

# Supporting public involvement in research design and grant development: a case study of a public involvement award scheme managed by a National Institute for Health Research (NIHR) Research Design Service (RDS)

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## Abstract

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**Keywords:** grant development, public involvement, research design, support and resources

**Background** It is good practice for the public to be involved in developing health research. Resources should be available for researchers to fund the involvement of the public in the development of their grants.

**Objective** To describe a funding award scheme to support public involvement in grant development, managed by an NIHR Research Design Service (RDS). Case examples of how the award contributed to successful grant applications and findings from a recent evaluation of the scheme are presented.

**Design** A case study of resource provision to support public involvement activities in one region of England.

**Participants** University and NHS-based researchers, and members of the public.

**Findings** Between 2009 and 2012, the RDS approved 45 public involvement funding awards (totalling nearly £19 000). These awards contributed to 27 submitted applications at the time of writing, of which 11 were successful (totalling over £7.5 million). The evaluation revealed difficulties encountered by some researchers when involving the public in grant development, which led to suggestions about how the scheme could be improved.

**Conclusion** This award scheme represents an efficient method of providing researchers with resources to involve the public in grant development and would appear to represent good value for money.

## Introduction

Public involvement is recognized in health research policies in the UK and in other countries.<sup>1–5</sup> In the UK, for example, the National Institute for Health Research (NIHR) is ‘committed to the Department of Health’s national strategy which puts patients at the centre of all National Health Service-related activity. To ensure that ‘patient benefit’ is not simply based on the views and options of research professionals and clinicians, the national strategy highlights the importance of involving patients, carers and the public at all stages of the research process’.<sup>4</sup> Most research programmes funded through the UK’s 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>

It is considered morally right and good practice for the public to be paid for the time that they spend contributing to the design and conduct of health research, and to have their out-of-pocket expenses met.<sup>6,7</sup> Payment and expenses to enable the public to be actively involved in research conduct can be built into a study’s budget and provided out of a study’s grant. It has been much harder for researchers to find resources to fund the involvement of the public at the pre-submission or design stage of research. A lack of resources to support public involvement in research design was highlighted in a recent review of the evidence base,<sup>8</sup> and Staniszewska<sup>9</sup> articulated the challenge of resource provision very clearly:

If user involvement remains an international policy imperative with little if any support at the vital stage of bid development, policy-makers, service user organizations, researchers, health service providers and commissioners will need to recognize the limited nature of involvement that may result and the impact this would have on the evidence base. Researchers will need to recognize the resource implications of involvement at this point, and user groups will need to decide whether to participate when there is the greatest

chance of influencing research but little or no funding (p. 175).

As a result of these concerns, organizations with a remit to support the design of health research are providing researchers with resources and assistance to enable them to engage with members of the public to develop research ideas and grant applications.<sup>8,10–12</sup> In the UK, the NIHR established ten Research Design Service (RDS) to support NHS and university-based researchers to develop applications for national, peer-reviewed funding competitions in health and social care.<sup>13,14</sup> As part of their remit, RDS are expected to support researchers to engage with the public during the development of their grants. To support this process, many RDS have established a funding award scheme to which researchers can apply, to finance public involvement activities during the grant development process.<sup>15,16</sup>

This paper describes the funding scheme to support public involvement in research design and grant development established by the NIHR Research Design Service for Yorkshire and the Humber (RDS YH). We present an outline of the award scheme, case examples of how the award contributed to successful grant capture and findings from a recent evaluation of the scheme. It is anticipated that this paper will contribute to the literature on public involvement at the design stage of research,<sup>8–10,16–23</sup> by providing a detailed case example of how an organization has provided financial support to researchers who wish to engage with patients, service users and the public during the development of their research ideas and the process by which the financial support was evaluated.

