

**Development and Evaluation of a Digistory about Autistic Spectrum Disorder – a pilot study.**

Authors

Anthony Codd\*, Bryan Burford\*, Gabriella Petruso\*, Neil Davidson\* and Gillian Vance\*

Anthony Codd: Academic Foundation Programme trainee; anthony.codd@ncl.ac.uk

Bryan Burford: Lecturer; bryan.burford@ncl.ac.uk

Gabriella Petruso: medical student; gabpet39@gmail.com

Neil Davidson: clinical research associate; neil.davidson@ncl.ac.uk

Gillian Vance: Clinical Senior Lecturer; gillian.vance@ncl.ac.uk (corresponding author)

Affiliated institution\*

School of Medical Education, Newcastle University

Contact details\*

The Medical School

Newcastle Upon Tyne

NE1 7RU

Telephone: + 44 191 208 4525

Fax: +44 (0191) 208 5016

## **Abstract**

### ***Background***

Digital storytelling ('digistories') offer a novel method of sharing the personal impact of a condition, if students have limited direct patient contact. Autistic spectrum disorder (ASD) exemplifies a common condition, where there is need to improve practise in primary care. Hence, we chose this condition to develop and evaluate a digistory. We considered stigmatising attitudes to ASD and wider educational effects.

### ***Methods***

In the digistory a mother of a boy with severe ASD describes her autobiographical experiences, illustrated by customised cartoons. Participants completed, pre-post, a validated attitude questionnaire and word association exercise. Views on educational value were gathered through free text and focus group.

### ***Results***

Questionnaire scores indicated positive attitudes, with no significant change. In contrast, content analysis of word association responses showed prevalent negative associations. Thematic analysis identified increased empathy of students with the family, enabled by the resource design. The digistory helped students challenge stereotypes associated with the condition and encouraged greater confidence to engage in future clinical encounters.

### ***Conclusion***

The digistory is an accessible and authentic patient analogue that gives additional insight into living with autistic spectrum disorder, with potential benefits for patient-centred teaching and learning.

**Key words:** Digistory; undergraduate; medical education; autistic spectrum disorder; patient-centredness

## Background

Medical schools encourage patient-centred practice, but educators face challenges in ensuring students have opportunities to understand patients' lived experiences. For instance, patient attendances are unpredictable and time-limited, while those in societally marginalised or stigmatised groups may access healthcare reluctantly [1], posing practical and ethical challenges to their involvement [2]. On the other hand, patient volunteers provide consistent and standardised teaching, but multiple student contacts may become burdensome.

Autistic spectrum disorder (ASD) exemplifies a stigmatised condition where direct experiential learning can be more challenging. Though a common condition, health professionals often lack knowledge and understanding of patients' unique needs [3], with consequences for the uptake and quality of primary care services [4]. The Royal College of General Practitioners identified ASD as a clinical priority (2014-17) and has been developing training materials to improve general practitioners' consultations with patients with ASD, but these may not be suitable for the learning needs of medical students undertaking short-term community placements [5]. Novel methods of providing insight into patient experiences are therefore desirable.

Storytelling is an age-old way of sharing the personal impact of a condition [6, 7], and oral stories can be presented in audio-visual media (termed 'digital storytelling') to create more widely accessible and cost-effective resources. However, despite awareness of students being the 'Net Generation' [8], investigation into digistories' use in undergraduate medical education has been limited [9, 10, 11], and little is known about their impact on students' attitudes towards a stigmatised condition, or learner perspectives of the tool as an educational resource.

Hence, in this work we aimed to develop, pilot and evaluate a digistory for autistic spectrum disorder (ASD) in an undergraduate medical programme, with the intention of supporting patient-centred learning. We examined effects on students' stigmatising attitudes and how it may help their understanding of the patient and family experience.

## **Methods**

### ***Development***

The digistory was based on the autobiographical narrative of 'Sam', a mother of a child with severe ASD. 'Sam' was interviewed about day-day living, with questions informed by the relevant literature. She described her son's behaviour, social reactions and experiences of healthcare encounters, and how these affected her, and family life. Her responses described challenges, and positive aspects of life with an autistic child.

