

**Central Commissioning Facility (CCF)  
Patient and Public Involvement and Engagement (PPIE)  
Annual Report 2016/17**

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## A. Background

For the CCF, our purpose in working with patients, carers and the public is to improve the quality and relevance of the research that we commission and the other research activities that we manage, and to raise public awareness of research. We operate within the framework of our [Patient and Public Involvement and Engagement \(PPIE\) Plan 2016/18](#). The PPIE Plan is managed and delivered by a central team of four staff who report to the Director of Involvement and Engagement and primarily focus on the following:

- **Commissioning for NIHR research programmes and infrastructure:** including matching research funding applications with individual public contributors<sup>1</sup> who have personal knowledge and experience of the research topic. We recruit, support and involve a bank of public contributors who, in 2016/17, delivered over 250 reviews of funding applications and a group of approximately 50 public contributors as standing members of panels making funding recommendations to the Department of Health (DH). We also support the involvement of public contributors in *ad hoc* funding competitions.
- **Monitoring and reporting:** including routine monitoring, by programme managers, of patient and public involvement (PPI) during the lifetime of research projects and programmes. This sometimes involves public contributors in review meetings with funded programmes and studies, such as stakeholder meetings and variation to contract meetings. We also review, provide feedback and publish the [PPI and engagement sections of NIHR annual reports](#) of over 100 NIHR initiatives.
- **Collaboration and coordination:** including working NIHR-wide to take forward the vision, strategic objectives and recommendations of the NIHR's strategic review of PPI: '[Going the Extra Mile](#)'. We work informally through networks with colleagues across the NIHR and beyond and formally through involvement in groups such as the NIHR PPI Senior Leadership Team and the Public Involvement Collaboration Group facilitated by [INVOLVE](#). We also participate as members of national working groups such as the [Public Involvement Standards Development Partnership](#).
- **Continual improvement:** all the projects in our 2016/17 Action Plan focused on delivering improvements to our PPIE activities. We used monthly team meetings to report, monitor and review progress. We also used [Plan-Do-Study-Act \(PDSA\) cycles](#) to test out changes within some of these projects. In April 2017, the team held a review meeting with three public contributors who had been involved in the development of the original PPIE Plan, to help us reflect on what had worked well, what had been challenging, what had been learned and what could be improved.

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<sup>1</sup> **Public contributor** is the general term we use to describe a member of the public involved in CCF's work:

- as a **public reviewer** of research applications; and/or
- as a **panel member** of our research programme decision-making committees and panels and/or
- in **other activities** such as developing guidance, sitting on interview panels, etc.

To give some sense of the variety of ways in which public contributors are involved in CCF's work and the numbers of people involved, **Figure 1** below, offers a numerical summary against key activities. This and other work is reported in more detail in **Section D**.



**Fig. 1:** Examples of how public contributors worked with CCF during 2016/17

## B. Purpose of the report

This report focuses on our work during 2016/17 to deliver five strategic objectives<sup>2</sup> through 19 key projects and activities described in our PPIE Plan. It is a performance management report that summarises and comments on the extent to which we successfully completed the work and the lessons learned. If you would like to know any more about our work please get in touch with our [PPI team](#):

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In a shorter, related report, [The public as our partners](#) we provide some examples of how this work makes a difference. We have also summarised in [Appendix A](#) how this PPIE Plan has supported delivery of the NIHR's overarching goals for PPI<sup>3</sup>.

Under each of our five PPIE strategic objectives - reach, support, knowledge, integration, communication and accessibility - this report provides:

- a summary of the 19 projects and activities in the PPIE Plan 2016/17 with key milestones and success indicators, and
- a brief description of key outputs and outcomes and the extent to which the projects and activities achieved their milestones and success indicators.

By '**outputs**' we mean the tangible products, resources or services resulting from delivery of the plan.

By '**outcomes**' we mean the changes, benefits, costs, learning or other effects that happened as a result of delivering the plan. They can be wanted or unwanted, expected or unexpected.

By '**milestones and success indicators**' we mean the tasks, outputs or outcomes that we agreed were significant to a project or activity from the outset, when the plan was first written.

Whilst the CCF PPI team is entirely responsible for the content of this report we acknowledge and thank the three public contributors who formed an advisory group that meet with the PPI team to review and discuss our 2016/17 work programme and to review and revise our plans for 2017/18.

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<sup>2</sup> See: [Patient and Public Involvement and Engagement \(PPIE\) Plan 2016/18](#) for more information.

<sup>3</sup> See: [Going the Extra Mile: Improving the nation's health and wellbeing through public involvement in research](#) (2015) for more information.

## C. Summary of projects undertaken in 2016/17

**Table 1** below, provides a numerical summary of projects and activities undertaken in 2016/17. For each of our PPIE Plan's five strategic objectives, the table lists the number of associated key milestones and success indicators. Overall, we completed 17 of our 19 (89%) projects and achieved 41 (84%) of our 49 milestones and success indicators of which 34 (69%) were achieved to time. We will complete the 8 (16%) outstanding milestones and indicators either as originally planned in 2016/17 or adapted for inclusion in our 2017/18 action plan.

