested that they be asked to create a new certificate themselves, as a tangible and manageable first task.

The young people were going to design a certificate and there was great anxiety about what that certificate was going to come back looking like and credit to everybody, they let the young people run with it and actually it was quite conservative (laughs) … you could see the learning coming from that … trusting the young people and their involvement. (AR3:-41-47)

Further on into the research, as tasks became more complex, the Involvement Facilitators found other ways to manage and harness the creative opportunities arising from the inevitable differences in priorities and expectations.

I think the way we managed to approach it was by inviting members of the management group to some of our early sessions to help them understand that it had to be very, very interactive, it had to be very task orientated and it wasn’t about standing in the front of a room and telling the young people what was happening… I think there were still tensions … and it was definitely a power imbalance - as a
management team we need to get this work done and it’s perhaps not getting done as quickly as we hoped. (AR8:-92-107)

The work of managing hopes and doubts was not just key in the initial phase but was returned to over time as the research progressed.

Values and attitudes appeared to shift steadily as the involvement work occurred. The ideas of those that initially championed involvement became part of the way the group began to think. As an adult researcher outlined, through “experiencing the difference and value of what young people bring in” a transformation occurred. They noted that:

[S]ome of the team members, in the anxieties they had about young people being involved, or being given responsibility, or whatever, well that’s in the past because the project team has grown with it, and has learnt from it (AR3:- 28-31)

However, this was not about a key moment of ‘conversion’ to new ways of working together. Rather, this was very much a process of growing and learning over time. An Involvement Facilitator described an element of the cyclical process:

Little cycles all the time where you think… “we’ve achieved collaboration”… back to… “we are being consulted again” (AR8:- 281-283)

As people came together they forged new ways of working and formative cycles occurred, as values, attitudes and practices around involvement developed over the course of the work.

Integrating effective involvement working into the research was not just about selecting the right methods but also about accommodating and managing hopes, expectations and anxieties, not least of the young people. Their hopes were focussed on the difference they might make in improving services for other users. They also placed an emphasis upon their own development, in terms of gaining skills. Similarly to the adult researchers, they recalled having doubts in the early stages but rather to do with the challenges of meeting new people and being in a group. For example, one young person noted how ‘I was doubtful I could last the two hours (of the first meeting) to be honest.’ (anonymised) member [anonymised][1]; Focus Group [FG]1:-24). Most of the young people had experience of accessing healthcare services for a range of physical, developmental and emotional conditions and most were not used to formal meetings and large group events.
The Involvement Facilitators hoped for adequate time to allow for a period of group formulation and up-skilling of the young people. Their own doubts and anxieties focussed on the interface between the adult researchers and the young people and managing their relationships with both groups when inevitable ‘breaches’ arose.

[We] were very, very clear what active involvement was and it wasn’t about changing the hearts and minds of the management team, because they truly believed they needed to actively involve the young people. They probably just hadn’t used such an embedded approach… in the past and I think it often challenged some of their beliefs and values around how much empowerment to give young people. (AR8:- 205-210)

These doubts and differences are understandable. Within the current landscape of involvement, the challenge is to accommodate doubts and differences and use them as reflective mechanisms for exploring new opportunities and ways of working, instead of moving towards a consensus or more reductionist methods.

Researchers see the end point, without thinking about all the ways to get there. Young people see all the possible ways forward, without necessarily keeping the end point in mind. You need both! (anonymised 2- FG4:- 48-50)

To facilitate such a coming together, those facilitating and leading on the involvement work required experience of involvement methods and needed to be able to effectively mediate between different stakeholders, accommodating the different ways of thinking but also the necessary emotional and social processes that played out.

