The Public As Our Partners
NIHR Central Commissioning Facility
2018/19 Highlights Report
INTRODUCTION

The National Institute for Health Research (NIHR) has a longstanding commitment to involving patients and the public in health and social care research. Patients, carers, community groups and families from a diversity of backgrounds and experiences support the NIHR to fund and deliver research that puts patients and people who use services at the centre of all that it does.

The patient and public involvement and engagement (PPIE) team at the Central Commissioning Facility, along with colleagues across the other NIHR coordinating centres develop and provide a wide range of opportunities for public contributors.

We are delighted to share with you examples of our work over the past year. As before we are reporting under the headings of each of the six UK Standards for Public Involvement.

For more information about the work in this Highlights Report or if you want to get involved with our work, please email ccfppi@nihr.ac.uk or phone 020 8843 8041.
Standard 1
INCLUSIVE OPPORTUNITIES
We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Supporting global health
The NIHR launched Research and Innovation for Global Health Transformation (RIGHT) in 2018. The aim of the programme is to deliver benefits to the health and economies of the poorest people living in low and middle income countries.

The programme emphasises that researchers applying for funding are expected to involve relevant community groups and organisations in an early and sustained manner throughout their research process (from developing the proposal through to dissemination and evaluation of the findings).

Our role was to support the recruitment of people from low and middle income countries to review shortlisted stage 2 applications from the perspective of someone who represents the community affected by the condition (for example, as patients or carers of someone who lives with the condition or a member of an organisation that represents those communities affected by the condition).

Ten international and four UK-based public reviewers commented on research applications in the first call of the RIGHT programme. Reviewers were positive about their experience and expressed an interest in continuing to review in future.

“ I am glad to be part of NIHR family. This review has made us not just colleagues in the review of applications but a strong team in the work agenda. The Foundation will be grateful to work in partnership with NIHR ... to improve the lives of people.”
Peter
Uganda, Public Reviewer

“ The public review idea is a unique one that provides more public opinion to enrich the applications and ensure better outcomes. I would recommend that other donors adopt it.”
Lydia
Uganda, Public Reviewer
Standard 2
WORKING TOGETHER
We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Working together to create ‘one NIHR’
Public contributors have told us getting involved in what the NIHR does can be confusing, so we have been working with the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) who also commission research to develop a joint system for recruiting new members of the public to get involved in NIHR’s work.

From now on, people interested in becoming a public reviewer or public committee member will only have to register through one system rather than applying to different coordinating centres. All registrations will be managed jointly by one team.

NIHR Standard Application Form review update
In 2017, the NIHR launched a streamlined application process for researchers applying for funding and introduced a new Standard Application Form (SAF). The form became shorter with fewer sections to complete including what had been a specific section outlining plans for public involvement. However, research teams were still expected to include appropriate and relevant plans for involving patients and members of the public in their proposal.

Following implementation, the new SAF form was reviewed and evaluated. NIHR public contributors were asked to give feedback on the impact of the changes in relation to the information on involvement. The recommendation about this was that the NIHR should strengthen the overall message to applicants regarding the requirement for, and importance of, meaningful patient and public involvement in their research applications. We are involved in planning a workshop with NIHR public contributors to discuss the ‘guidance for applicants’ document and make recommendations for improvement. The new guidance document is expected to be introduced across the NIHR by the end of 2019.

It has made good sense to work with our NIHR colleagues at CCF to develop joint public reviewer and committee member recruitment processes and materials... this joint work highlights our drive towards this and our passion for keeping the public at the heart of everything we do ... as well as having the added bonus of developing closer relationships with colleagues at CCF.

Heidi Surridge, Research Manager (PPI team), NETSCC
Building patient and public involvement capacity in Policy Research Units

NIHR Policy Research Units (PRUs) carry out research to inform government and arms-length bodies making policy decisions about health and social care. The NIHR funds 15 units which provide both a long-term resource for policy research and a rapid-response service to inform policy decision making.

Central to the work of the units is the involvement of patients and the public and the units are contractually required to develop a patient and public involvement and engagement strategy by the end of their first year (early 2020).

The CCF PPIE and Policy Research Programme teams held a workshop for PPIE leads and public contributors supporting the work of the units. The purpose of the workshop was to create an opportunity for colleagues to meet and gain a better understanding of PRU work programmes and discuss how patient and public involvement can inform and support the delivery of those work programmes.