<b>PPIE strategic objectives 2016/17</b>	<b>No. of key projects completed</b>	<b>Milestones and success indicators achieved</b>	<b>Milestones and indicators achieved to time</b>
1. Reach	3 of 3	9 of 10	6 of 10
2. Support	4 of 4	12 of 12	11 of 12
3. Knowledge	3 of 4	8 of 10	8 of 10
4. Integration	3 of 3	5 of 5	4 of 5
5. Communication and accessibility	4 of 5	7 of 12	5 of 12
<b>Totals</b>	<b>17 of 19</b>	<b>41 of 49</b>	<b>34 of 49</b>

**Table 1:** CCF PPIE Action Plan 2016/17: Numbers of key projects undertaken and completed, key milestones and success indicators achieved.

## D. Delivery of projects in 2016/17 Action Plan

This section details each of the 19 projects and activities in the 2016/17 Action Plan with their associated milestones and success indicators. For each project, there is a report on key outputs and outcomes and whether milestones and indicators were achieved.

### Objective 1: REACH

To involve a diverse community of public contributors providing knowledge, experience and insight from a wide range of perspectives.

#### Project/Activity 1.1

We will recruit and support public contributors with diverse knowledge and experience as patients and/or carers to review funding applications and to sit on advisory panels for the funding competitions and research programmes that CCF manages.

#### Milestones and success indicators

- A.** By December 2016, recruit and support the induction of 11 public contributors as members of research programmes' panels. (These are the research programmes that CCF manages: Research for Patient Benefit Programme (RfPB), Programme Grants for Applied Research (PGfAR), Invention for Innovation Programme (i4i) and the Policy Research Programme (PRP).)
- B.** During 2016/17, recruit, support and review the involvement of public contributors for the following competitions: NIHR Nominations to the Advisory Committee on Clinical Excellence Awards, Biomedical Research Centres, Clinical Research Facilities, Horizon Scanning Research and Intelligence Centre, Diagnostic Evidence Co-operatives, Patient Safety Translational Research Centres and Senior Investigators' competition.
- C.** Provide a public review per full funding application to the research programmes managed by CCF. (In 2015/16, this was a total of 264 reviews).
- D.** By March 2017, recruit, support and involve 35 new reviewers, representing an increase of approximately 15% on the number of reviewers active in 2015/16.

#### Key outputs and outcomes

- From July 2016 to March 2017, 31 applications received for the role of public member on a programme panel, from whom 21 were interviewed and 11 recruited to join PGfAR, RfPB and PRP panels. Induction (incl. welcome pack, observing a panel meeting, meeting the Chair and CCF staff, phone briefing/debriefing) took place from July 2016 onwards.
- From May 2016 to January 2017, 11 public contributors were involved as reviewers and panel members for the following six competitions: NIHR Nominations to the Advisory Committee on Clinical Excellence Awards, Biomedical Research Centres, Clinical Research Facilities, Horizon Scanning Research and Intelligence Centre, Patient Safety Translational Research Centres and Senior Investigators' competition. This included a process of briefing and debriefing public contributors to review, learn from and improve both PPI in the selection process as well as PPI in the applications.
- In 2016/17, a total of 265 full applications were reviewed by 187 public reviewers and submitted to four research programmes: RfPB, i4i, PGfAR and PRP.
- At year end, an additional 77 public contributors registered on Reviewer Match representing an increase of 35%. However, almost all (64 of the 77) were not 'new' to CCF but were existing reviewers who had not previously registered on Reviewer Match.

### **Milestones and indicators achieved**

- **A, B** and **C** were achieved and met to time.
- Indicator **D** was not met as only 6% of reviewers were genuinely 'new'. The PPI team has undertaken a number of activities to develop its knowledge and understanding of involving young people (see Project/Activity 1.3 below). These plans are still in development and have not yet resulted in the recruitment of reviewers. However, this work will be taken forward as part of our 2017/18 action plan with an initial focus on working with 15-25 year olds.

### **Project/Activity 1.2**

We will continue to develop and test [Reviewer Match](#) to record, search and maintain information about public contributors' experience of health conditions as patients or carers so we can match their experiences with research topics in individual funding applications.

We will analyse the experiences of reviewers to identify if there are any significant gaps between the topics of research applications we receive and reviewers' experiences. Where there are significant gaps we will work with community, patient/carer and other groups to recruit reviewers. We will use the [health categories](#) from the [UKCRC Health Research Classification System](#) to help do this. This can't be an exact process, as not all research studies or health needs fit neatly into 'health categories' - for example, obesity, frailty, long term conditions, multiple morbidities, or rare diseases. So, we encourage our reviewers to use whichever categories fit their experience and they may choose several.

### **Milestones and success indicators**

- A.** By September 2016, analysis of baseline data, comparison with topics of funding applications over two previous years to identify any significant gaps.
- B.** By April 2017, recruit one or more new reviewers per identified gap.
- C.** By April 2017, repeat snapshot of current patient/carer experiences and compare with baseline data.

### **Key outputs and outcomes**

- Analysis of the Reviewer Match baseline data was undertaken in December 2016 and compared to research application topics received between 2014 and 2016. Completion of this work was delayed as it took longer than expected to access the applications dataset and other projects with less flexible deadlines were prioritised.
- Analysis of the data showed that there is a reasonable match between the topics of research applications that CCF receives and reviewers' lived experiences as patients and/or carers. For further information, please read the [summary report](#).
- The [Research Involvement and Engagement](#) journal has recently adopted the same classification list used by CCF in Reviewer Match for matching their public reviewers.

### **Milestones and indicators achieved**

- **A** was achieved but not to time. There was a delay in accessing information about the funding applications that had been reviewed over the previous two years.
- **B** was achieved in as much as the analysis didn't identify any significant gaps between the topics of research applications we receive and reviewers' experiences as patients and carers.
- **C** was achieved but not completed to time.