**Negotiating the work**

Interactions and negotiations between and within groups were central. For example, early in the process the Involvement Facilitators described the importance of getting to know the young people and protecting time for the new group to form. The adult researchers were understandably keen for the young people to start taking on tasks as soon as possible. To accommodate these different needs, the Involvement Facilitators suggested that young people with prior experience of being in an NHS youth group be recruited, to provide some early input to research tasks and to act as Peer Support Workers for the newly recruited members of the (anonymised- young people’s) group. Initially, the Involvement Facilitators reported thinking that:
“Let us just let the group form; think what we want in the role of the peer support workers; the added benefits to the research—what identity did the group want?; how did they want to be represented?” So within 5 or 6 sessions, I think everybody had almost found their identity and role in that group. (AR8: 178-182)

During this early period, the Involvement Lead was prioritising initial research tasks with the adult researchers and ‘commissioning briefs’ were identified as a useful way for young people and adult researchers to communicate and begin working together. Acting as a mediator, the Involvement Lead began to challenge the appraisals and expectations that emerged at points within research management meetings, working to negotiate increased freedom and decision-making for the young people. They had to work to offer a ‘vision’ of the possibilities to both young people and adult researchers, whilst also managing both groups’ expectations. This process was ongoing and developmental, with one phase of work shaping the views and expectations for the next phase.

It is apparent that the work of involvement is more than a predefined, theoretical or logistical exercise, but one that requires a range of skills. The Involvement Facilitators reflected on this dynamic process, stating that they had to demonstrate resilience (e.g. to be able to constructively challenge and assimilate various views); sensitivity (e.g. to convey outcomes that did not meet with initial expectations); negotiation skills (e.g. to manage points of power, responsibility and decision-making); reflexivity (i.e. to move between representing the young people’s views and expressing their own opinions) and; pragmatism (e.g. balancing the desire for a priori conceptual alignment with getting on with the work of task delivery). They were also aware of the importance of their de-briefing and reflective discussions, to maintain flexibility and creativity and avoid being drawn towards more stable and comfortable ways forward.

It was very much about keeping a strong foundation about the core beliefs around involvement, but actually being pragmatic as to how we were going to deliver within the timescales the (adult researcher) management group needed. (AR8: 118-121)

The young people reported that they felt they were given a structure and an overall aim but with the freedom to work within that. They seemed to embrace this and experience less anxiety when considering all the possible ways of being involved, compared to the adult researchers. The ideas about the potential process had breached the adult researchers’ initial
expectations. They came already immersed within the structures of academia, whereas the young people were less embedded within any given system in relation to their new role.

I think researchers often struggle with stripping themselves bare because they’ve gone through a journey of fighting for funding, fighting for a role, fighting for evidence based literature, fighting for their place in research, proving something or adding value … and then involvement strips all that back again, because you have to leave yourself open and transparent. (AR8: 355-362)

The adult researchers reflected upon the impact upon themselves of witnessing and experiencing such a new way of doing things.

**Witnessing involvement work**

One of the first tasks of the young people was to contribute to the programme’s launch event. This was a visible role at a relatively early stage. They appeared to have made a lasting impression and, importantly, set a foundation for their further involvement. The adult researchers often referred back to this moment in interviews. For example, one person outlined how their expectations were breached.

> I thought “the [adult] researchers will say what we’re doing, and then somebody important will say something, and somebody else will say something, and then the young people will say something almost as an afterthought”. That’s just a reflection of my poor thinking at the time. Actually putting them [the young people] up first was just terrific, it just set the tone. (AR5: 157-163)

In this way, we see a shift from involvement work rendered as potential tokenistic practice, ‘an afterthought’, to being positioned as something that frames the direction, ‘the tone’, of that research event.

Beyond the launch event, contact between the adult researchers and young people was often mediated by a range of proxy actors. Throughout the first two years, for example, the Involvement Lead often took on a proxy role, presenting the work of the young people – in the language of grants and the broader researcher team, the young people’s ‘deliverables’ - to the adult researchers. The young people’s work, which included such things as consultation on specific conceptual issues around aspects of research questions, as well as more practical tasks, such as commenting on and designing recruitment materials, were outlined and discussed at the formal research management meetings. This was a space that attempted to
build an overview and coordinate the diverse elements of the whole research programme and was attended by the senior researchers. Although often subject to debate and questioning, echoing how reports from each area of the programme were discussed with inquisitive rigour, the young people’s work was well received. As a further example, a junior researcher also acted as a proxy, when they met with the young people in order to discuss a key data collection tool. Again, the young people’s input was seen as central to shaping the development of the tool, and this was reported back to the adult researchers.