## Description of the RDS YH Public Involvement in Grant Applications Funding Award

The RDS YH established its Public Involvement in Grant Applications Funding Award in 2009 to provide resources for researchers based

in the Yorkshire and Humber region of England to engage with the public during the development of grant applications for projects that will form part of the NIHR Portfolio.<sup>24</sup> Applicants can apply for up to £500. Four funding calls are held each financial year, and the RDS YH funds up to five awards per call on a competitive basis. Applicants are notified of the outcome approximately 1 month after the call deadline, and unsuccessful applicants may reapply at subsequent calls. Guidance notes and an application form are available on the RDS YH website, along with reports of previous calls and reports from successful applicants about how the funding has been used. The guidance notes set out for what the award can and cannot be used. Only one funding application may be made for any single grant in development, and only one application will be accepted from an individual lead applicant per call. Successful applicants are asked to write a short report to state how the award was used, the extent and ways in which the public contributed to the development of the grant application and whether the grant application was successful.<sup>25</sup>

Applicants are asked to provide information on

1. The specific type(s) of members of the public who will be involved in developing the grant(s) (e.g. older people, children etc.).
2. How they intend to gain access to, and approach, members of the public to invite them to become involved, detailing whether they have already identified any specific voluntary or support groups relevant to their research.
3. How members of the public will be actively involved in developing the grant application (s), including an indication of the duration, location and degree of complexity of involvement activities.
4. How the involvement of members of the public in the development of the grant application(s) will be evaluated.
5. How they intend to continue to actively involve members of the public should they be successful in winning the grant(s).
6. How the grant will be spent (e.g. venue hire, travel, subsistence, payments to members of the public).

Members of the RDS YH's Patient and Public Involvement (PPI) Forum, which includes lay people and RDS YH staff members, review all applications received at each call.<sup>26</sup> Reviewers undertake their initial reviews independently and then meet as a group to agree upon the applications that the RDS YH should fund. The lay members of the PPI Forum are paid a fee for undertaking their reviews and for attending the review meeting. Applications are rated on a three-point scale:

1. A rating of 1 – the reviewer recommends to fund the application
2. A rating of 2 – the reviewer recommends to fund the application subject to conditions
3. A rating of 3 – the reviewer recommends not to fund the application.

### Usage of the scheme 2009–2012

At the time of writing, the RDS YH has received 80 applications for a Public Involvement in Grant Applications Funding Award, of which 45 were approved (totalling nearly £19 000). These awards have so far contributed to 27 submitted grant applications, of which 11 were successful (totalling over £7.5 million).

As displayed in Table 1, successful lead applicants were from either local universities or NHS trusts, and most intended to involve the public in preparing grant applications to funding schemes managed by the NIHR. The most popular NIHR funding scheme targeted was Research for Patient Benefit (a regionally focused funding stream, now offering up to £350 000 of funding),<sup>27</sup> followed by Programme Grant for Applied Research, which fund large-scale (up to £2 million) programmes of research.<sup>28</sup> Applicants intended to involve a wide range of people, reflecting the many topic areas of grants being developed and intended to use the award for a range of activities, including reimbursement of time, and payment of out-of-pocket expenses. Some researchers