### Project/Activity 1.3

We will continue to ask all public contributors who have completed Reviewer Match to complete an equality and diversity monitoring form. The anonymised data that people provide, gives us information about 'protected characteristics' such as age, gender and ethnicity. This helps us to understand more about the diversity of our reviewer population. By comparing this data to similar data for the UK population we can focus our recruitment of new reviewers on people with protected characteristics who are currently seldom involved in our work.

We will explore with colleagues in the NIHR if there is an opportunity to use our Equality and Diversity Reporting System (EDRS) as a way of measuring 'Reach', one of the three indices of success described in Recommendation 5 in the [Going the Extra Mile](#) report (2015).

#### Milestones and success indicators

- A.** During 2016/17, 50% or more response rate from those invited to complete the form.
- B.** By September 2016, analyse and publish baseline data in comparison with UK-wide data for each protected characteristic to identify any significant gaps.
- C.** By April 2017, we will work with groups and communities who are currently seldom involved in our work to help us recruit and support new reviewers for protected characteristics that are identified as significant gaps. We will continue to monitor numbers for changes over time.

#### Key outputs and outcomes

- In September 2016, the EDRS diversity data was analysed and compared with the UK-wide ONS data for each protected characteristic. A [summary report](#) on the diversity of CCF public contributors was published on the NIHR website.
- Given the small numbers of people involved (122 out of a potential 220) we are cautious of over interpreting the data. It did however indicate that there appear to be relatively few people under the age 40 involved as reviewers and this was explored further by the PPI team. Two specific projects focused on involving younger people will be carried forward in our 2017/18 PPIE Plan.
- Work has started to involve young people as reviewers in the form of two separate projects: (a) involving young people (15-25 years) as reviewers of funding applications where the research participants are young people and (b) involving people under the age of 40 as public reviewers of all/any funding applications. For project (a), we approached a Children and Young People's Group in London for advice and guidance and invited an external adviser to run a workshop for the PPI team to help us develop the outline of a project for our 2017/18 action plan. As a result of these initial discussions a decision was made to work with young people (15-25 years old) rather than children at this stage, given the need for additional resources. For project (b), we contacted the Centre for Public Engagement and again have worked with them to develop a project that will aim to recruit young students (18-25 years old) as public reviewers. This work is featured in our [PPI Highlights Report 2016/17](#).
- By April 2017, four people under 21 years old applied to join CCF funding panels, with one of those people appointed to join the Invention for Innovation Challenge Fund Panel.

#### Milestones and indicators achieved

- **A** and **B** were achieved but not to time.
- **C** was achieved in so far as we have identified that we need to reach and involve more young people. We have started collaborating with individuals, groups and organisations to inform and develop our understanding of the issues.

## Objective 2: SUPPORT

To provide information, resources, learning and support that enables public contributors and CCF's staff to work together competently and confidently.

### Project/Activity 2.1

We will monitor and review implementation of the [CCF Policy: Learning and support for patient and public involvement](#).

#### Milestones and success indicators

- A.** By September 2016, policy approved and made publicly available.
- B.** Quarterly monitoring of delivery of the policy by the CCF PPI team to ensure feedback from learning and support activities is regularly collected and reviewed.
- C.** By February 2017, report on delivery of the policy to date with any recommendations for change.

#### Key outputs and outcomes

- The policy was endorsed by CCF's Senior Leadership Team in August and circulated to public contributors and staff in September. It was made publicly available on the NIHR website and then shared via newsletters, NIHR news stories, external networks (e.g. [CHAIN](#)) and social media. It is routinely shared with all new public contributors and forms part of CCF staff induction for PPI.
- The PPI team has developed an implementation checklist for monitoring and reviewing the feedback that is collected from learning and support activities on a quarterly basis and this informs regular discussions at team meetings. Feedback provides the basis for making improvements to future events followed by review of the outcomes of changes made. This is a continual improvement process.
- As at March 2017, the PPI team is completing a report on progress with delivery of the policy and some suggested changes. This will be submitted to CCF's Senior Leadership Team for review and endorsement.

#### Milestones and indicators achieved

- **A** and **B** were achieved and met to time.
- **C** was achieved but not met to time. This work was delayed as other projects and activities were prioritised by the PPI team.

### Project/Activity 2.2

Involving workshop participants, we will design and deliver a learning and support workshop that brings together public members, the Programme Director, panel chairs and programme managers of the Research for Patient Benefit Programme.

#### Milestones and success indicators

- A.** By December 2016, participants are successfully involved in the development and delivery of the workshop, according to feedback from participants.
- B.** By December 2016, the aims of the workshop are met, according to feedback from participants.
- C.** By April 2017, progress on any actions from the workshop are reported and followed up, as agreed by participants.

### **Key outputs and outcomes**

- The workshop for the RfPB programme was designed with the involvement of all those taking part. It focused on identifying and addressing areas for improvement and information sharing. Whilst a workshop is resource intensive for all involved, it is particularly useful for addressing programme specific issues, and in reviewing and (re)aligning PPI objectives. The workshop was rated highly by those who attended. There is more information about this event in our [PPI Highlights report 2016/17](#).
- Further learning was achieved by inviting PPI colleagues from the NIHR Evaluations, Trials and Studies Coordinating Centre (NETSCC) to attend the RfPB workshop and CCF PPI team attendance at a NETSCC workshop for public contributors.
- During 2016/17, all four the PPI team members observed RfPB, i4i, PGfAR and PRP panel meetings to increase their knowledge and understanding of individual programme decision-making processes and to review and reflect on the support offered to public members.

