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# ‘But is it a question worth asking?’ A reflective case study describing how public involvement can lead to researchers’ ideas being abandoned

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## Abstract

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**Keywords:** consultation, public involvement, reflective case study, research design

**Background** It is good practice for the public to be involved in developing research ideas into grant applications. Some positive accounts of this process have been published, but little is known about when their reactions are negative and when researchers’ ideas are abandoned.

**Objective** To present a case study account of when an academic-led idea for funding was not supported by stroke survivors and carers who were asked to contribute to its development, together with a reflection on the implications of the case from all the stakeholders involved.

**Design** A reflective case study of a research idea, developed by an academic researcher, on which stakeholders were consulted.

**Participants** University researchers, clinicians, public involvement managers, and stroke survivors and carers from the NIHR’s Stroke Research Network.

**Findings** Although the idea met with the approval of health professionals, who were keen to develop it into a funding bid, the stroke survivors and carers did not think the idea worth pursuing. This lack of patient and carer support led to the idea being abandoned. Reflecting on this, those involved in the consultation believed that the savings accrued from abandoning the idea, in terms of ensuring that public money is not wasted, should be seen as an important benefit of public involvement in the research process.

**Conclusion** Little is known about the role of the public in the abandonment of research ideas. We recommend that further research is undertaken into this important contribution that patients and the public can make to health research.

## Introduction

Public involvement is recognized in health research policies in the UK and in other countries.<sup>1–3</sup> In the UK, for example, it is expected that research undertaken in the National Health Service (NHS) is, ‘pursued with the active involvement of service users and carers including, where appropriate, those from hard to reach groups such as homeless people’.<sup>3</sup> Most research funding programmes in the UK, such as Research for Patient Benefit funded through the National Institute for Health Research (NIHR), require researchers to demonstrate how members of the public were involved in the design and development of the grant application, and how they will be actively involved in managing the research, undertaking the analysis and disseminating the findings if funding is awarded.<sup>4</sup>

The arguments in support of public involvement in research have been grouped into epistemological, moral and consequentialist categories.<sup>5</sup> The epistemological argument stresses the knowledge and experiential insights that patients and the public can bring to research.<sup>6</sup> The moral argument, often expressed in terms of rights and democratic accountability, states that the public, as taxpayers, have the right to be actively involved in any publicly funded research that may impact on their health or the services that they receive.<sup>7</sup> The consequentialist argument states that public involvement has the potential to improve the quality, relevance and impact of health research.<sup>8</sup>

Although public involvement has been a policy imperative for sometime, its underpinning evidence is regarded as weak, and in need of strengthening.<sup>9</sup> A recent scoping report on the impact of public involvement in health research has highlighted the paucity of high-quality evidence in the field.<sup>10</sup> Much of the published literature can be classified as descriptive, context-specific case studies, thus lacking in generalisability.<sup>11</sup>

It was against this policy and empirical background that INVOLVE, the body that promotes public involvement in research in England, together with the NIHR’s Health

Services Research (HSR) Programme, issued a call inviting outline bids for funding to conduct high-quality primary research into the impact of public involvement in health research.<sup>12</sup> This funding call provides the context for the case study described in this paper, where the lead author (an academic researcher with a track record of research in the field of public involvement) had an idea for a potential bid for this funding. To develop the idea, he consulted with fellow academics, public involvement managers of the NIHR’s topic-specific clinical research networks in England and stroke survivor and carer members of the NIHR’s Stroke Research Network. This consultation was undertaken to gauge the level of support for the idea among those who would be involved in overseeing its delivery and to invite interested parties to be co-applicants, to work up the proposal, and to advise on the progress of the research should it be funded.

The aim of this paper therefore is to present a reflective case study account of the involvement of members of the public in a consultation about a professionally driven research idea, together with reflections on the rationale for the consultation and the level and method of public involvement adopted. The following sections of the paper describe the funding call in more detail, the idea that was put forward for consultation, the reactions to the idea from academics, public involvement managers and from patients and carers, and reasons for the eventual decision to abandon the idea. It is anticipated that this paper will contribute to the literature on public involvement at the design stage of health research, where a number of largely positive accounts of the process have been published,<sup>13–19</sup> but where very little is known about when the reactions of the public to ideas developed by health researchers are equivocal or negative, and when research ideas are subsequently abandoned. The implications of the case described in this paper, from the perspective of all stakeholders involved in the consultation, are also considered.