**Table 1** Summary of the 45 Public Involvement in Grant Applications Funding Awards Supported by the RDS YH 2009–2012

Information category	N*
<i>Employing organization of lead applicant</i>	
University of Sheffield	14
University of Leeds	15
Sheffield Teaching Hospitals NHS Foundation Trust	4
University of Bradford	2
Yorkshire Ambulance Service NHS Trust	1
Sheffield Hallam University	1
Leeds Teaching Hospitals NHS Trust	2
Sheffield Children's Hospital NHS Foundation Trust	1
Leeds Partnerships NHS Foundation Trust	1
Hull and East Yorkshire Hospitals NHS Trust	1
South West Yorkshire Partnership NHS Foundation Trust	1
Calderdale & Huddersfield NHS Foundation Trust	1
University of Huddersfield	1
<i>Funding scheme being targeted</i>	
Medical Research Council	2
NIHR Efficacy and Mechanism Evaluation	2
Multiple Sclerosis Society	1
NIHR Research for Patient Benefit	17
NIHR Programme Grant for Applied Research	8
NIHR Health Technology Assessment	6
NIHR Fellowship	2
NIHR Health Services Research	2
National Awareness and Early Diagnosis Initiative	1
NIHR Programme Development Grant	1
NIHR Service Delivery and Organisation	1
NIHR Invention for Innovation	1
NIHR Health Services and Delivery Research	3
<i>Types of members of the public applicants intended to involve</i>	
Parents of young children	6
Children	2
Advocates of under-represented groups	1
Bariatric surgery patients	2
People with multiple sclerosis	2
People with diabetes	3
Patients with experience of emergency medicine	1
Pregnant Pakistani and Bangladeshi women and their partners	1
People with haemorrhoids	1
Cancer patients	1
People with Temporomandibular joint disorder	3
People who have experience of bronchoscopy	1
Males with abdominal aortic aneurysm	1
People with an interest in NICE guidance	1
People with vascular disease	1
People with trigeminal neuralgia	1
Patients with non-epileptic attack disorder	1
Women with hormonal and menstrual disorders	1

**Table 1.** Continued

Information category	N*
People with mental health problems	1
Patients with experience of outpatient antibiotic IV therapy	2
People with experience of alcohol addiction	1
People with chronic kidney disease	1
People with postural orthostatic tachycardia syndrome	1
Representatives of people with learning disabilities	1
People with experience of histopathology	1
Stroke survivors	1
Patients with pre-tibial lacerations	1
People with dementia and their carers	1
Adults with COPD/asthma	1
Users of telehealth interventions for long-term conditions	1
People with shoulder pain	1
People with amelogenesis imperfecta	1
Elderly people at risk of falls	1
Patients scheduled for surgery	1
<i>Types of costs requested to met by the award</i>	
Payment for time	37
Out-of-pocket expenses (travel and subsistence)	42
Postage and stationery	5
Refreshments	29
Overnight accommodation	2
Venue/room hire	9
Carer costs	1
<i>Types of involvement activities that applicants intend to carry out</i>	
Consultation event/focus group/workshop	28
Attendance at research planning meetings	9
Establishment of a panel	4
Support for a member of the public as a co-applicant	3
One-to-one consultation with the public	1
<i>Specific issues on which the public will be consulted</i>	
Choice of content of a proposed trial's control arm	1
The intervention to be researched	10
Choice of outcomes and proposed outcome measures	10
The planned randomization, recruitment and consent process	13
Feasibility of proposed data collection process and procedures	13
Overall views on the draft proposal, including lay summary	6
Data collection material (such as participant information sheet and interview schedules)	12
Options for how the public could be involved in the conduct of the research	5

\*Note that some categories may add up to more than 45 as multiple coding was possible in some instances.

chose to offer reimbursement of travel expenses, but not payment for time. The rationale for this, given by some researchers in their applications, was that the public they wished to involve would not be able to accept such a payment, due to their being on benefits. Rather than risk people not agreeing to get involved, researchers often wanted to offer a payment to a local charity in lieu of a payment to the individual members of the public concerned.

Focus groups and consultation meetings were the most commonly stated methods of involving the public, but other sorts of involvement activities were also planned, including attendance of the public at research planning meetings, the establishment of a panel of public advisors and supporting a member of the public to be a coapplicant on the grant application. Successful applicants intended to seek the advice of the public on a wide range of different design issues including the following: the feasibility of proposed data collection processes and procedures; trial design and views on randomization; the planned recruitment and consent processes; the intervention to be researched; data collection material (such as participant information sheets and interview schedules); the choice of outcomes and proposed outcome measures; options for how the public could be involved in the conduct of the research; and their overall views of the whole research proposal, including the lay summary.

### **Case examples of how the award contributed to successful grant applications**

The RDS YH's Public Involvement in Grant Applications Funding Award has so far contributed to 11 successful grant applications. In this section of the paper, we provide further details of the specific contributions that the public made to the development of five of these successful grants, as described in the reports that the RDS YH has so far received from the researchers.