### **Milestones and indicators achieved**

- All three indicators and milestones were achieved and met ahead of time.

## **Project/Activity 2.3**

We will work with the NIHR Faculty to plan and deliver learning and support about patient and public involvement and engagement (PPIE) in research as part of a training camp for approximately 80 NIHR trainees.

### **Milestones and success indicators**

- A.** Throughout 2016/17, participate in regular conference calls with the planning team, helping to shape the PPIE agenda and recruit public contributors to offer advice and guidance to the trainees at the training camp.
- B.** In July 2016, support a range of activities at the training camp (including a workshop, one-to-one advice, guidance from public contributors and a public panel member).
- C.** By end of August 2016, seek feedback from trainees and other participants about their learning experience, participate in a debriefing meeting to explore feedback, document and share organisational learning from the event.

### **Key outputs and outcomes**

- As a member of the core planning team, CCF used feedback from the previous year's event in 2015 to make changes to the PPI activities. For example, two public contributors were involved in designing and delivering a PPI workshop at the 2016 camp.
- In addition, two former and two new public contributors were recruited to act as PPI advisors to trainees attending the event and another public contributor was involved as a member of a mock funding panel.
- At the camp, a broad range of PPI learning and support opportunities were made available to trainees including a workshop, one-to-one advice, guidance from pairs of public advisors, questioning and assessment from a public panel member.
- Feedback was gathered from both trainees and public contributors and is being used to shape the event in 2017.

### **Milestones and success indicators**

- All three milestones and indicators were achieved and met to time.

## **Project/Activity 2.4**

We will work with colleagues in NIHR Blood and Transplant Research Units (BTRUs) and public contributors to plan and deliver a learning and support workshop to underpin the development and coordination of their strategic and operational plans for involvement, engagement and participation.

### **Milestones and success indicators**

- A.** By June 2016, participants are successfully involved in the development and delivery of the workshop, according to feedback from participants.
- B.** By June 2016, the aims of workshop are met, according to feedback from participants.
- C.** By September 2016, progress on any actions from the workshop are reported and followed up, as agreed by participants.

### **Key outputs and outcomes**

- The workshop marked the start of the BTRUs' five-year contracts. It was designed and delivered by the PPI team with the public member of the BTRUs' competition advisory panel and with input from the four BTRUs and NHS Blood and Transplant (NHSBT).
- The PPI team produced a summary report for the BTRUs including materials (slides, links to key resources) shared at the workshop. Feedback from participants reflected that the workshop had been informative and had met its aims.
- In March 2017, NHSBT and the BTRUs organised a follow up workshop that gave the PPI leads an opportunity to update on progress being made and to share learning. Whilst CCF staff and the public panel member were workshop participants the emphasis was very much on the future of the group being led by NHSBT and the BTRUs. The group plans to invite BTRU public members to its next meeting in October 2017.

### **Milestones and indicators achieved**

- All three milestones and indicators were achieved and met to time.

## Objective 3: KNOWLEDGE

To contribute to developing and sharing knowledge about patient and public involvement, engagement and participation and to putting it into practice.

### Project/Activity 3.1

We will monitor and provide feedback to parts of the NIHR managed by the CCF, such as research schools, research centres, facilities and units, on their progress in developing and delivering their strategic plans for patient and public involvement, engagement and participation (PPIEP).

#### Milestones and success indicators

- A. By September 2016, complete reviews of the PPIEP section of annual progress reports from over 100 NIHR infrastructure initiatives, schools and units.
- B. By October 2016, compile and publish the PPIEP sections of annual monitoring reports submitted to the CCF as a method of highlighting and sharing good practice.
- C. October 2016 - April 2017, meetings with PPI leads to highlight and discuss successes, good practice and areas for improvement as identified in annual progress reports.
- D. Throughout 2016/17, PPI team to provide input for all site visits undertaken by CCF's Infrastructure team and to attend site visits where PPIEP has been highlighted for review.

#### Key outputs and outcomes

- From June to September 2016, the PPI team reviewed and drafted written feedback on the PPIEP content of over 100 annual progress reports.
- In October 2016, CCF published the PPIEP sections of annual reports on the NIHR website. By April 2017, over 11,000 copies of the reports for 2014/15 and 2015/16 have been downloaded. Feedback from organisations and public contributors about the publication of PPIEP sections of annual reports continues to be positive.
- This year we provided three dedicated feedback sessions on the PPIEP content of annual reports to groups of PPI leads as there were four major funding competitions that were active during the year.
- A regular six-monthly meeting with the Department of Health, the Director of INVOLVE and the NIHR National Director for Patients and the Public in Research has been established as a further mechanism for ensuring that learning from annual reports is reviewed and reflected in NIHR-wide strategic and operational plans.
- CCF regularly visits the research schools, centres, units and facilities that it manages to review and monitor their progress. In 2016/17, the PPI team took part in several meetings to discuss and review progress in the delivery of PPIEP plans with Centre Directors, public contributors, Managers and PPI leads in Blood and Transplant Research Units, Patient Safety Translational Research Centres, Collaborations for Leadership in Applied Health Research and Care and Biomedical Research Centres and Units.

#### Milestones and indicators achieved:

- All four milestones and indicators were achieved and met to time.

## Project/Activity 3.2

We will review and map the different types and sources of PPI data (such as funding applications, reviews, progress and finance reports) that are routinely collected by CCF's information systems. We will look to identify ways in which such data could potentially be put to additional use to support the development of NIHR intelligence, knowledge and good practice.

