

# THE PUBLIC AS OUR PARTNERS: NIHR CENTRAL COMMISSIONING FACILITY

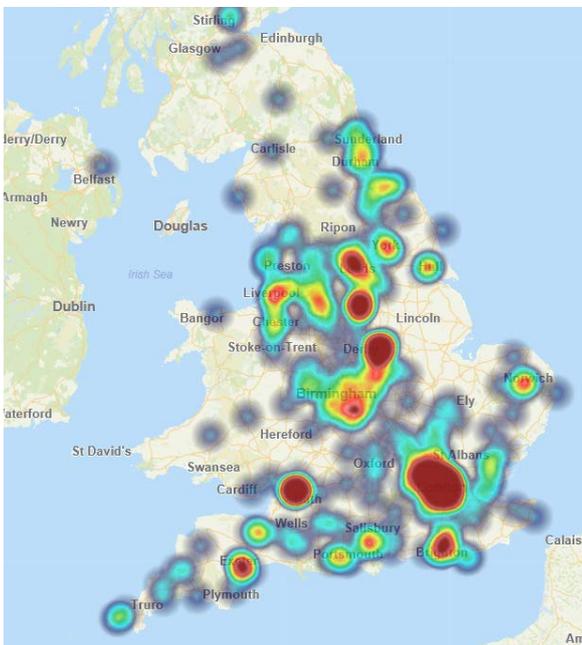
## 2017/18 Highlights Report

The National Institute for Health Research ([NIHR](#)) is fortunate to have many hundreds of members of the public who are passionate about research and who get involved in its work. Here at the NIHR Central Commissioning Facility ([CCF](#)), by drawing on people’s insights and experiences as patients, carers and service users we are able to improve the quality and relevance of the research that we commission and the other research activities that we manage. This report highlights some of that work during 2017/18.

Each year we develop and deliver a [work plan](#). Unsurprisingly, not everything works out the way we think it will and some projects prove to be unexpectedly challenging. This report reflects that reality. But whatever the end results we always can and do learn from what happens. In turn, that help us to improve what we do next.

In this report we align our work with the new [UK-wide standards for public involvement in research](#) and we reflect on the extent to which we currently meet the standards. The standards were launched in March 2018 and each one is a statement of good practice that describes one of six core elements of public involvement in research.

### A HEAT MAP OF CCF’S 329 PUBLIC REVIEWERS (APRIL 2018)



◀ This map shows the geographical spread of our public reviewers. Red indicates where the number of reviewers is relatively high (e.g. London and Derby) and the darker colours indicates where numbers are relatively low (e.g. Bangor and Belfast).

### INVOLVEMENT IN NUMBERS 2017/18

# 159

members of the public reviewed 227 funding applications



“It was my first review for the NIHR and I think the whole process was fairly easy. I think the prompt questions were good. They were really specific so that helped in terms of what to include in my answers. I was well supported by a member of the PPI team, I enjoyed this experience and I look forward to doing it again.”

**Margaret Opoku**  
Public reviewer



#### INVOLVEMENT IN NUMBERS 2017/18:

# 32

members of the public joined our community of 329 public reviewers



## STANDARD 1: **INCLUSIVE OPPORTUNITIES**

**We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.**

In 2016, we did some work to compare the number of funding applications that had children and young people as participants (around 15%) to the number of children and young people we involved as reviewers (none). Whilst family members and carers can and do provide excellent reviews of funding applications we would also like to include the perspectives of more young people (under 25s) themselves.

In 2017/18, our work focussed on three areas:

- ▶ **Developing and piloting a webinar to recruit students as public reviewers:** Working with a public contributor and students at Kingston University and St George's London, our aim was to recruit at least 10 students as reviewers. Whilst so far only two students have signed up, the content of the [webinar](#) was well received and we learned a lot from working with the Student Union. We intend to run similar webinars in future.
- ▶ **Recruiting young people to decision-making panels:** In 2017, the [Invention for Innovation Programme](#) recruited a person of school age, as a member of their Mental Health Challenge Award panel. Through the experience of supporting this panel member we are learning about different needs and different ways of communicating, to help us involve young people in our work.
- ▶ **Developing a resource pack to involve groups of young people in reviewing funding applications:** We hosted a meeting with six charities who were interested in exploring this idea with us. We shared our experiences of working with young people and talked through the practicalities of bringing groups together and working to tight deadlines with limited resources. We concluded that currently we don't have the capacity to take this project forward and so we've parked this idea for now.