The structure of the paper draws on Marks-Maran and Rose's 'reflection cycle'.<sup>20</sup> This reflection cycle has four key components: (i) the incident – a statement of what actually happened; (ii) reflective observation – thoughts and feelings arising from the incident; (iii) related theory – making sense of the incident in the light of current knowledge; (iv) future action – what was learned and how it will influence future action. Reflection is an important part of the learning cycle because it allows stakeholders to think critically about an experience and learn from it by: exploring that experience in terms of feelings and significant features; processing the significant features and identifying learning; finding new solutions to dilemmas; and using the process as a tool to help develop future practice.

### The incident

This section describes the funding call, the idea that was put forward for consultation; and the nature of the consultation undertaken with health professionals, academics and stroke survivors and carers.

### The funding call

INVOLVE and the NIHR's HSR Programme issued a call in February 2010 inviting outline bids for funding to conduct a high-quality primary research into the impact of public involvement in health research.<sup>12</sup> The deadline for submission of outline bids was 6 May 2010. It was stated in the call that the funders were seeking, 'robust primary research to develop the evidence base and enhance our understanding, knowledge and learning about public involvement in research', with the intention of collecting evidence on:

1. *Impact*: to increase knowledge and understanding of the impact of public involvement in research
2. *Evaluation*: to identify methods of evaluating public involvement in research and
3. *Implementation*: to identify effective ways of involving the public in research.<sup>12</sup>

The call made it clear to potential applicants that the active involvement of the public within the research process was a criterion of funding:

The minimum requirement for projects is that they demonstrate a collaborative approach to involving members of the public and involve a diverse range of people. Applicants should be explicit as to how members of the public have been involved in the development of the research proposal and explain how patients/members of the public will be involved in the research process.<sup>12</sup>

### The idea

This section presents the origins of the idea, the paper from which the idea developed, together with a consideration of its limitations; and a discussion of the research idea that was sent out for consultation.

#### *The origins of the idea*

The lead author developed an idea for the NIHR HSR/INVOLVE funding call independently, based on a recent paper he published reviewing the literature on public involvement at the design stage of health research.<sup>5</sup> This review paper presented a narrative synthesis of peer-reviewed accounts of public involvement in the design of individual health research projects. Included in the review was a randomized controlled trial on the impact of public involvement in the design of a patient information sheet, where a consent document designed by researchers was compared with the one adapted by members of the public.<sup>16</sup> Although the results of this trial were disappointing (there was no significant difference between the recruitment rates into the parent trial where participants were given the public-designed compared with the researcher-designed consent document), it is, to the authors' knowledge, the only experimental study on the impact of public involvement in health research, making it a novel methodological contribution to the field.<sup>16</sup>

The review paper concluded by presenting possible avenues for further research on the impact of public involvement on research design:

The methodology Guarino *et al.* (2006) set out, where the impact of public involvement was measured by way of an embedded, multi-centre, cluster, randomized trial, and using a validated data collection tool, suggests a promising approach for further research into the impact of public involvement on primary research design. In particular, future research to measure the impact of public involvement in the design of an informed consent document and the design of a patient information sheet is to be recommended.<sup>5</sup>

The lead author developed an idea that built on the work of Guarino *et al.*<sup>16</sup> in a number of respects, which would, he thought, make a suitable application for the NIHR HSR/INVOLVE funding call, as it focused both on demonstrating impact as well as the methodology for measuring impact. Before the idea is presented, more detail is now given of the original study on which it was based,<sup>16</sup> together with a consideration of its limitations.