### Milestones and success indicators:

**A.** By October 2016, publish a report outlining types and sources of CCF's PPI data and ways in which some of these data could be put to additional use.

**B.** By April 2017, organise a seminar or workshop with the NIHR PPI Senior Leadership Team and use the report as a catalyst for further NIHR-wide development of the three indices - Reach, Relevance, Refinement and improvement – described in [Going the Extra Mile](#).

### Key outputs and outcomes

- In October 2016, we published a [Review of PPI routine data collected by CCF](#). The review documented the wealth of PPI data that already exists within just one of the five NIHR Coordinating Centres. It mapped data collected by the CCF as an intrinsic part of NIHR research management and decision-making processes and considered the additional ways the data could potentially be used to describe the impact of PPI on NIHR-funded research.
- In December 2016, CCF convened a workshop on behalf of the NIHR PPI Senior Leadership Team and worked with NIHR public contributors, PPI leads, CCF's Impact team and others to explore:
  - developing an NIHR approach to assessing PPI impact on research
  - using PPI routine data to develop and share NIHR intelligence and knowledge of PPI impact.
- A [workshop report](#) summarising discussions and presentations was published in February 2017. In March 2017, the NIHR Senior Leadership Team discussed the workshop and an additional paper written by the CCF PPI team which set out four options for developing an NIHR-wide approach to PPI impact. This has informed the development of Project/Activity 4.2 in next year's action plan

### Milestones and indicators achieved

- Both milestones and indicators were achieved and met to time.

## Project/Activity 3.3

We will work with CCF staff, public contributors and others to monitor the delivery of PPI in funded research projects and programmes. We will develop and share examples of good practice that demonstrate how PPI is monitored by CCF programme managers during the delivery of a research project. This will include reflections from the perspectives of:

- public contributors
- programme managers
- research teams

The aim of providing these examples is to help both researchers and CCF staff develop a better understanding of what good practice looks like in relation to delivering PPI during the lifetime of a research project.

#### **Milestones and success indicators**

**A.** By April 2017, each of the four research programmes managed by CCF will produce one example of how their programme monitors the delivery of PPI in funded research projects and programmes.

**B.** Once available online, we will monitor the number of times these documents are accessed and downloaded as a way of gauging their reach.

#### **Key outputs and outcomes**

- This project was delayed as other activities took precedence and were prioritised by the PPI team.
- The project was developed and is being delivered by CCF's internal [PPI Working Group](#). This group brings together the PPI team with other members of CCF staff who have specific responsibility for PPI in their team's work.
- The key output of this project will now be a guidance document for both researchers and CCF programme managers. '*Guidance on effective practice in monitoring PPI*' will outline the areas of PPI activity that researchers are expected to report on whilst projects are underway. It will include examples of good practice drawn from previous monitoring reports. The guidance also aims to aid programme managers when monitoring the delivery of PPI in research projects.

#### **Milestones and indicators achieved**

- **A** and **B** have not yet been met. However, this project will be completed in 2017.

### **Project/Activity 3.4**

We will publish an annual report that summarises progress in delivering this Action Plan within CCF's Patient and Public Involvement and Engagement Plan 2016-18.

#### **Milestones and success indicators**

**A.** By July 2017, publication of our annual progress report.

**B.** Once available online, we will monitor the number of times our annual progress report for 2015/16 is accessed and downloaded during 2016/17 as a way of gauging reach.

#### **Key outputs and outcomes**

- Throughout 2016/17, the PPI team held monthly meetings to monitor delivery of all projects in the PPIE Plan. Progress was recorded and summarised in an internal monthly report. Where remedial action was required it was discussed, agreed and acted upon. Our Director of Involvement and Engagement has reported regularly to the Director of CCF on progress in delivery of the Plan.
- This annual report was published in June 2017 in conjunction with a shorter, highlights report of our PPIE activities in 2016/17, [The public as our partners](#). Both documents are publicly available on the NIHR website.
- In 2015/16, our annual report was downloaded just over 500 times. Whereas the Highlights report for the same year was downloaded well over 3,000 times.

#### **Milestones and indicators achieved**

- Both milestones and indicators were achieved and met to time.

## Objective 4: INTEGRATION

To ensure that patient and public involvement, engagement and participation are integrated strategically and effectively across the NIHR.

### Project/Activity 4.1

We will take an active part in the NIHR PPI Senior Leadership Group (SLT), established to provide strategic coordination and to oversee the implementation of the recommendations from the NIHR strategic review, *Going the Extra Mile*.

#### Milestones and success indicators

A. Current success indicators for the work of this Group are defined in relation to progress in delivery of the recommendations from [Going the Extra Mile](#).

#### Key outputs and outcomes

- During the year CCF has continued to take on responsibility for oversight and delivery of two recommendations in the *Going the Extra Mile* report - Recommendations 2 (Standards - jointly with INVOLVE) and 9 (Plans and reporting). Through the PPI SLT, CCF has also initiated some NIHR-wide working on the collection of PPI routine data and assessing PPI impact (Recommendation 5).
- Public contributors working with the PPI team have also contributed to the delivery of other recommendations in *Going the Extra Mile* including: 1b (NIHR website), 1c (New media competition), 4 (Learning and development), 6 (Co-production), 7b (Joint planning and resourcing).
- CCF instigated and, working with INVOLVE, planned a PPI SLT strategy day that provided an opportunity to step back and review strategic direction and priorities.