It seems that such events where adult researchers witnessed, either first-hand or through proxies, the work of the young people, were critical steps in the reflexive development of the involvement work. The adult researchers described transformative moments in their thinking and the increasing value they placed on working with the young people, when the relatively invisible work of involvement became visible to them. For example, three young people acting as the Peer Support Workers were also proxies for (anonymised- young people’s group) members in the first months. An adult researcher noted:

[T]hat for me was the single thing that was most powerful, a couple of young people [Peer Support Workers] being able to articulate their own views and the views of others at a very practical level, talking about how the young people felt and what the young people said they would be able to do. (AR4:-49-53)

However, this transformation in perception and values seems to have occurred even more powerfully when they engaged with the (anonymised- young people’s group) members directly and not via proxies.

The adult researchers routinely remarked on how the young people delivered beyond their expectations. They outlined how they demonstrated ideals like ‘professionalism’ and ‘objectivity’.

I just didn’t really know to what extent we’d get real insights from the young people and so I think I’ve had my eyes opened wide about a lot of things. This last meeting we attended when they were presenting the results of their initial consultations about health passports … it was a really skilled piece of (I.T.) programming …it was just admirable to see what they’d produced. (AR5:- 175-185)
Having a proxy, some form of mediator, likely helps to manage anxieties and the complexity of the interactions required for active involvement. However, when the groups did meet in person, the ‘real life messiness’ of bringing different systems together was manageable.

We shouldn’t be having things done to young people …we do need to listen and hear and value their experience and that definitely needs to inform both what we ask -[the] questions - [and] how we interpret the findings. …We do have to impose structure and rigor and all those kind of things but unless we have this live experience and the interactions, I think it’s our loss. (AR9:- 619-624)

Directly engaging with the young people, appear to be times when the adult researchers became aware of the advantages that the young people were able to confer upon ‘their system’ and felt more confident in the processes through which this was being supported and actively managed.

The young people in our study highlighted the importance of face-to-face interactions too. When asked if they thought the adult researchers appreciated their input, one young person noted that ‘Yes, they make the effort whenever they see us to make us feel that way’. (anonymised 3:FG4 68-69). In looking to the final stages of the programme, the young people described wanting to negotiate further opportunities for witnessing and working together, suggesting that the cycles of involvement will continue through the course of the programme.

For example, a young person outlined that

We would like the managers to come and tell us about their work, or make a short video for us, like we did for them, to see at one of our meetings. (anonymised 4;FG4: 83-85)

This suggests that even once involvement processes are occurring and working well, it remains important to be aware of the continuing alignment of different stakeholder views.

Appraising the value

Having witnessed the impacts of young people’s input, the adult researchers appeared to place an increasing value on it; particularly on a sense of the ‘authentic voice’ that they considered it had conferred upon the research. They often highlighted that young people offered a ‘real life’ angle and in this way, a more interesting, multi-dimensional narrative had been achieved. For the adult researchers, ‘The whole is greater than the parts. By their angle coming in as well, it makes the whole thing much more interesting and relevant’. (AR1:- 469-
They also noted how, at times, the young people offered a particular clarity and directness of message.

The adult researchers became aware of the more evolving nature of the process that had taken the work forward. They reflected upon the importance of not taking a more mechanistic approach with over-defined, a priori goals.