#### **Example 1: A trial to lessen seasonal exacerbations in childhood asthma**

The award was used to fund a consultation event during the development of a grant to carry out a cluster, randomized trial of an intervention to lessen seasonal exacerbations in childhood asthma. The consultation event was held to ascertain the views of children and their parents/guardians about the wording of the intervention (a GP letter to remind the parent/guardian to stock up with the child's asthma medication in preparation for the start of the new school year). Consultees were also asked their views about to whom the letter should be sent (the parent/guardian or the child). This event was written up as a University of Sheffield report,<sup>29</sup> which was referenced in the section of the grant application form which asked for details of public involvement. This study, named PLEASANT (Preventing and Lessening Exacerbations of Asthma in School-age Asthmatics associated with a New Term), has been funded by the NIHR Health Technology Assessment Clinical Evaluation and Trials.<sup>30</sup>

#### **Example 2: Novel devices to predict pre-term birth**

The award was used to establish a panel of mothers with experience of pre-term birth, to advise on the development of research studies on the topic. At the first meeting of the panel, members received a presentation about their role and the rationale for public involvement in research from the lead author of this paper and a presentation from the chair of the panel about two research proposals being developed, to produce novel devices to predict the risk of pre-term birth. Panel members were informed that, should the projects be funded, pregnant women would be interviewed about their experiences of these novel devices. Panel members gave feedback to the qualitative researcher who attended the meeting on the wording of the questions in the draft interview schedule and also gave their views on the timing and location of the interviews. All these suggestions

were included in subsequent drafts of the grant applications. Funding to develop these devices has been awarded from the MRC Developmental Pathway Funding Scheme<sup>31</sup> and from NIHR Invention for Innovation Stage 2.<sup>32</sup>

#### Example 3: A trial to compare treatment for haemorrhoids

The award was used to fund a consultation event with patients who had experienced rubber band ligation or haemorrhoidal artery ligation, to review a proposed randomized controlled trial.<sup>33</sup> Four patients attended the meeting, and they were asked to provide feedback on the proposed design of the trial from a patient perspective, as well as the proposed patient information sheet and the questionnaires that the research team intended to use during data collection. Although the attendees proffered no comments with regard to the study's design when given the opportunity to do so, they did recommend some changes to the wording of the participant information sheet and provided alternative phrasing to ensure it would be fully understood by patients. They also recommended an additional 'punch line' sentence to highlight why the trial is being carried out. Small changes were suggested to the questionnaires to improve clarity. Participants were happy with the length and intensity of the planned follow-up data collection. Funding to carry out this trial has been awarded funding by NIHR HTA Clinical Evaluation and Trials.<sup>30</sup>

#### Example 4: A consultation to discuss approaches to public involvement

The award was used to fund a workshop to discuss how a patient/public perspective could be incorporated into a study that focused primarily on the working practices of health professionals. The study intended to develop and evaluate interventions to promote better use of clinical guidelines in general practice. The event was held to work out, with people providing a patient/public perspective, how the research team could ensure meaningful and influential

engagement with patients and the public in implementation research. Workshop participants expressed strong support for the proposed programme and put forward strategies to maximize the potential benefits arising from their involvement (e.g. two members volunteered to be panel members on the funded programme of work). Participants stressed the need to include 'typical' practices in the study so that the intervention could be used more widely across primary care. Following the workshop, a number of modifications were made to the funding application. Funding for this project has been confirmed by NIHR Programme Grants for Applied Research.<sup>28</sup>

#### Example 5: A consultation event to support an NIHR fellowship application

The award was used to run a focus group in support of an NIHR Fellowship application on the topic of physiotherapy. The focus group included four lay people who were currently receiving physiotherapy, and they were asked for their views on whether the proposed methodology within the randomized controlled trial aspect of the work was acceptable to patients and to ascertain whether enhancements could be made in relation to elements that matter most to patients. The lay people at the focus group found the proposal to be generally acceptable, but were able to suggest enhancements to the study design relating to recruitment, retention, blinding and acceptability of the intervention. Additionally, the focus group was used to recruit lay members to the trial steering committee, assuming the study were to be funded. The fellowship application was successful and is currently on-going at the University of Sheffield. The PPI focus group carried out during the design stage of the project has been written up for publication.<sup>34</sup>