#### Milestones and indicators achieved

- In relation to the projects where CCF has a leadership role their milestones and indicators are recorded under Project/Activity: 3.2 and 4.2.

### Project/Activity 4.2

We will continue to work with INVOLVE and others across and beyond the NIHR, to develop a set of NIHR-wide, organisational standards for PPI. This project addresses Recommendation 2 in the 'Going the Extra Mile' report.

#### Milestones and success indicators

- A. During 2016/17, monitor the number of downloads of the [PPI standards workshop summary report](#) published in May 2016.
- B. In July 2016, work with INVOLVE to agree next steps and develop an outline project plan.
- C. By October 2016, set up a communications platform for the project, for example, a website and email distribution list.
- D. By April 2017, complete the development of an initial set of standards for piloting in 2017/18.

### Key outputs and outcomes

- Over the course of the year the Standards Partnership has extended from NIHR and Health and Care Research Wales to also encompass the Chief Scientist's Office, Scotland and the Public Health Agency, Northern Ireland.
- By April 2017, the Partnership developed a set of six draft standards and indicators that will be put out for review and improvement in June 2017 to as wide a network of stakeholders as possible.
- By April 2017, the Partnership established the opportunity to collaborate with the [Research Design Service](#) to manage the consultation process, analyse responses and make recommendations for improvement to the Partnership.
- In March 2017, CCF created and launched a [Public Involvement Standards Development](#) website as a communication platform for the project. Over 200 people have joined the [Standards Network](#) through which they receive updates and can get involved in the project.

### Milestones and indicators achieved

- **A** and **B** were achieved and met to time. In the year, over 2,000 copies of the [PPI standards workshop summary report](#) were downloaded.
- **C** was achieved but not to time as the preparatory work involved proved to take much longer than originally planned.
- **D** was achieved and met to time. The process of piloting is expected to take place in 2018 with a handful of 'pathfinder' groups, teams and organisations.

## Project/Activity 4.3

CCF is exploring the feasibility of establishing a CCF External Reference Group. If established, any such group will involve public contributors in its membership.

### Milestones and success indicators

**A.** If the Group is established, to work with public contributors and develop suitable processes for recruiting and supporting public members of the Group.

### Key outputs and outcomes

- In 2016/17 plans for establishing a CCF External Reference Group were put on hold whilst a contract tender process for the CCF was underway.
- If such a group is eventually established the PPI team will work with the public contributors who have been involved in CCF's PPI annual planning and reporting cycle to develop suitable processes for recruiting and supporting public members in the Group.

### Milestones and indicators achieved

- **A** was 'achieved' in as much as the Group was not established and therefore no further action was taken.
- This activity will not be taken forward as a project in our next action plan as it was already carried forward from the previous year's plan.

## Objective 5: COMMUNICATION AND ACCESSIBILITY

To raise public awareness of research, to encourage people to get involved and make research more accessible to the public.

### Project/Activity 5.1

CCF will work with colleagues across the NIHR to review and refresh the [NIHR website](#). CCF's PPI team is part of a working group, which has been established to restructure and redevelop the 'Get Involved' section of the site. This project addresses Recommendation 1b in the '*Going the Extra Mile*' report.

We will also work with public contributors and other colleagues to develop new visual materials and content to ensure that opportunities for involvement are visible, attractive and easily accessible to patients and the public.

#### Milestones and success indicators

- A.** By June 2016, recruit and support public contributors to the 'Get involved' working group.
- B.** By August 2016, involve public contributors as test users of the current site to redevelop the structure and content of the 'Get Involved' pages.
- C.** By October 2016, revised structure and content of website completed with successful user testing by public contributors leading to further improvements.

#### Key outputs and outcomes

- CCF collaborated with other NIHR Coordinating Centres and public contributors to redevelop the NIHR website. A 'Get Involved' working group was established in April 2016 to manage and direct work on the patients and public section of the website.
- In May 2016, three public contributors joined the group (increasing to four in July)
- In late June/July 2016, interviews were carried out with members of the public to assess the look and content of the 'Get involved' section of the website. A new name for the section, *Patients and the Public*, was agreed by the group.
- New structure and content of the [Patients and the Public](#) section was completed in October 2016 and the refreshed NIHR website was launched on 24 October 2016.
- Following further improvements, a consultation on the *Patients and the Public* section of the website took place between January and March 2017, with the results expected in spring 2017.

#### Milestones and indicators achieved

- **A** and **B** were achieved and met to time.
- **C** was achieved but not met to time.

## Project/Activity 5.2

We will support campaigns and events that aim to make research more accessible to the public and raise awareness of research. We will support the *OK to ask* campaign as members of a NIHR-wide working group by managing *OK to ask* on Facebook and publicising the campaign via social media, newsletters, emails, staff meetings etc. Also as part of the campaign, CCF will take part in a local (Twickenham) street market to raise awareness of research, the NIHR and opportunities to get involved in research.

### Milestones and success indicators

**A.** In June 2016, benchmark *OK to ask* level of activity on Facebook in 2015. Keep Facebook active throughout the year and look to extend reach in 2016 in comparison to benchmark.

**B.** Engage 100+ people in conversation at the street market and provide them with further information about getting involved in research such as signing up to [Join Dementia Research](#) or finding out about opportunities to get involved in CCF.

### Key outputs and outcomes

- CCF's Communications team managed the *OK to ask* campaign Facebook page. Activity during May 2016 around International Clinical Trials Days is summarised below and will form the benchmark for activity in 2017.