“It was great to be a buddy for a new public panel member, to

give some tips and hints about dealing with the volume of paperwork, and to answer all the practical questions that people might otherwise feel uncomfortable asking. I only wish the buddy system had been in place when I was first recruited!”

**Philip Hurst**  
Panel member

## STANDARD 2: **WORKING TOGETHER**

**We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.**

Each year around 50 members of the public take on a vital role for the NIHR as members of research programmes’ decision making panels. They are appointed for up to five years and CCF runs an annual, open recruitment process so that as experienced members move on, new members join.

In 2017, we advertised nationally for new public members and received 100 applications. Existing and former public panel members worked with CCF staff and the chairs of panels to shortlist and interview applicants. Thirty one people were invited for an interview of whom 11 were selected to join four research programmes.

Throughout their time on a panel, we encourage and support public members to get involved in other activities. For example, current members play a significant role in supporting new members. Following their appointment in 2017, all 11 new members attended their first meeting as an observer. This gave them the opportunity to meet other people and watch the panel at work before actively contributing to it. They were also offered a ‘buddy’ - another public member who had volunteered to take on this role - to provide additional, informal support for their first few meetings.

During 2017/18, more examples of panel members’ contributions to the NIHR included:

- ▶ reviewing and improving guidance documents for funding applicants, panel members and public reviewers
- ▶ planning and participating in workshops to support the development of organisational strategies for involvement and engagement
- ▶ reviewing the [Future of Health](#) report as part of a review and refresh of the NIHR’s strategy *Best Research for Best Health*.

### INVOLVEMENT IN NUMBERS 2017/18

# 56

members of the public involved as panel members





“We get to focus on the practical aspects of delivering PPI in the Working Group. It also gives us the opportunity to influence NIHR-wide projects by commenting on draft documents and campaign materials, like the *Two sides of health research campaign.*”

**Emma Blamont**  
CCF PPI Working Group member

## STANDARD 3: **SUPPORT AND LEARNING**

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

There is always something to learn about public involvement in research, whoever you are. CCF offers a range of [learning and support opportunities](#) and in 2017/18 this included:

- ▶ **Attending the INVOLVE Conference:** In November 2017, the [INVOLVE conference](#) brought together over 300 people to share their experiences, develop their knowledge and encourage conversations between enthusiastic public contributors, animated researchers and others. CCF operated a simple lottery to allocate eight supported places to members of the public who contribute to our work and it was a pleasure to finally put some faces to names.
- ▶ **CCF Patient and Public Involvement (PPI) Working Group:** We facilitate an internal working group for CCF staff who lead on PPI within their own team - such as research programmes or communications. The group works together to avoid unnecessary duplication, acquire skills, share ideas and good practice. One of our projects in 2017/18, was to develop a set of prompts and examples for monitoring involvement in funded research. These are now included in our reporting template both to help researchers write their reports and programme managers to assess their progress.
- ▶ **Shared Learning Workshops:** In 2017/18, CCF's PPI team facilitated and supported a number of workshops that brought together people from across the NIHR - 'PPI leads' - with responsibility for developing and delivering PPI in their part of the NIHR. These workshops often focused on just one or two topics to allow people to discuss challenges, share examples of good practice and explore opportunities to collaborate. For example, PPI leads in Biomedical Research Centres are helping one another to build a common understanding of what PPI impact means to their Centres.

### INVOLVEMENT IN NUMBERS 2017/18

# 18

members of the public participated in shared learning workshops



## STANDARD 4:

# COMMUNICATIONS

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

CCF is a founding member of the [Standards Development Partnership](#) and has been working with INVOLVE, Health and Care Research Wales, the Chief Scientist Office in Scotland and the Public Health Agency in Northern Ireland to develop, launch and pilot a set of [UK standards for public involvement in research](#).

Effective communications was and remains a critical factor to the Partnership. Without continuing to inform and engage the public and a wide range of other collaborators, supporters and challengers, the standards risk becoming a tick box exercise. Rather than being a practical tool to help people identify what they are doing well and what needs improving.