There’s a lot more trust and faith in [the young people] than I think people would’ve imagined possible … and whatever our ambitions at the start, we succeeded. Whether or not it looks like what it was meant to look like (pause) but I think that’s fine with public engagement … I think we should have that more emergent agenda, rather than a “we will do this and then we will do this”. (AR6: 677-671)

In this way, their vision of how ‘good’ involvement could and should be organised was transformed away from a more consultative approach. They all felt that they would engage with the process again, with a renewed sense of the possibilities of involvement, albeit with increasing expectations. They also stressed that such work should be led by those with the appropriate skills and experiences in involvement work. The focus on the more emergent nature of the work was also echoed by the Involvement Facilitators.

There are lots of examples of good practice. To get it right every time is really, really challenging … [We] could spend the next 10 years coming up with a fantastic tool kit … but actually, depending on the nature of the research, the method of the research and the individuals, their role and development, there is not a one size fits all model. (AR8: 456-463)

The Involvement Facilitators stressed the more emergent nature of the methods and practices as well as the broader agenda itself.

Our findings informed the work within the programme moving into the final year. More opportunities for face-to-face working were sought and discussions about the potential for young people’s input, despite questions as to how this might be achieved, happened.

Now, they don’t necessarily have that skill to stand up in front of people and tell them the key results the research programme. Maybe they do maybe they don’t. But if they don’t, we have an obligation to, if they’re willing to do it, train them to do so. … Supporting them in writing pieces for publications, or being involved in media opportunities. Why shouldn’t they be the ones to actually to get the message across to
young people? But they can’t do that in isolation, they need some sort of support from us. (AR7:- 369-373)

It is clear that building upon the positive experiences across the whole research team, cycles of understanding, behaviour and value formation continued to occur through the course of the programme. Three of the young people did take key roles in the formal, national dissemination event at the close of the programme, including presenting the results of their own work streams and being on the interactive expert panel.

The central challenge in the field is to support all those involved in research, to understand and manage the cyclical work that seems necessary to enable non-academic researchers in a project to make their creative, rich and dynamic impact. We must understand and share this more fully, to ensure that involvement endeavours are useful, accountable and manageable for all stakeholders.

Discussion

Involvement is now embedded within healthcare research and the funding process, with the success of applications dependent upon adequate involvement strategies. As with other approaches in academia, it does have to stand up to scrutiny and a more nuanced, conceptual understanding is needed to support this work. The findings suggest that the specific research questions and the local factors are likely to be as important in defining the parameters and possibilities, as much as central evidence and models. We are negotiating a balance between: ‘ill-informed social experiments where any [involvement] practice is legitimate… [and] …the determinism of top-down control by experts’.263

Constructivist approaches to adult learning264 stress the importance of recurring experiential opportunities, as well as knowledge acquisition, in the on-going transformation of thinking and practice. Similarly, the learning of children and young people is reported as a social and cyclical process, based on cooperation and interdependence, with face-to-face working as a key mechanism.265 Within our own study, we have seen how direct social and verbal exchanges facilitated deeper levels of understanding and the mutual negotiation of meaning.

In order to navigate the, as yet, uncharted territory inherent in this steady alignment of different systems, researchers need to acknowledge the doubts and questions within their teams. Involvement tools for research teams are in development266, 267 that might aid such exploratory discussions about expectations, values and more practical issues. However, it is suggested that currently, no easy consensus will be reached:
Both literature and practice remain mired in a ‘conceptual muddle’…and the principles underlying the why, whom and how of (involvement) remain confusing and contradictory.

As we have shown, the processes of involvement will play out within each specific study, for further learning to occur and for teams to be able to report a more detailed exploration of the key issues.

In recent decades, qualitative practitioners have managed some of the challenges in making and reporting on their contribution to the academic agenda. The result has been a steadily increasing understanding and acceptance of issues such as the work of qualitative methods, the value it can confer, and the need for specialist knowledge and skills. We must, however, recognise a difference to other academic approaches that have navigated similar territory: Involvement relies on creating new interactions between people; people with varied norms and experiences. The power and dynamism of their input comes from actual participation rather than theoretical discussion and debate. Neither should engagement be simplified by mechanistic models and approaches, as this could hamper the development of stakeholder understanding, engagement and value formation. In a desire to build the best involvement partnerships that we can, we must be careful not to rush towards seemingly easy options or apparently straightforward solutions.