The recording was edited to shorter length through piloting with medical students, whilst ensuring detail of key social and personal themes were retained. The narrative was then illustrated with cartoons by a student researcher (GP), before further piloting and final edits. Development steps are shown in table 1.

The resource was distributed online to all students at the regional medical school in the north east of England.

### **Insert table 1**

### ***Evaluation***

#### ***Questionnaire***

Respondents gave demographic information and details on previous exposure to ASD before completing two activities before and after watching the digistory: a word association exercise where they listed words or phrases associated with "living with autism", and the Societal Attitudes Towards Autism (SATA) questionnaire. [12] Participants were invited to provide free-text feedback.

#### ***Focus Group***

Educational effects of the digistory were considered in a focus group with eight volunteer respondents.

## ***Analysis***

Pre- and post-digistory SATA questionnaire scores were compared using unpaired t-tests. Responses to the word association exercise were coded independently by two researchers blinded to pre- and post- timing of data. Codes were positive, negative, mixed (ambiguous or both positive and negative) or neutral (no judgment of positive or negative). Pre- and post- frequencies were compared by Fisher's exact test. Qualitative analysis pooled data from focus group and questionnaire free-text. Inductive thematic analysis was used to develop narratives and explanatory themes. [13]

## **Results**

104 students responded to the questionnaire, although responses to individual items varied.

Respondents were mostly female (70 of 100 reporting gender) and from all undergraduate year groups (13% were in year 1, 8% year 2, 25% year 3, 24% year 4, 29% year 5).

Most students reported some previous contact with individuals who had ASD (75% [46/61]), but only 7 indicated that their experience was through the undergraduate programme.

## ***Questionnaire***

### *SATA*

There was no significant difference between pre (mean 50.1; sd 3.9) and post (49.8; sd 4.05) scores (64 complete responses), which indicated very positive attitudes. [A fully positive SATA score = 64]

### *Word association task*

The task was completed by 87 respondents before, and 66 after viewing the digistory. The majority of words and phrases were coded as negative, both before and after, and frequencies did not change (Table 2). While the number of responses per respondent varied, adjusting for this did not change the overall finding.

## Insert table 2

### **Focus Group**

Analysis examined student perceptions of the educational impact of the digistory – what they learnt, and how the digistory enabled that learning.

#### *Understanding the family's life*

Survey data indicated that the digistory gave many students their first exposure to a patient with ASD. The qualitative data suggested that this lack of experience affected students' confidence to communicate, or step beyond the specific medical problem.

*'I think there's an anxiety in meeting people like that, because you don't know what you kind of, you know, what level to pitch it at, or just how to converse.'*

*'You know, if their child comes in with a cough, you don't talk about the autism side of things, you're just there to deal with the cough.'*

The digistory provided a memorable 'anchor' for learning, as direct patient exposure would do, but had additional value in revealing aspects of the patient's experience that may not be possible in typical clinical encounters.

*'It's more detail than you might get in a kind of consultation, looking at intimate details of day-to-day life... where else would you really talk about things like that, unless they had a really long time to just sit and talk to you.'*

Hence, the digistory gave students more detailed understanding of the impact of the condition on families, and this encouraged confidence about engaging with real-time patients, with implications for learning-in-practice.

*'I think just having a little of that story in the back of your mind helps you feel more prepared to engage in that respect.'*

The digistory therefore grounded clinical understanding in the patient's point of view.

### *Challenge stereotypes*

There were indications that the digistory facilitated patient/family-centred learning through challenging simplistic stereotypes of individuals with autism as highly-functioning individuals who have communication difficulties.

Some students were made more aware of the potential severity of the condition, and how disabling it can be. Conversely, others were struck by the 'good' the parent saw in the condition and that this outlook could mitigate difficulties. Therefore, while questionnaire data did not show quantitative changes in attitudes, there were *qualitative gains* in how some respondents thought about ASD.