#### *Brief summary of the Guarino et al.<sup>16</sup> study*

This study examined, by way of an embedded multi-centre, cluster and randomized trial, the impact of a consent document designed by researchers compared with one adapted by members of the public with an interest in the topic area. The trial was embedded within a parent trial of cognitive behavioural therapy for servicemen suffering from various illnesses having served in the Gulf War. At the design stage of this study, a small group of Gulf War veterans were given the consent form designed by the researchers and could make any changes they felt were necessary to improve it. Seven main changes were made by the veterans, including revising the procedures section into shorter paragraphs and providing lists to make the document easier to read and comprehend. Using a validated instrument – the Informed Consent Questionnaire-4 (ICQ-4)<sup>21</sup> – no significant difference was found, during the conduct of the parent trial, in participants' understanding of the consent form designed by the group of Gulf War veterans compared with the consent form designed by researchers. There were also no sig-

nificant differences in satisfaction, adherence to the protocol or in the proportion of servicemen who agreed to participate in the parent trial.

#### *Key limitations of the Guarino et al.<sup>16</sup> study*

1. The research can be criticized for its lack of generalizability or external validity, in that we do not know whether the results would be replicated in trials relating to other health-related interventions and where different population groups are involved in developing patient information sheets and consent forms.
2. The veterans only adapted the consent document; they did not develop the document completely independently of the research team.

#### *The proposed idea*

It was proposed to undertake a replication and extension study of the methodology developed by Guarino *et al.*<sup>16</sup> by:

1. Embedding a trial comparing a public-designed and a researcher-designed patient information sheet and consent form within up to 5 parent trials (ideally one trial adopted on to each of the NIHR's topic-specific clinical research networks within England, that is, one trial on dementia or other neurological disorders; one on medicines for children; one on mental health; one on diabetes; one on cancer; and one on stroke).
2. Having members of the public actively involved in each trial design the information sheet and consent form *independently of* the research team in each case (subject to compulsory guidance on the content and layout of consent forms provided by England's National Research Ethics Service).

Two main outcome measures were proposed:

1. Accrual into each trial comparing the number of participants entering each parent trial on the basis of having read the *public*-designed patient information sheet and consent form, compared with the number of participants

entering the parent trial having read the *researcher*-designed patient information sheet and consent form.

2. Perceived quality of informed choice (because a public-designed information sheet and consent form might actually reduce accrual, because of a heavier emphasis being placed on possible risks and side effects).

The perceived understandability of the public-designed patient information sheet and consent form, compared with perceived understandability of the *researcher*-designed patient information sheet and consent form, was proposed as a secondary outcome measure.

It was thought that the following preparatory work and ‘buy-ins’ from key stakeholders and gatekeepers would be needed to develop the idea into an application for funding:

1. Support from the Associate Directors and Patient and Public Involvement Managers of each of the NIHR’s topic-specific clinical networks to help identify suitable parent trials.
2. Co-operation from Chief Investigators of trials about to start recruiting participants, who would need to agree to embed the trial within their respective parent trials.
3. Each trial would need active public involvement, so that a public-designed information sheet and consent form could be developed.
4. Substantial amendments to the protocols of the parent trials may be needed, to embed the public involvement trial in each parent trial.

The lead author planned to consult stakeholders about the following key questions:

1. Does the Guarino *et al.* study<sup>16</sup> provide enough justification and evidence to develop a comparative, multi-trial approach at this point?
2. Given that the Guarino *et al.* study<sup>16</sup> was undertaken in the USA, and in a different ethical and governance system, is it preferable to undertake a pilot/feasibility trial first?
3. What would be the most appropriate form of public involvement for both developing the

bid and also throughout the conduct of the research, assuming it was successfully funded?

### The consultation

Reflecting the ‘buy-ins’ identified to make the project idea feasible, and the key questions to be asked of interested stakeholders, the lead author sent an email describing the idea to the Patient and Public Involvement Managers of the NIHR’s topic-specific clinical research networks,<sup>22–27</sup> along with the public involvement leads of the UK Clinical Research Collaboration,<sup>28</sup> to gauge the level of interest in the idea, and to ask for expressions of interest in becoming co-applicants. This email contained a copy of the brief from the funder and a summary of the proposed research study. Each person who responded during the consultation process has agreed for his/her emailed response to be used in this paper, and each person was also given the opportunity to be a co-author on this paper.