Within the involvement field, we have to understand how the parameters of different projects, the context of different organisations and the characteristics of different groups of stakeholders, influence the types of involvement experiences and interactions that we have reported here. In our study context, the burden of proof may have been heightened by the age of the young people; by perceptions about their lack of professional and work-based experience. This may have also added to the initial anxieties and the sense of ‘surprise’ that the adult researchers reported when they witnessed the young people’s work. Adult service users may have a range of different work-based experiences or experience of other structures that will shape their approach to their research role. Yet, questions would probably still arise about their research competencies or ‘credentials’. Emergent practices of involvement work breach (current) norms.
Conclusion

To strengthen the debate, we need to move beyond a focus on somehow proving the worth of involvement outputs, and consider involvement as a complex social process\textsuperscript{120, 253, 254} influenced by multiple local factors through the course of a study. We echo suggestions that the working relationships developed between academic researchers and their non-academic research partners, and the active reflection on these social processes, are key\textsuperscript{257-259, 268, 269} We need to better describe and explore the dynamic and socially embedded processes of involvement.
**Example: Newsletter for participants**

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**NICE Guidelines for Transition: Our thoughts**

The National Institute for Clinical Excellence (NICE) is a group established by the government. They look at the evidence for new treatments and advise on broader topics such as ‘lifestyle’ or in this case transition from children’s services. For a topic like transition, there is little good quality evidence – but the committee still makes recommendations which then must be taken account of by the NHS.

Below is a summary of the main recommendations of the guidance ([https://www.nice.org.uk/transition/](https://www.nice.org.uk/transition/)). We have highlighted those areas where the Transition Research Programme is hoping to provide evidence.

### Overview

- Connecting young people and their carers in service design, delivery and evaluation.
- Ensure transition support is developmentally appropriate and transition support focuses on the strengths of the individual
- Use person-centred approaches such as treating the young person as an equal partner in the process, agreeing goals, etc.

### Transition Planning

1. Start transition planning early (aged 13-14yrs), ensure the transition planning is developmentally appropriate and involves the young person.
2. Ensure there are resources available such as written information, communication materials, and materials for planning.
3. Help the young person identify a single practitioner (a key worker) to coordinate their transition care and support.
4. Be proactive – put young people in touch with peer support groups if they want such contacts.
5. Be proactive – ensure the young person regular contact with the young person’s parents/carers to understand their expectations.

### Support before and after transfer

- Before transfer: make sure that a practitioner from the adult service makes contact with the young person before they leave from children’s services. This could be by arranging an appointment or making contact.
- After transfer: if a young person has moved to adult services and does not attend meetings or consultations, services should try to contact the young person and their family.

### Supporting infrastructure

- Each health organisation, in both children’s and adult services, should nominate a senior executive to be accountable for developing transition strategies and policies, and a senior manager to be accountable for implementing transition strategies and policies. The senior executive should be responsible for championing the transition (at a strategic level).
- Joint planning services for all young people making a transition from children’s to adult services.
- Service managers should ensure there are...
Developmentally Appropriate Healthcare (DAH)

Workshop Facilitator Notes
A practical guide to facilitate focus group sessions.
Acknowledgements
With special thanks to the young people involved in the Transition Research Programme for their engagement and input into these guides.

Purpose
This toolkit is designed to share the learning from the Transition Research Programme with young people to help them understand the research and to see if their experience of transition is similar to what the research tells us.

Notes for facilitators
The activities below should be facilitated by skilled and knowledgeable staff who know the young people well, and are confident in supporting young people to discuss and process their experiences. Further guidance and information is available in Appendix 1.

For difference groups of young people, difference images and language may be more or less appropriate. The facilitators should select the most appropriate images/language for the young people who will be involved in the activities. The questions/statements can be rewarded if needed, as long as the core meaning remains intact.