*'I was thinking, I'm sure I've kind of judged someone's parenting skills at some point, and never thought, maybe there's something else going on.'*

Some students felt that a single story could misrepresent the plurality of a spectrum disorder. However, this criticism could be applied to any real-time patient contact, and so while it is a risk, it does not arise from the digistory *per se*. On the other hand, students saw a strength in the 'distance' from the patient inherent in a digistory, as this could, in fact, help them to get closer to real-time patients with taboo, or 'too afraid to ask' subjects, such as living with HIV or a stoma. Hence, the digistory may have the potential to reduce preconceptions and biases, and help overcome a barrier in direct clinical encounters.

### *Enabling an emotional connection*

Students consistently reported how the digistory created an emotional connection with Sam and her son, despite never seeing their faces. This was largely enabled by the authenticity of Sam's narrative, with the cartoons creating memorable images, while being less distracting than moving pictures might be.

*'It felt honest and realistic rather than scripted. I could feel that this mother really loves her little boy and dedicates her life to looking after him. The mum's tone of*

*voice and her truthfulness about it not always being easy made it feel realistic to me.'*

Notably, this emotional effect conflicted with some students' 'medical' way of thinking. Some felt that the 'social' perspective would be more appropriate earlier in the undergraduate course, while others explicitly placed this on the periphery of the medical learning model.

*'Good for understanding patient's / carer's perspective, but otherwise not useful in terms of MBBS [the institution's undergraduate medical degree] education.'*

This is a reminder that students often expect learning resources to discretely map to the formal curriculum, and provide explicitly learnable, and implicitly testable knowledge or skills. However, this view may be related less to the specific condition than to students' overall perceptions of learning priorities.

## **Discussion**

This pilot study aimed to develop a digistory about ASD and consider its educational value. Key findings for educators were that the digistory was perceived as a meaningful learning resource, and that it provided holistic understanding of the condition, with potential benefits for students' confidence in future clinical encounters.

### ***Patient-centred learning***

Few students had had direct contact with ASD and Sam's autobiographical narrative was able to provide a depth of information about the real-life impact of the condition that is critical to patient-centred learning. Qualitative data also suggested that the digistory could help challenge stigmatising attitudes to ASD through challenging social stereotypes from which they stem. In keeping with the literature, this may relate to students connecting with the unique context of the child and his family, rather than an abstract case [14]. Our findings support value for use in patient-centred teaching in

primary care, where educators must address misconceptions or preconceptions associated with certain conditions.

The digistory engendered participants' empathy with 'Sam', illustrating an emotional aspect to their learning. While previous studies have reported similar findings, those effects were attributed to real-time patient involvement [15] or to students actively creating a digistory [10, 11]. Thus, this pilot is noteworthy in that benefits were gained from students simply viewing the video, and offers potential advantages for cost-effective and scalable delivery.

Authenticity of the digistory was key to enabling an empathetic connection, though there was a paradox in the apparent unreality of the format seeming to enhance the authenticity of the spoken voice. Further study with other patient groups in primary care may help to identify what elements of design underpin authenticity.

### ***Implications for educational practice***

We have demonstrated feasibility and educational benefit of a simple, cost-effective online resource. Wider use of digistories may give medical students a better understanding of conditions that they may not see in short general practice placements and help to standardise awareness across student cohorts. While this study focused on ASD, our findings are likely transferable to other clinical conditions where there may be similar barriers to patient-centred learning, such as dementia and mental health.

Notably the digistory was not accepted universally. A number of students felt that the digistory failed to support 'hard' (and implicitly more valued) medical skills. This illustrates a biomedical, doctor-centred viewpoint that remains an educational challenge. Some students may therefore better engage with such resources if presented alongside, and complementing, traditional skills-based teaching. It is also a reminder that the broad constituency of medical students has varied

expectations of undergraduate learning, and successful curricular integration of digistories will need further consideration of the learning outcomes they are to deliver.

### **Limitations**

This was an exploratory study within a single medical school and findings may not transfer to other locations. However, a range of views, negative and positive, were identified. With limited resources, we could only develop one digistory and chose a common condition in primary care. However, our findings encourage examination of digistories for other conditions where the biopsychosocial context must be considered.