Initial reaction to the idea from one of the two public involvement leads for the UK Clinical Research Collaboration contacted was positive (email 1 in Table 1). Among the topic-specific clinical research networks, the NIHR Stroke Research Network (SRN) showed particular enthusiasm for the idea (email 2 in Table 1). To obtain feedback on the idea from stroke survivors and carers involved in the work of the NIHR SRN, and to assess whether any of them would be interested in developing the idea, the Patient, Carer and Public Involvement Manager for the NIHR SRN agreed to circulate an email describing the proposal among the members of the Network’s group of lay members. The group is made up of individuals who have either had a stroke or who care for someone who has had a stroke. All the lay members were recruited to the NIHR SRN in 2007, and each individual was appointed to one of the seven clinical study groups. After appointment, the lay members became a virtual group that responds to requests from a wider internal and external audience. They meet twice a year to share information and

**Table 1** Emails received in response to the consultation process

	Consultee	Email response
1	Patient and Public Involvement Manager, NIHR Clinical Research Network Coordinating Centre	My initial reaction to your research idea is one of real enthusiasm, as it fits in with a style of working we're all trying to achieve – one of a more co-ordinated approach across networks, and one that results in some real evidence/change that can be clearly demonstrated as a result of patient and public involvement, which is importantly, linked to: (i) study relevance/quality to patients; (ii) recruitment/retention; (iii) ultimately, improved care/treatment/health services for those that need them as a result of such studies.
2	Clinical Professor of Stroke Care, Newcastle University and Associate Director for Patient, Carer and Public Involvement, NIHR Stroke Research Network	Many thanks for sending an outline of your proposal. I think that this is an excellent idea. I was wondering what you would think about a 2 by 2 factorial design – in which the other intervention would be input from writers trained to prepare materials for the public? (see BMJ paper last week from Fiona Godlee and Iain Chalmers <sup>29</sup> ). I'm not sure that accrual into a study is the right primary outcome. The aim of improving the documentation is about having the information in order to make an informed choice. And it may be that this may result in lower levels of recruitment. We will need to give some thought about how individual trials are selected e.g. time.
3	Patient, Carer and Public Involvement member, NIHR Stroke Research Network	I have had a look at this proposal and I'm not impressed! I'm not convinced that there will be much difference between a consent form written by researchers and adapted by the public, and one developed by the public. In my opinion, there needs at least to be feasibility study first. Sorry not to be more positive.
4	Patient, Carer and Public Involvement member, NIHR Stroke Research Network	More explanation of the problem with evidence would have been helpful, e.g. recruitment problems influenced/caused by the quality of the materials used, 'selling' the relevance of the research to potential recruits, etc. The strategic importance of the proposed research. Its cost. Does it have sign up from other Clinical Research Networks?
5	Patient, Carer and Public Involvement member, NIHR Stroke Research Network	It may be that there is just not information shown here, but this seems a rather disappointing application to me. The aim is to have an experimental study of a researcher-designed vs. a public-adapted consent form. The assumption is, presumably, as it is not spelt out, that the public-adapted one will be more understandable. The consent form used in the Guarino study <sup>16</sup> seems to be one which has been developed and validated over time, and presumably honed to be as easy to understand as possible (and there are various tools around to rate the understandability/reading age of documents). A public-adapted one COULD be an improvement (but in fact this could be easily tested, using such readability tools), but it depends on the work that went into the original document, whether there was jargon left, etc. The premise of this research – which has not been made explicit – seems to be that making the changes suggested by 'the public' will always improve the quality of a document, which sounds a bit odd. You'll know from your experience that it is really hard accommodating a range of comments from different individuals and producing something coherent! And researchers, after all, could be or have been patients themselves, and could be very experienced designers of research materials. And the new study also proposes having a researcher-designed form VERSUS a public designed form. How will that help NIHR research networks? If it turns out that the study materials designed by the 'public' for this particular study happen to be more understandable than those designed by researchers, that is not necessarily going to be the case for other studies – <i>it will always depend on the skills of the people involved, whether researchers, or lay people</i> . If it finds there is no difference, does that mean we can dispense with public involvement? Surely we are actually aiming for collaboration here, a sharing of skills, not one vs. the other. And any research study worth its salt would pilot the materials too (in fact, you could argue that discussing draft materials with 'the public' is a preliminary way of piloting, of testing their practicability). But there are other possible ways in which public involvement could improve recruitment, which could be tested experimentally. For example, Are potential participants TOLD that the public have been involved in designing the materials? Maybe, in fact, people may be more likely to participate if they are told that members of the public, people in the same position as themselves, felt this was so important that they have helped to design the materials because they want to encourage people to take part in the study. In other words, the public involvement acts as a kind of endorsement to potential participants that people like them feel the study is valuable. You could imagine a simple study where people get the same (researcher and lay designed) consent form but one group are told about how people like them (or who have been in their position) were consulted about the materials, and contributed to designing them, because they believed the study was important; vs. a second group, who get exactly the same form, but are told nothing about how it was designed