About the TRP

Purpose: The Transition Research Programme is a 5-year programme of research examining how health services can contribute most effectively to the successful transition of young people with complex health needs from childhood to adulthood.

Aims: The overall aim of the Programme is to provide NHS commissioners and trusts with evidence about what might help young people with long-term health problems as they transfer from child to adult services. This will help them to allocate resources and structure services accordingly. Within this larger aim, the Programme has three objectives. These are to:

1) To work with young people with complex health needs to determine what successful transition means to them and what is important in their transitional care
2) To identify the features of transitional care that are effective and efficient
3) To determine how transitional care should be organised, provided and commissioned

Young people’s involvement: The Programme has a young person's working group called UP. As the TRP is about improving young people's experiences of transition we think it's vital that young people have a say in how our Programme is run. This is where UP come in! They offer us help and advice and also complete various tasks for the Programme. Their help has been invaluable to the Programme.

Northumbria Healthcare NHS Foundation Trust
Newcastle University
After the activities
We are keen to hear how many young people are engaged in activities relating to the research and whether their views agree with the findings. We would be grateful if you could keep track of the following from the session you facilitate and report it to us via the survey in Appendix 2:

- Number of young people who were involved in the session?
- Did all of the young people agree on which statements they felt were true or false? If not, in what ways did they disagree?
- Did the young people identify similar influencing factors from the Transition’s Got Talent activity?

The research
At the beginning of the study the researchers were aiming to determine the barriers and facilitators to the implementation of Developmentally Appropriate Healthcare (DAH) for young people.

What is Developmentally Assisted Healthcare (DAH)?
- Person-centred / individual
- Physical / mental / emotional capacities
- Need to understand more about this
  - When is it done well? / When is it done badly?
- DAH can help children and young people understand more about their health and how to manage conditions

With the initial scope of the research in mind, they began by talking to and interviewing managers and clinicians and other healthcare professionals in order to try and find out more about what DAH was and how it was being implemented. During the initial stages of this process they soon realised that the situation was not clear cut, there were differences in opinion about what DAH was, in many cases there was no set definition or recognition of DAH and it was not at the same stage in the process of implementation across all of the research sites.

Also, during the course of the research we realised that a factor implemented in a specific way in a specific context could be a barrier in one context but a facilitator in another. As a result of this we have shifted focus and in what follows we have arranged our findings around a list of the key factors that influence the implementation of DAH:

1. Everyone has a different idea about DAH
   There is a lack of a clearly defined and embedded concept. If there is no clearly defined concept and set of associated practices then this makes it difficult for
people to associate the work they do with DAH and understand it: ‘when you use that word I don’t know what it means’ (Interview).

There is a need to find a way for health professionals to agree on a unified idea about DAH.

2. **Find a way to make sure all health professionals use it properly.**
   A clearly defined policy or strategy enables people to develop familiarity with the idea and develop an understanding of the associated practices that staff are required to do to put it into effect. But for implementation to be successful people need to agree with it and put it into practice: ‘just because there is a policy does not mean to say that people are going to look at it or stick to it’ (Field note).

Find a way to make sure all health professionals use it properly

3. **Find the evidence to show it works.**
   The role of research can contribute to the base of knowledge that is needed to identify and provide DAH services for young people, as well as raise the profile of the issue. Notably, two of the participant organisations have a history of research on transitional care, which serves as an important foundation: ‘the research I was doing got a bit of momentum. It kind of just became more visible ... informing, certainly, the XXXX services within our trust (Interview).’

4. **Get spokespersons to talk about it.**
   Get Leaders / Key people / Champions / Health Professionals / Charities / Government / Children and Young People, etc. who are invested in pushing DAH forward are an important part of the implementation process. The emphasis here is on more than one person because: ‘it doesn’t work if you just have one enthusiast in one clinic. Of course it helps in that particular clinic, but it doesn’t take the Trust forward’ (Interview).