### Evaluation of the Public Involvement in Grant Applications Funding Award

To evaluate the experiences of researchers who have involved the public in grant development

supported by a Public Involvement in Grant Applications Funding Award, a questionnaire was sent by email to all 45 successful applicants in January 2012. These researchers were also asked to forward on a similar questionnaire to at least one member of the public that they had actively involved in the development of their grant (The RDS YH was unable to contact members of the public directly because it does not get involved in the recruitment process for involvement activities funded through a Public Involvement in Grant Applications Award: the RDS YH takes the view that recruitment is the responsibility of each successful applicant and so does not maintain a database of contact details of those who have taken part in involvement activities funded through the award). The wording of both questionnaires used in the evaluation, along with the accompanying email/letter, was agreed with members of the RDS YH PPI Forum. The questions asked of researchers and members of the public in the evaluation are given in Boxes 1 and 2. Completed questionnaires were received from 25 researchers, giving a response rate of 56%. Only one questionnaire was received from a member of the public.

**Box 1** Questions asked of researchers during the evaluation of the RDS YH Public Involvement in Grant Applications Funding Award

1. Do you think the public demonstrably improved the quality of your grant application?
2. Did you encounter any problems or difficulties in involving the public in the development of your grant application?
3. Do you think the RDS YH Public Involvement in Grant Application Funding Award provides a good model for helping researchers to involve the public in the grant development process?
4. Would you recommend the RDS YH Public Involvement in Grant Application Funding Award to other researchers in the region?
5. Do you have any suggestions for how the RDS YH Public Involvement in Grant Application Funding Award could be improved?

**Box 2** Questions directed at the public during the evaluation of the RDS YH Public Involvement in Grant Applications Funding Award

1. Please describe what you were asked to do by the researcher during the activity in which you participated (for example, were you asked to comment on a summary of the research idea, a recruitment letter, an information sheet, or a questionnaire?)
2. Did the researcher tell you how they would use your input in their grant application?
3. Do you know if your contribution has made a difference to the research?
4. Did you enjoy the experience of assisting the researcher with their research?
5. Can you let us know in what ways the researcher could have improved your experience?
6. Thinking about your experience, would you be willing to take part in similar activities in the future to help researchers develop their ideas and their research proposals?

Of the 25 researchers who responded to the evaluation, 19 reported that they had completed or partially completed their funded involvement activity. Of these 19 researchers, 17 stated that they thought that the public demonstrably improved the quality of their grant application, while two were unsure. Box 3 provides a selection of responses received from researchers on how members of the public improved their application. One of the two researchers who were not sure whether the public demonstrably improved the quality of their grant application offered this reflection: 'They offered few suggestions or modifications. The grant was not awarded'. Nine researchers reported that they had experienced problems or difficulties in involving the public in the development of the grant application, and a selection of problems and difficulties are displayed in Box 4. All the researchers who responded to the evaluation believed that the award represented a good model for helping researchers to involve the public in the grant development process. Box 5 provides a selection of reflections from researchers about the award scheme.

**Box 3** Feedback from researchers on how the RDS YH Public Involvement in Grant applications Funding Award improved their grant applications