Communications over the last year included:

- ▶ After developing a website we launched the [Standards Network](#) to join up with people who shared our interest in the standards. Four hundred and twenty two people registered during 2017/18 and we shared news of what happened at [Partnership meetings](#), encouraged involvement in the [consultation phase](#), celebrated the launch of the standards and stimulated involvement in the [testing phase](#).
- ▶ In response to some insightful feedback, we made sure documents were in plain language and available in different formats, including an [Easy Read booklet](#) and a [short video](#) that we have shared on social media and the website.
- ▶ We took to social media to engage people more widely using the [#ppistandards](#) hashtag. Since August 2017 the standards have been tweeted more than 2,000 times. We hosted a tweet chat as part of the standards consultation and in March 2018 we used social media to announce the ten selected [test bed projects](#).

“In the future, we want the standards to be seen by groups and organisations large and small; public, private and charitable as an essential tool in guiding their public involvement.”

**Simon Denegri OBE**  
NIHR National Director for Patients, Carers and the Public



### INVOLVEMENT IN NUMBERS 2017/18

# 837

tweets using  
[#ppistandards](#)  
reached over 2.7m  
people over 7 days





## STANDARD 5: **IMPACT**

**To drive improvement, we capture and share the difference that public involvement makes to research.**

Much work is being done by researchers, public contributors and others to learn about, and from, the difference that patient and public involvement makes to research. For example, there are now journals such as [Research Involvement and Engagement](#) and [Research for All](#) and colleagues in the USA have created an [Engagement in Health Research Literature Explorer](#).

During 2017/18, CCF was involved in the formation of a more strategic, NIHR-wide approach to impact, led by Simon Denegri. In November, hot on the heels of the INVOLVE conference and with colleagues from the Western Australian Health Translation Network's [Consumer and Community Health Research Network](#), we convened an [Impact Exchange Workshop](#). This brought together organisations and public contributors from the UK, Australia, Canada and the USA to share what we are all currently doing in relation to impact and to explore areas for future collaboration. For the NIHR, this cemented our plans for a national survey to ask NIHR public contributors about their experiences of involvement.

CCF is now part of an NIHR working group that also involves colleagues from research charities and industry. The group met for the first time in March 2018 to begin to identify and prioritise a work programme. Ideas included:

- ▶ developing an 'impact statement' for public involvement in research
- ▶ creating better mechanisms for patients, carers and the public to give and receive feedback on the difference they have made
- ▶ using the data and information we already collect about public involvement in a more helpful way
- ▶ encouraging the research community to work more closely together to develop the evidence and useful tools
- ▶ getting better at communicating our impact to others.

"With the Impact Exchange Workshop it was evident there is a real appetite for developing international as well as national approaches to capturing the impact of public involvement in research. We are excited to be part of this."

**Anne McKenzie AM**

Head, Consumer and Community Health Research Network Western Australia

**INVOLVEMENT IN NUMBERS  
2017/18**

**1,276**

downloads of the workshop report



## STANDARD 6: GOVERNANCE

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

Simon Denegri, NIHR National Director for Patients, Carers and the Public, is a member of the Contract Management Board that meets four times a year to review delivery of CCF's services. We have some way to go yet before we involve public contributors in our governance and leadership structures.

In 2018/19 however, we will be establishing an External Reference Group to support CCF's work. This group will meet twice a year and provides a way of involving key NIHR stakeholders in the management of CCF by bringing external perspectives to bear from academics, patients and public, the NHS, industry and research management. The group will include two public members and it will act as a critical friend to CCF by providing feedback, offering insights and advice, identifying opportunities to further develop CCF and much more. The External Reference Group is a significant development for CCF as for the first time we will be involving some of our stakeholders, including public contributors, in our management and governance.

▼ CCF's PPI team: (left to right) Yvonne Anderson, Katalin Torok, Philippa Yeeles, Hothan Esmael, Haydee Garcia



**Thank you ...  
and please spread  
the word**

If you are one of the many members of the public who are already involved in the NIHR, firstly we'd like to say a heartfelt thank you for your continued involvement and support.

Secondly we'd like to ask you to talk to your family and friends about what you do for the NIHR. Might they be interested to get involved? If they are, please encourage them to take a look at the [Patients and the Public](#) section on the NIHR website. Or to get in touch with the [CCF PPI team](#).

### CONTACT US

Please contact us if you are a member of the public and would like a paper copy of this report or any others we mention in this report.



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