their experiences. Three responses to the research idea were received from lay members of the NIHR SRN, of varying length, but all equivocal or less than positive (emails 3–5 in Table 1).

Having invited comments from relevant clinical research networks, the UK Clinical Research Collaboration and members of the NIHR SRN's group of lay members, a decision was reached, by the lead author, not to develop the idea into an outline bid for funding. This was primarily because, although there was enthusiasm for the idea among researchers and health professionals (emails 1–2 in Table 1), the stroke survivors and carers who were consulted were not convinced of its value (emails 3–5 in Table 1). On reflection, the lead author agreed in particular with the critique received from one lay member of the NIHR SRN (email 5 in Table 1), in that the research idea risked isolating or polarising the roles and the contributions of members of the public and researchers within the research process, while running counter to a central tenet of public involvement: the synergistic gains for research processes and outcomes that can result when researchers and the public work together.

## Discussion

Much of the literature on public involvement at the research design stage describes the mainly positive, tangible contributions that members of the public can make, such as selecting patient-defined outcomes and outcome measures, reviewing consent and data collection procedures and writing lay summaries.<sup>5</sup> We know very little however about ideas that are not developed into research proposals and applications for funding because the public are not convinced of their value. It is hoped that the case study described in this paper provides a useful example of how an idea, developed by an academic researcher based on an identified gap in the literature, can be abandoned because the public brought into question its value. The purpose of the following discussion is to reflect on the implications of this reflective case study from the perspective of all the stakeholders

involved, including a discussion of the rationale underpinning the described consultation, and the level and method of public involvement that was adopted. Drawing on the three remaining components of the 'reflection cycle',<sup>20</sup> the discussion is divided into the following three sections: (i) reflective observation from stakeholders; (ii) related theory; and (iii) learning from the case study and future action.

### Reflective observation from stakeholders

From the perspective of the lead author (an academic researcher by background), the experience has been a salutary reminder that professionals are not always right when it comes to what health research should, or needs to, be undertaken. The case also highlights the degree of influence that members of the public can have in the development (or abandonment) of research ideas. Not everyone involved in health research is convinced of the value of public involvement,<sup>7,30</sup> and some researchers may be concerned about the implications of the case described in this paper, arguing that the lead researcher could have pressed ahead with the idea, on purely scientific grounds, to develop new knowledge. The lead author took the view that using public money to develop new knowledge of questionable value to the public is inappropriate, but accepts that some researchers may not hold this view, especially those involved in sensitive and controversial fields such as stem cell research. Some might also suggest that the lead author should have been more resilient and consulted with other members of the public to ascertain the extent to which the views of the lay members of the NIHR SRN were shared. The lead researcher took the view that the criticisms of the idea from the stroke survivors and carers consulted were reasonable and valid, and so, on reflection, it was decided that the research was not worth pursuing. Of course, there is personal disappointment at seeing a potential research idea abandoned and a funding opportunity missed; however, there is also satisfaction in knowing that the right process was followed for the right reasons. As for the gap in the literature

that is still unaddressed at the end of this reported consultation,<sup>5</sup> it remains to be seen if the research idea is developed into a full proposal and grant application by other researchers, despite the concerns raised by members of the public reported in this paper.