However, in terms of sustainability of these services, particularly in a Trust without a specific agenda to push DAH forward, champions may be vital for the continued existence of these services: ‘champions are a good thing to have because not everybody champions the adolescent cause’ (Interview).

This is also true for other Trust-wide initiatives in Trusts without a specific agenda to push DAH forward: ‘we do different stuff. But it’s, I suppose, it relies on me doing it. (…) if I dropped dead tomorrow, everyone would carry on doing what they’re doing without, you know…’ (Interview).
5. **Make it a priority - Children and young people matter!**

Small numbers of young people and competing demands. Young people are often perceived to be 'very rarely unwell', and there are larger populations that the hospital needs to provide for such as the elderly: 'I don't look after any children or young adults. The median age of my patients is about 70' (Email correspondence). As such, for some, innovations around young people's health are not always seen as a priority.

6. **Ask the children and young people to help design services.**

This can be through feedback, participation, planning, etc. Young person's involvement in creating change. Involving young people in the design of the service can serve to inform and legitimise the work that is being undertaken: 'developmentally appropriate young people’s healthcare isn’t just about the delivery of healthcare, it's about the involvement of young people in designing the delivery, in checking the delivery and in informing what you need to do when things aren’t right' (Interview).

7. **Better training for health professionals to work with children and young people.**

Training around Adolescent Healthcare or DAH. Training can help to raise awareness and understanding of DAH (and adolescent development) and lead to a better understanding of the requirements of DAH in practice. Although, not a substitute for practical experience, it serves as a good way of creating a network or body of people who are engaged in adolescence and DAH: 'a good group of people across the Trust that we can actually send these youngsters to who've got more awareness of the issues that they could have’ (Interview).

8. **Culture change – change the idea that health professionals ‘don’t have enough time’.**

Also, there are too many Doctors involved with one child or young person. Continuity and Change in the structure of the organisation, at the level of staffing: 'the turnover's too fast, of staff... We’ll never follow a young person through. ... Nurses have been swapped over to cover different areas. Somebody's just left, so the young person, young, uh, the nurse has left to move into her role, there's a new one moved in. She's been off sick. There's maternity leave. It's not about people. The consultant's changed. So, you, it's not about a key worker, it just doesn't work ... it's about consistency of approach, not a person’ (Interview). This can create practical issues, where continuity of care in terms of specific personal is a problem, whereas continuity in terms of procedures enables innovations and good practice to be sustained.
9. **Different approaches to DAH.**

Some people suggested that a particular approach for dealing with young people was needed: impacting upon communication skills (communicating with young people and their family, information giving, teaching self-management skills), consultation dynamics (giving young people time on their own, incorporating the family, managing times and spaces) and assessment criteria (covering psychosocial and vocational aspects as much as biological/physical aspects): ‘We need to be a bit less formal with them ... a bit more of an informal type approach, and bit more person-centred rather than a rigid clinic system where you’re in and out, see the doctor, and that’s it’ (Interview).

Others think that DAH does not impact on their clinical approach or, indeed, that DAH is not about the clinical approach but environmental issues: ‘So as I say you’re not mixing two year olds with 14 year olds, so I think it’s really the physical environment. I personally don’t think that your approach to the patient is any different (...) clinically, whether they are 2, 12, 22; it makes no difference, you treat -- you’re there to treat their medical condition. But I think the environment in which they receive that treatment is probably more important’ (Interview).

10. **Finding time.**

Time is an important (but perhaps disputed) factor in the provision of DAH. Paediatric patients often get considerably more time in their appointments than their adult counterparts (the exception may be the young adult clinics). Yet in some cases this seems to be less frequently acknowledged than some of the other factors: ‘X says that would be difficult for Adult clinicians due to the time that they get for their clinic appointments. Y and Z suggest that clinicians could make time if they wanted to, and that actually it is more about the anxieties that clinicians feel when talking to YP’ (Field note).