1. We could justify some aspects of the design with reference to [their] suggestions, which seemed to appeal to the [funding] panel.
2. Made [the] project proposal more patient-centred.
3. I had something to put in the application form's PPI boxes.
4. The feedback from the reference group provided very positive affirmation of the overall research aims [and] helpful advice on the best time to interview patients following discharge, balancing the need to recall the experience of therapy with the need to experience coping without therapy. Good advice was also given on how to recruit patients and how to inform patients they did not meet the study criteria.
5. More confidence that [the research] was designed around the clients we were going to interview. Confidence in our lay summary and also our decision making about data collection.
6. PPI was seen as key by the funding streams, and there was positive feedback at the interview stage of our application that we had developed what they considered robust PPI in the bid and the execution of the grant.
7. The quality of the application was enhanced because of the shift in focus necessitated by including the expertise of people with dementia and their carers. This is particularly evident in the draft instruments of data collection, where greater simplicity of wording resulted and the order in which questions appear was changed in response to feedback given. Also, we learned that many people with dementia felt the proposed interviews should be undertaken with an option to include the 'family carer', in preference to our initial plan to separate these two people (where applicable).

**Box 4** Reported difficulties in involving the public in the development of grants supported by an RDS YH Public Involvement in Grant Applications Funding Award

1. Recruitment was difficult. We only planned a small focus group discussion with six participants. We had six people signed up, but only four turned up on the day. Despite this, the participants who did attend made a very worthwhile contribution.
2. The main difficulty was that one service user in the reference group wanted to talk in detail about their problems and therefore use it as a therapeutic session. This was dealt with sensitively.

**Box 4** Continued

3. Poor attendance at meeting despite refunding travel expenses.
4. Consulting people with dementia in group sessions – while practicable – was problematic, in terms of ensuring that each person had an opportunity to contribute in a detailed way. One-to-one consultations were much more productive. Access to people with dementia relied upon collaboration with other agencies in the city, and as a result, to a certain extent, the selection process was taken out of our hands.
5. Getting people together, especially those who were housebound but keen to be involved.
6. Finding appropriate patients. Poor showing at meeting despite contacting patients personally by phone and being promised attendance (and refunding expenses).

**Box 5** Researchers' views about the RDS YH Public involvement in Grant Applications Funding Award

1. It encourages researchers to spend quality time considering this issue.
2. Small pots of cash are crucial to reduce the cost to the academics to deliver meaningful PPI prior to receiving grants.
3. It was extremely useful to have some funding and 'legitimacy' added by the small grant.
4. This model is competitive. It helps to get financial support for public involvement. It factors in reimbursement of expenses.
5. Public involvement in grant applications is essential and people's time and expertise as service users should be paid for so a small amount of funding through this grant is helpful. It also sends an important positive message about the importance of PPI.
6. The process made me think about and plan the activity more rigorously.
7. Members of the public should be paid for their contributions, and this is a great vehicle for ensuring this happens.
8. The process of applying for the funding forces the researcher to think about how to effectively undertake the PPI work. Providing funding enables researchers to actively engage with a panel of patients, rather than doing token PPI work that I have observed in the development of other proposals.
9. To know that the RDS can provide some financial support really emphasizes the importance of it and allows it to happen in an effective way.



All but one of the researchers who responded to the evaluation stated that they would recommend the award to other researchers in the region. Two researchers also offered advice on how the award scheme could be improved:

1. I wonder if the RDS could be more forthcoming with feedback relating to the submissions though. There is a wealth of PPI experience [in the RDS YH PPI Forum], and it would be useful if this experience could be captured when feeding back to applicants – successful or otherwise.
2. Insist that recipient universities have admin systems in place to allow payments to be made to the public in a variety of ways – perhaps by drawing up a list of ‘must have’ methods, including cash to deal with taxi fares and actual payment at the rate per person monies were awarded.

The member of the public who responded to the evaluation stated that they attended a consultation event to address, ‘general questions about usage of inhalers in care homes’ and for the researcher to ascertain, ‘our thoughts on what could be done to train staff in the care and understanding of people with breathing difficulties’. This respondent stated that the researcher informed attendees of the consultation how their responses would be used in the grant application, but she/he reported that they do not know whether their contribution has influenced the proposed research, because no feedback has yet been received. The respondent reported that they had enjoyed the experience of contributing to the grant in development and offered these reflections:

1. Lung disease has been a long-time ignored illness. People in care homes still are ignored. Staff are not trained in problems caused by breathing difficulties or how to administer inhalers. I hope my input helps others. I found [the researcher] very thoughtful, understanding and genuinely interested in what we were saying. As a person who has COPD it’s been a long battle getting help and informa-

tion. I hope in the long run this [proposed research study] helps elderly people.