From the perspective of the NIHR SRN's Patient, Carer and Public Involvement Manager, who acted as a conduit between the lead researcher and the stroke survivors and carers during the consultation, the experience reinforces the argument made by Staniszewska *et al.*,<sup>13</sup> in that researchers' ideas should be developed in conjunction with the public, rather than in isolation from them, and that an early face-to-face discussion may have been useful:

Perhaps there should have been conversations about what was best to develop as a collaboration with integrated discussions held early on during the exploration stage rather than a consultation which occurred after the first draft was written. It is so easy to get caught up in academic discussions without the opportunity or understanding to reflect whether this is what people really want. If academics and professionals decide upon research priorities by only finding gaps in the literature, then if the literature to date hasn't involved lay members then perhaps one has to question whether or not the current published literature is truly the appropriate measure of what is best to further develop new (but relevant) knowledge\*.

One of the lay members of the NIHR SRN provides the following reflections on the consultation and the decision to abandon the project, mainly as a result of the criticisms made by the lay panel members of the NIHR SRN consulted:

My response [to the consultation] was never intended to be a veto. Rather, I understood I was participating in a dialogue on how limited resources could be used to generate evidence about the value of public involvement in research. I am concerned that lay members' comments are seen as the 'public view' vs. the 'scientific view' of the

health professionals' comments. A bit like the proposed study itself, I am uncomfortable with pitching stakeholders against each other. My understanding of the rationale for public involvement at the research design stage is that the involvement of a wider range of stakeholders will make it more likely that relevant issues will be raised and debated early on in the process, hence improving the quality of the final product. If, after this process, it is not possible to develop a quality study to answer the research question, then the savings accrued from abandoning it should be chalked up as a benefit of public involvement.

### Related theory

This section is discussed in two parts: (i) the rationale for the consultation process and (ii) the level and method of public involvement adopted in the consultation.

#### *The rationale for the consultation process*

The NIHR HSR/INVOLVE funding call that provided the context for the consultation<sup>12</sup> is a demonstration of the strong commitment to public involvement evident in UK Department of Health research policy since the 1990s. It was not surprising to see, therefore, within the funding call, a requirement for applicants to demonstrate public involvement in the bid development process. A desire to satisfy the requirements of the funding body was, of course, one of the drivers for the described consultation. It was not, however, the only driver for involving the public: there were epistemological, moral and consequentialist reasons also. Epistemologically, it was considered important for the research idea to be informed by, and developed with, the knowledge and experience of members of the public who have had direct experience of active involvement in the research process. Beresford<sup>6</sup> developed the epistemological argument for public involvement into a hypothesis, proposing that, 'the shorter the distance between direct experience and interpretation (for example as can be offered by public involvement in research), then the less distorted, inaccurate and damaging resulting knowledge can be'. From this standpoint, the consultation was undertaken

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\*The literature review, on which the research idea was based, was not undertaken and written up in collaboration with patients or members of the public.<sup>5</sup> This was primarily because the literature review was undertaken as a non-funded piece of work.

to shorten the distance between the originator of the idea (an academic researcher) and members of the public who have had direct experience of active public involvement.

The consultation was also undertaken for moral reasons. All members of the team involved in developing the research idea are believers in the moral case for public involvement in research, and believe it right for the public, as taxpayers and financial contributors to the NIHR and the research funding it distributes, to be actively involved in assessing the value of ideas developed by academic researchers. From a consequentialist standpoint, it was hoped that, should the research idea have met with the approval of the public during the consultation and gone on to be funded, that the lay members of the NIHR SRN would be actively involved throughout the research either as co-researchers or as members of the project's steering committee.

*The level and method of public involvement adopted in the consultation*

Three levels of public involvement in research have been identified<sup>5</sup>: (i) consultation (where researchers seek the views of the public on key aspects of the research); (ii) collaboration (an ongoing partnership between researchers and the public throughout the research process); (iii) 'publicly led' (where the public designs and undertakes the research and where researchers are only invited to participate at the invitation of the public). As the research idea under discussion was generated by an academic researcher and members of the public were invited to contribute at his request, the level of public involvement described in this paper is most accurately labelled as consultation rather than as collaboration or publicly led. However, if the research idea had met the approval of those lay members of the NIHR SRN consulted, and had one or more expressed interest in becoming a co-applicant and co-researcher if the bid was funded, then the level of involvement would have evolved from consultation to collaboration.