In May 2016, there were:

- 500 page views = number of people who visited the page
- 8,198 people reached = number of people who saw some part of the page content
- 77 page likes = number of people who chose to endorse the page
- 166 video views = number of times any videos linked to the page were viewed
- On Twitter, CCF's Communications team and PPI team also actively supported the *OK to ask* campaign through @NIHR\_CCF (1,000+ people), the CCF newsletter (2,500+ people), emails to public contributors (350+ people), CCF staff meetings (100+ people).
- In June, a group of CCF staff took part in a Twickenham street fair to support the *OK to ask* campaign. We ran a mock trial with 200 cupcakes, talked and handed out leaflets/postcards to over 240 local residents about research and the NIHR. Most people were unaware of the NIHR or [Join Dementia Research](#) but interested to find out more and supportive of publicly funded research.

### Milestones and indicators achieved

- Both milestones and indicators were achieved and met to time.

## Project/Activity 5.3

Building on CCF's involvement in the NIHR Digital Engagement Group we will continue to use social media and e-communications to raise awareness of research and support involvement, engagement and participation in research.

### Milestones and success indicators

**A.** In 2016/17, increase in our reach as a result of using of social media in comparison with baseline data collected in the previous year.

### **Key outputs and outcomes**

- From October 2016 and as a result of new processes and access put in place around the management of the @OfficialNIHR Twitter account, CCF was able to input directly to the feed. Posting through the @OfficialNIHR feed which has a following of 32.7K (vs 1.2K on CCF's account) ensures a much wider reach including patients and the public. There was an overlap of over 90% of CCF Twitter followers and @OfficialNIHR. The CCF account was closed in October.
- Throughout the year, the CCF Communications Team tweeted about opportunities to get involved and sent live tweets from CCF PPI workshops, events attended, etc.
- It is no longer possible to track individual tweets that relate to CCF's PPI activities and NETSCC reports on reach and other usage of @OfficialNIHR Twitter account. We need to discuss with all colleagues using @OfficialNIHR how we can best track the impact of our PPI related activities.

### **Milestones and indicators achieved**

- A was achieved and met to time. Last year at year end, using the CCF Twitter account, our reach was through 700 followers whereas now our reach is over 30,000.

## **Project/Activity 5.4**

We will support the production of content for a page of PPI resources on the Faculty Trainees section of the NIHR website. This will include inspirational video clips of researchers and those working in research environments talking about the impact PPI has had on their research.

### **Milestones and success indicators**

- A. By August 2016, complete filming and editing of video clips
- B. By October 2016, resources page completed
- C. In 2016/17, we will monitor the numbers of those visiting the webpage and the resources that are accessed to shape future improvements.

### **Key outputs and outcomes**

- In June, 10 researchers and public contributors who responded to a request for interviewees were filmed talking about the ways in which PPI had contributed to their research. Unfortunately, it was not possible to use the video clips in the way that was originally planned.
- However, as part of our 2017/18 action plan the CCF Communications team will use audio clips and photographs from the films to develop a series of 'behind the research' stories that will be used to promote the [Two sides of health](#) campaign.

### **Milestones and indicators achieved**

- None of the milestones and indicators were achieved.

## **Project/Activity 5.5**

CCF's office is in a small street in Twickenham. We will install a screen that is visible from the street, to raise awareness of research and provide information about opportunities to get involved in research such as 'Join dementia research'.

**Milestones and success indicators**

- A.** By September 2016, screen installed, materials and systems developed and tested. System ready to go live.
- B.** By November 2016, collect baseline data. Review how, and how many, people stop to view the screen. Ask passers-by how we could improve the information provided.
- C.** By February 2016, repeat review of how, and how many, people stop to view the screen. Ask passers-by how we could improve the information provided. Compare with baseline data.

**Key outputs and outcomes**

- This screen is one of several that have been installed at CCF's offices. All screens were installed by September 2016 however the underlying system needed to display materials on the screens was not successfully installed and tested until March 2017.
- The PPI team has developed a core slide set for display in the street. This includes information about research and the NIHR, visual materials from NIHR campaigns (*OK to ask* and *Two sides of health research*), Join Dementia Research and the UK Clinical Trials Gateway.

**Milestones and indicators achieved**

**A** was achieved but not to time.

**B** and **C** were not achieved. This project will be taken forward as part of our 2017/18 action plan.

**Appendix A:  
How CCF’s Plan supports delivery of the NIHR’s strategic objectives for 2025**

The [Going the Extra Mile](#) report followed an independent review of public involvement in the NIHR. Together its vision, mission, strategic goals and principles aim to provide “a clear sense of direction for the next decade and to make transparent the purpose and intent of public involvement to all the NIHR’s partners, but most especially to the public and researchers.”. **Figure 1** below lists the six NIHR public involvement strategic goals.

NIHR Strategic goals for 2025
<ul style="list-style-type: none"> <li>① Opportunities to engage and become involved in research are visible and seized by the public.</li> <li>② The experience of patients, service users and carers is a fundamental and valued source of knowledge.</li> <li>③ Public involvement is a required part of high quality research conducted by researchers and their institutions.</li> <li>④ Public involvement is locally driven and relevant whilst strategically consistent with the NIHR’s goals.</li> <li>⑤ Evidence of what works is accessible so that others can put it into practice.</li> <li>⑥ The NIHR has maintained its global presence and influence for working in partnership with the public.</li> </ul>

**Figure 1.** NIHR Public Involvement Strategic Goals for 2025

In developing our Action Plan for 2016/17, we reviewed and aligned our activities with these NIHR-wide strategic goals. **Figure 2** maps how projects within the Action Plan have contributed or are contributing towards the collective delivery of NIHR-wide strategic goals.