## Discussion

One of the most important stages of the research process for members of the public to be involved is that of research design and grant development, because they have the opportunity at this stage to ensure that the research question is relevant to their needs and experiences; relevant outcomes and outcome measures are addressed in the proposal; data collection instruments reflect issues that they want to see addressed; issues pertaining to participant recruitment, information provided to participants and consent procedures are thought through; and consideration is given to the level and extent of public involvement in the study, assuming it is successfully funded.<sup>8,9</sup>

It is important therefore that resources are available to researchers at the research design stage, to enable them to engage with patients and the public in the development of their grant applications.<sup>6,7,9</sup> Reflecting this requirement, this paper contributes to the literature on public involvement at the design stage of research,<sup>8–10,16–23</sup> by describing a funding award to support public involvement in grant development provided by an NIHR Research Design Service, together with findings from an evaluation of the award scheme. In this section of the paper, we reflect on the specific contributions made by the public who participated in involvement activities funded through the award; we consider the issues raised by operating the funding scheme on a competitive, call basis; we discuss how the success of such a funding scheme should be evaluated; and we consider some of the issues raised by the researchers who participated in the evaluation.

The specific research design issues on which successful applicants for Public Involvement in Grant Application Funding Award intended to consult the public reflect case examples of public involvement in research design in the published literature. For example, we reported that

ten applicants intended to consult the public on the choice of outcomes and outcome measures to be used in the research, mirroring Ali *et al.*'s<sup>17</sup> account of stroke survivors being asked about their choice of outcomes for a trial of routine oxygen supplementation after acute stroke. Five applicants intended to use the award to consult with the public to seek their views on trial design and issues relating to the randomization of participants. This resonates with similar accounts of public involvement in the design of trials to examine hormone replacement therapy for women with breast cancer<sup>20</sup> and osteopathy for children with cerebral palsy.<sup>23</sup> Twelve applicants intended to ascertain the public's views on draft data collection instruments and patient information material, to improve the readability of draft patient information sheets. Koops and Lindley<sup>22</sup> discussed a similar account of the public changing the content of patient information material relating to a trial of thrombolysis for acute ischaemic stroke, where it was reported that the stroke survivors who were consulted disliked adjectives in the draft information sheet such as 'large', 'small' or 'massive' and preferred to have risks explained in percentages, leading to the information sheet being revised.

Some of the researchers who responded to the evaluation of the award scheme stated that the involvement activities they undertook when preparing their grant helped to make their application more patient-centred and grounded in the lived experiences of people from whom they intended to collect data (see Box 3). Responses from other researchers revealed that they recognized the importance of engaging with patients and the public at the pre-submission stage, and the importance that funding panels place on public involvement when they review funding applications. It is of course impossible to more than speculate on whether these responses were from researchers who believe in the value of public involvement or were from those merely undertaking involvement activities as a means to securing a grant.

It is notable that, when examining the case examples of researchers who have successfully utilized the award scheme, the predominant model or approach to public involvement was that of 'consultation'. Four of the five examples described consultation events held with the public to obtain feedback on research ideas that were already fairly well developed by the research teams. It should be noted that the RDS YH does not specify that applicants for a Public Involvement in Grant Applications Funding Award should employ a particular model or method of public involvement, and we would welcome more collaborative and user-led approaches to public involvement at the design stage, as well as the consultative models reported in this paper. The RDS YH has yet to be approached by a user-led organization or a service user researcher, asking for a Public Involvement in Grant Applications Funding Award to support a user-led grant application.