It is also useful to analyse the described consultation by way of a recently published

conceptual model of public involvement in health research,<sup>31</sup> which builds on the three levels of public involvement described above. This model proposes that public involvement in any research activity can be evaluated by way of two factors: (i) the degree of empowerment of the public in the research process, expressed dichotomously in the model as 'top down' vs. 'bottom up'; (ii) the degree of public collaboration in the research process, again expressed dichotomously as 'more collaborative' vs. 'less collaborative'. This two-factor approach to public involvement generates four quadrants: (i) public ignored, (ii) public acknowledged, (iii) public engaged and (iv) public advised. Using this model, it is possible to classify the described consultation as 'public acknowledged', defined as research 'designed, undertaken and disseminated with acknowledgement of a public perspective on ideas that are professionally led'.<sup>31</sup> Of course, the consultation did not lead to a protocol that was funded, undertaken and disseminated; however, the design stage (so far as it went) was professionally led in the sense that the idea was generated by an academic rather than a patient, carer or service user. 'Public acknowledged' is considered to be a 'top-down' approach to public involvement, with little scope for the public to have an impact because of their limited power in the research process.<sup>31</sup>

Owing to time and budgetary constraints, the consultation was conducted through the medium of email, rather than through focus groups or one-to-one discussions; methods of engagement considered useful in published accounts of public involvement at the design stage of research.<sup>13-19</sup> Email may not have been the most helpful medium to achieve constructive dialogue between researchers and the lay members of the NIHR SRN: a face-to-face discussion or a teleconference among those with a real interest in the proposed study may have been more creative and productive. However, funding for such activity was not available at the outline submission stage: only if the outline bid for funding was successful and a full proposal was invited by the funders could the research team apply for a bursary to pay for the time and

expenses incurred by members of the public in developing the full proposal.<sup>12</sup>

### Learning from the reflective case study and future action

There are two key learning points arising from this reflective case study. Firstly, it is important for academic researchers developing research ideas from gaps that they have identified in the literature, to be mindful of the extent to which the public were involved in the research on which the literature is based. As was found in the case described in this paper, the gap in the literature – identified by an academic researcher and based on a literature review that did not involve the public – was not deemed sufficiently important, by the stroke survivors and carers consulted, to address through primary research.

Secondly, we would recommend that research ideas developed by academic researchers are discussed as early as possible with relevant patients, carers and service users, and groups that represent their interests. This would lessen the time that researchers spend developing research ideas of little interest to the public and would maximize the input of the public at the design stage of research, when preliminary ideas are still embryonic. As highlighted in this case study, email is perhaps not the best means of communicating research ideas with the public and inviting their feedback. More interactive methods of engagement, such as teleconferencing or face-to-face meetings, are recommended.

INVOLVE argues that an important function of public involvement is to help ensure that money and resources are not wasted on research that has little or no relevance.<sup>32</sup> It is clear from the case described in this paper that the stroke survivors and carers who were consulted thought the researcher's idea was of questionable value. Little systematic research has been undertaken into the role of the public in the abandonment of research ideas. Specifically, we know little about the nature of these abandoned ideas (the proposed topic areas and population groups concerned), the reasons for the public's

rejections of them and the levels and methods used to engage the public in such deliberations. We recommend that further research is undertaken into this important contribution that patients and the public can make to health research.

### Conclusion

This paper has reported the use of a reflection cycle<sup>20</sup> to consider learning points arising from a decision not to proceed with a research idea primarily because the members of the public who were consulted about the idea questioned its value. This reflection cycle has provided an opportunity for stakeholders to reflect critically on the incident, to relate the incident to theory and to think through the lessons learned. The authors suggest therefore that a reflection cycle can be usefully employed as a tool to structure ongoing dialogue about the motivations, contributions and experiences of researchers and members of the public when they work together to develop and conduct health research studies.

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