### **Conclusion**

While direct patient contact remains the gold standard for medical education, a digistory can support patient-centred learning by sharing an authentic patient voice. This may provide valuable additional insight into the lived patient experience, with benefits for patient-centred learning in primary care settings, through a cost-effective, practical resource.

## List of Abbreviations

Digistory      Digital Storytelling

ASD            Autism Spectrum Disorder

SATA          Societal Attitudes Towards Autism questionnaire

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## **Declarations**

### ***Ethics approval and consent to participate.***

The study gained full ethical approval from Newcastle University Faculty of Medical Sciences Research Ethics Committee, reference number 00903/2015. Informed consent was given by participants in accordance with ethical research principles.

### ***Disclosure Statement***

The authors declare that they have no competing interests in this work.

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### ***Notes on contributors***

Anthony Codd (AC) is an academic Foundation Programme trainee in medical education research.

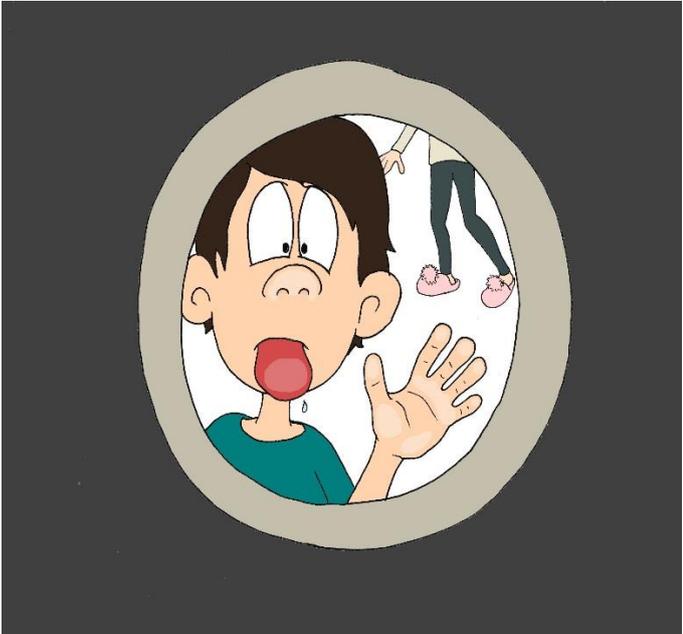
Gabriella Petruso (GP) is a Foundation Year One trainee who conducted the study as a 4<sup>th</sup> year undergraduate student with placement (SSC) in medical education. Neil Davidson (ND) is a paediatric trainee and has completed an NIHR Ph.D. Fellowship in use of mobile technology to support patient education. Bryan Burford (BB) is a lecturer in medical education. Gillian Vance (GV) is a clinical senior lecturer in medical education and honorary paediatric allergist.

The study was conceived and designed by GV, ND & BB. GP and ND designed and developed the digistory. GP, ND and AC led data collection and all authors contributed to data analysis and interpretation. AC and GV wrote the original manuscript, and all authors contributed to subsequent revisions, and approved the final manuscript.

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**Table 1: Steps in development of the digistory**

1. Literature search: identify gaps in education.	
2. Develop & refine interview schedule.	
3. Audio recording with parent in AV suite (38 minutes)	
4. Initial edit after repeated listening and note making to identify and capture key areas of discussion (10.24 minutes).	
5. Cartoons added using video editing software (see example shown – <i>'licking the washing machine'</i> ).	
6. Pilot with students from the medical education research student advisory group (MERSAG).	
7. Further edit of format and presentation (9 minutes).	
8. Final online package approved by MERSAG students.	
9. Cascaded to all students.	

**Table 2: Frequency of statements in word association exercise coded by positivity**

	<b>Pre</b>	<b>Post</b>
Positive	31 (11%)	44 (16%)
Neutral	47 (16%)	37 (13%)
Negative	180 (62%)	167 (61%)
Mixed	31 (11%)	28 (10%)
	289	276