The award scheme at the time the evaluation was undertaken was administered on a competitive basis, with four calls per year. There are advantages and disadvantages of this approach for researchers. The main advantage is that as the RDS YH has a finite, yearly budget to spend on the award, a competitive, call-based system ensures that funding for public involvement in the region can be spread out evenly throughout each financial year. Limiting the award to one application per researcher per call also prevents the scheme being monopolized by a small number of researchers. A potential disadvantage is that a call-based scheme tends to favour researchers seeking to involve the public in the development of grants for *researcher-led* rather than *commissioner-led* funding calls. In the case of the former, which have rolling deadlines, if a researcher does not get their public involvement activities completed in time, she/he can wait for the next call to submit their application. Commissioner-led calls, on the other hand, are usually one-off calls (i.e. not repeated), with a generally much smaller timeframe between the call being announced and the submission deadline. The

tight deadlines for commissioner-led calls means that researchers have a much smaller window in which to undertake public involvement activities compared with those applying for researcher-led calls, which have rolling deadlines. The RDS YH has recognized this problem and has since adapted the award scheme so that applications from researchers wishing to use the award to support a grant submission in response to a *commissioned call* are reviewed on a fast-track basis, with the outcome communicated to the researcher within three working days.

Evaluating the impact of a funding award scheme to support public involvement in research is far from straightforward. In crude financial terms, comparing outlay with grant capture, the award scheme reported in this paper could be judged a success because each £1 of outlay has resulted in approximately £395 in grant capture (i.e. £19 000 in awards compared with successful grant applications totalling over £7.5 million). However, as Purtell and Wyatt have pointed out, 'successful involvement could potentially result in the failure of a project, scheme or plan: if the patients involved thought the research idea to be unnecessary or the design inappropriate, then they may turn down the work' (p. 606).<sup>35</sup> In these terms, the award scheme could be judged a success if it resulted in instances of the public persuading the researcher that their project idea was not worth pursuing. Although no examples were found of this occurring in any of the involvement activities funded by the RDS YH, examples of public involvement leading to the abandonment of research ideas are beginning to be published.<sup>36</sup> Using grant capture as a measure of success is also limited because the RDS YH has, of course, no influence over the decisions of individual funding panels: a Public Involvement in Grant Application Funding Award could be used by researchers to support meaningful involvement of the public in the development of their grant, but it might still not be funded due to methodological issues, or because the topic area is not

seen as sufficiently important, or due to budgetary restraints.

The evaluation only invited responses from successful applicants, and not from the wider health research community in the region. Also, a poor response was received to the evaluation questionnaire from members of the public who were actively involved in involvement activities funded by the RDS YH. The RDS YH was reliant on each researcher sending out an evaluation questionnaire to the members of the public that they involved, and we have no way of knowing how many of these invitations to participate were issued. These limitations are acknowledged, and an online resource for members of the public to feedback on their experiences directly to the RDS YH is currently in development.

Researchers who participated in the evaluation made helpful suggestions for how the administration of the funding scheme could be improved. In particular, the RDS YH is working with university departments and NHS trusts in the region to improve the way that the awards are administered locally, to speed up the time it takes to process claims from the public for their time and out-of-pocket expenses in relation to their involvement in research design activities. To improve the local administration of the award, the guidance notes have recently been amended: (i) to ask for the contact details of the finance officer within the researcher's host institution, who would be responsible for administering the award locally; and (ii) to advise researchers to liaise with their host institution's finance and human resources departments, to ascertain whether their organization has a payments and expenses policy for work undertaken with and by service users. Institutional payments and expenses policies would assist researchers in ensuring that they have costed their award appropriately for their respective host institution to administer locally. The RDS YH is about to undertake work to ascertain the extent to which such policies exist within the universities and NHS trusts within the region.

## Conclusion

This paper has presented a description of a funding award scheme to support the involvement of the public in research design and grant application development, managed by an NIHR Research Design Service, together with data on its usage over a three-year period, and an evaluation of the scheme. We believe that this award scheme represents an efficient method of providing researchers with financial support to involve the public in grant development and would appear to represent good value for money when outlay is compared with grant capture.

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