<p><b>Objective 1: REACH</b> To involve a diverse community of public contributors providing knowledge, experience and insight from a wide range of perspectives.</p>	
<p><b>1.1</b> Recruit and support public contributors with diverse knowledge and experience as patients and/or carers to review funding applications and to sit on advisory panels for the funding competitions and research programmes that CCF manages.</p> <p><b>1.2</b> Continue to develop and test <i>Reviewer Match</i> to record, search and maintain information about public contributors’ experience of health conditions as patients or carers so we can match their experiences with research topics in individual funding applications.</p> <p><b>1.3</b> We will continue to ask all public contributors who have completed <i>Reviewer Match</i> to complete an equality and diversity monitoring form.</p>	<p>① ②</p> <p>② ④</p> <p>① ④</p>

<p><b>Objective 2: SUPPORT</b>  <b>To provide information, resources, learning and support that enables public contributors and the CCF's staff to work together competently and confidently.</b></p>	
<p><b>2.1</b> Monitor and review implementation of 'CCF Policy: Learning and support for patient and public involvement'.</p> <p><b>2.2</b> Design and deliver a learning and support workshop that brings together public members, the Programme Director, panel chairs and programme managers of the Research for Patient Benefit Programme.</p> <p><b>2.3</b> Work with the NIHR Faculty to plan and deliver learning and support about patient and public involvement and engagement (PPIE) in research as part of a training camp for approximately 80 NIHR trainees.</p> <p><b>2.4</b> Work with colleagues in NIHR Blood and Transplant Research Units (BTRUs) and public contributors to plan and deliver a learning and support workshop to underpin the development and coordination of their strategic and operational plans for involvement, engagement and participation.</p>	<p>② ⑤</p> <p>② ④</p> <p>③ ④ ⑤</p> <p>③ ④ ⑤</p>

<p><b>Objective 3: KNOWLEDGE</b>  <b>To contribute to developing and sharing knowledge about patient and public involvement and engagement and to putting it into practice.</b></p>	
<p><b>3.1</b> Monitor and provide feedback to parts of the NIHR managed by the CCF, such as research schools, research centres, facilities and units, on their progress in developing and delivering their strategic plans for patient and public involvement, engagement and participation (PPIEP).</p> <p><b>3.2</b> Review and map the different types and sources of PPI data (such as funding applications, reviews, progress and finance reports) that are routinely collected by CCF's information systems. We will look to identify ways in which such data could potentially be put to additional use to support the development of NIHR intelligence, knowledge and good practice.</p> <p><b>3.3</b> Develop and share examples of good practice that demonstrate how PPI is monitored by CCF programme managers during the delivery of a research project.</p> <p><b>3.4</b> Publish an annual report that summarises progress in delivering this Action Plan within CCF's Patient and Public Involvement and Engagement Plan 2016-18.</p>	<p>③ ⑤</p> <p>③ ⑤</p> <p>③ ⑤</p> <p>⑤</p>

<p><b>Objective 4: INTEGRATION</b>  <b>To ensure that patient and public involvement, engagement and participation are integrated strategically and effectively across the NIHR.</b></p>	
<p><b>4.1</b> Take an active part in the NIHR PPI Senior Leadership Group (SLT), established to provide strategic coordination and to oversee the implementation of the recommendations from the NIHR strategic review, <i>Going the Extra Mile</i>.</p> <p><b>4.2</b> Continue to work with INVOLVE and others across and beyond the NIHR, to develop a set of NIHR-wide, organisational standards for PPI. This project addresses Recommendation 2 in the 'Going the Extra Mile' report.</p> <p><b>4.3</b> CCF is exploring the feasibility of establishing a CCF External Reference Group. If established, any such group will involve public contributors in its membership.</p>	<p>④ ⑤ ⑥</p> <p>③ ④</p> <p>② ④</p>

<p><b>Objective 5: COMMUNICATION AND ACCESSIBILITY</b>  <b>To raise public awareness of research, to encourage people to get involved and make research more accessible to the public.</b></p>	
<p><b>5.1</b> CCF will work with colleagues across the NIHR to review and refresh the NIHR website. CCF's PPI team is part of a working group, which has been established to restructure and redevelop the 'Get Involved' section of the site.</p> <p><b>5.2</b> Support the OK to ask campaign as members of a NIHR-wide working group by managing OK to ask on Facebook and publicising the campaign via social media, newsletters, emails, staff meetings etc. Also as part of the OK to ask campaign, CCF will take part in a local (Twickenham) street market to raise awareness of research, the NIHR and opportunities to get involved in research.</p> <p><b>5.3</b> Continue to use social media and e-communications to raise awareness of research and support involvement, engagement and participation in research.</p> <p><b>5.4</b> Support the production of content for a page of PPI resources on the Faculty Trainees section of the NIHR website.</p> <p><b>5.5</b> Install a screen that is visible from the street, to raise awareness of research and provide information about opportunities to get involved in research such as 'Join dementia research'.</p>	<p>① ② ④</p> <p>① ② ④</p> <p>① ② ④ ⑥</p> <p>① ② ④</p> <p>① ② ④</p>

**Figure 2.** CCF PPI objectives for 2016/17 mapped to *Going the Extra Mile* strategic goals