11. **Physical spaces – Children and young people have nowhere to meet.**

There is often no fixed space for adolescence, and any space that is allocated for adolescence is often subsumed within the spaces for children or adults. In such situations, clinicians need to work to find alternative solutions, drawing on a range of resources within their scope of influence. Children and young people have nowhere to meet.

12. **Teamwork.**

Teamwork is an important feature of being able to provide DAH. Part of this is consistency and joined up working both within and across specialties and organisations – however much of the evidence to emerge from our findings suggests that this does not always happen.
Health professionals should support each other to enable there is not a repeat of advice and services for the children and young person.

13. Cultural differences and distinction.
The difference between paediatrics and adults are a factor: ‘Paediatrics is quite different to adult medicine, most adult physicians have become, what I’d call, ologists in that they’ve specialised in a very specific area [...] Whereas paediatricians are general physicians and they look after everybody’ and ‘the adult teams don’t necessarily, their way of working doesn’t necessarily fit with how the children’s ward works. Um, the, um, communication between, you know, we all think we speak the same language but reality is we just don’t’ (Interview).

What this might mean for young people
DAH is about the experience a young person may have when attending a clinical or medical appointment. It attempts to identify a set of principles and a way of working that can improve a young person’s experience.

Young people may identify with any or all of the research statements. During the activities and the discussion, the young person may well begin to identify with different statements. This may reflect a change in knowledge or understanding of their experiences of transition. It is valuable for the facilitators and the young people to discuss and reflect on any changes. It is also helpful for young people to articulate if they do not identify with any of the statements.

Video Example Questions
- Are all children and young people are the same?
- Respect – do you feel children and young people are always respected?
  - What do you think this means?
- Does it help if health people try to ‘relate’
- How would health people gain your trust?
- Stereotypes – How can this hurt?
Activity 1: Factors that influence... True or False

Facilitator to use the key factors outlined from 1-14 and to ask young people to suggest if they agree or disagree that the factor would influence their experience of seeing a medical professional (GP, consultant, nurse).
(For smaller groups this can be done as one group with people raising their hands for each statement)

Activity 2: Transition’s got Talent

https://research.ncl.ac.uk/transition/youngpeoplepage/theyoungpeoplesworkinggroup-up/

Using the film clip, Transition’s Got Talent developed by UP young people’s group, facilitators should play each scenario in the clip giving the young people in the room an opportunity to be the ‘judging panel’.

After each short scenario, pause the film and ask the young people:

- Is this a good example of working with young people?
- How would this make you feel?
- Complete the sentence, ‘This situation would be better for young people if...’
- All children and young people are the same
- Respect – do you feel children and young people are always respected
  - What do you think this means?
- Does it help if health people try to ‘relate’
- How would health people gain your trust?
- Stereotypes – how can this hurt children and young people?

Record the sentences on flip chart to share back at the end of the session.

At the end of all of the scenarios read back the statements that the young people completed as part of this activity.

Facilitate a short discussion on:

- Are they similar to the influencing factors that the research suggests?
- Are there any differences?
- Which do they think are the most important?
Appendix 1: Guidance and Further Information

The activities in this toolkit should be facilitated by skilled and knowledgeable staff who know the young people well, and are confident in supporting young people to discuss and process their experiences. This includes providing emotional support to deal with difficult experiences or reactions. The young people should be comfortable in discussing their experiences and feelings in the setting.

Appendix 2: Please share young people’s feedback on the research and activities with us via our online survey:
https://www.surveymonkey.co.uk/r/TransitionResearchProgrammeDAH

- Number of young people who were involved in the session?
- Did all of the young people agree on which statements they felt were true or false? If not, in what ways did they disagree?
- Did the young people identify similar influencing factors from the Transition’s Got Talent activity?

Acknowledgements

This workshop/presentation summarises independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0610-10112). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The research team acknowledges the support of the National Institute for Health Research Clinical Research Network.

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Published June 2017