We offer and promote support and learning that builds confidence and skills for public involvement in research.

Webinar: sharing knowledge and learning in global health

Community and public involvement is an important component of global health applications and it is essential to set out an involvement plan in the Stage 2 submission. To support applicants we held a webinar about community and public involvement in November 2018. The webinar was joined by 30 participants from the UK and overseas. You can listen to the webinar here: youtube.com

Involving people in CJD research

In June 2018 the CCF PPIE team and the Policy Research Programme (PRP) worked with external facilitators to develop and run a workshop about patient and public involvement (PPI) for research into Creutzfeldt-Jakob Disease (CJD). CJD is a rare and fatal condition that affects the brain. It causes brain damage that worsens rapidly over time.

Researchers who responded to a request for feedback about the workshop found particularly useful the clarification about what patient and public involvement is in this context and guidance about public involvement in research applications.

I very much enjoyed every single one of my reviewing opportunities, mainly because I know that there is someone on the other end who truly cares and loves her job. I wish everyone could have Yvonne’s passion, commitment and work ethic.

Public Reviewer
Feedback Survey 2018
Standard 4

COMMUNICATIONS

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

GDPR: communicating change

The European General Data Protection Regulations (GDPR) giving individuals a greater level of control over how their personal information is collected and used by others, including NIHR. We were obligated to scrutinise our systems and processes to ensure compliance. As a result, the PPIE team reviewed all our data-storing and handling practices and processes.

We updated the policy on our website and sent an e-bulletin to our public contributors informing them about the updated policy. We also produced and shared a GDPR information sheet with the UK Standards Network about the new regulations. The network includes members of the public, PPIE professionals, researchers and academics.

“Create a forum or mechanism where public contributors can interact, or a way in which public contributors in the same region can interact or engage with each other. Other professionals do, so we (public reviewers) are not in parity.”

Public Reviewer Feedback Survey 2018
Standard 5
IMPACT
To drive improvement, we capture and share the difference that public involvement makes to research.

NIHR Value framework
Over the past year, the PPIE team have been involved in an NIHR-wide ‘Value Framework’ project to define what ‘impact’ means for the NIHR and interested audiences. This includes exploring how to report on the impact patient and public involvement has on NIHR’s work and the research it funds.

So far this has included:

- Pulling together a list of the information NIHR Centres routinely collect on their public involvement activities, describing how it is collected and used.
- Working with colleagues and public contributors across the NIHR to think through and explain the chosen approach for developing the value framework and for PPI impact, what it will focus on.

By mid 2019, an impact statement in conjunction with the NIHR Public Involvement Impact Working Group will be agreed and we will continue to be involved in the work.
Standard 6

GOVERNANCE

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

PPIE advisory group

This year we re-established our Patient and Public Involvement and Engagement Advisory Group. Its members provide insight, advice and guidance from the perspective of being a public contributor for CCF acting as a critical friend. They challenge us to be ambitious and creative in our thinking and practice on how we involve and work with patients and communities.

One of the key work areas that members have asked us to prioritise is to increase the diversity of our public contributors, so that more people from different backgrounds have their say and get involved in health and social care research.

Each year we recruit new public contributors to join NIHR research programme committees.

Last year we received 45 applications to our call for public committee members from advertising through our community and partnerships database.

We are delighted to report that 11 were appointed to public member roles across four research programmes and 7 candidates put on a reserve list. All successful applicants have completed a comprehensive induction programme and have also been offered a buddy (current public member on the same committee) to provide informal peer support.

“My interest in PPI in research has grown steadily over several years and I was looking for the most impactful way to channel my skill set. I found the recruitment process was relevant, thorough and fair.

The interview required the analysis of a redacted Programme Grants for Applied Research (PGfAR) funding application. I was surprised by the proportions and attention to detail required but this approach to recruitment set realistic expectations for the work ahead and confirmed my desire to undertake the work.

The induction event was useful to network and observing a committee meeting showcased the degree of depth required when assessing the high quality projects the (PGfAR) attracts. It also highlighted the broad range of skills, high calibre of colleagues and dedication from all those involved as part of the committees.

In the short time I have been part of the PGfAR team I do feel privileged to work with such a dedicated and talented team who believe and promote the value of PPI in ensuring relevance and quality of the research that is funded.”

Ngawai Moss, PGfAR public committee member recruited in 2018