

# Centre for Implementation Science and King's Improvement Science Patient and Public Involvement Workshop Report

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## Involvement strategy development February 2018

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## List of abbreviations

AIRD: Active Involvement in Research Day

BAME: Black, Asian, and Minority Ethnic

BME: Black and Minority Ethnic

CIS: Centre for Implementation Science

CLAHRC South London: Collaboration for Leadership in Applied Research and Care  
South London

D&I: Diversity and Inclusion

KCL: King's College London

KIS: King's Improvement Science

LGBTQQ: Lesbian, Gay, Bisexual, Transgender, Queer, Questioning

NIHR: National Institute for Health Research

PPI: Patient and Public Involvement

PPI SOG: Patient and Public Involvement Strategic Oversight Group

SURE: Service User Research Enterprise

# 1. Background

## 1.1 Introduction to report

This report provides a detailed summary of the Patient and Public Involvement (PPI) workshop that was collaboratively delivered, on the 27<sup>th</sup> September 2017, by the Centre for Implementation Science (CIS) & King's Improvement Science (KIS) with the overarching aim of developing a PPI strategy to embed into the research and activities of CIS & KIS.

This report includes a detailed summary of the background, planning, delivery, evaluation, and outcomes of the consensus-based workshop that aimed to develop the PPI strategy of CIS & KIS. The report also provides an overview of the next steps that we plan to pursue to build upon the workshop to further develop the CIS & KIS PPI strategy.

In addition, the purpose of this report is to reflect and share our experiences of organising and delivering the workshop, highlighting the challenges and lessons learnt.

**This report is lengthy. It can be read in its entirety or sections can be selected based on reader interest.**

This report is intended to be relevant and of interest to:

- Centre for Implementation Science (CIS) staff, including the CIS Implementation Research team, King's Improvement Science (KIS) and the Patient and Public Involvement (PPI) theme.
- Patients and members of the public that attended the workshop.
- Patients and members of the public that live or use health services in South London.
- The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London Executive.
- CLAHRC South London Patient and Public Involvement (PPI) Strategic Oversight Group (SOG).
- PPI champions of the CLAHRC South London.

This report may be of interest to anyone developing PPI in their applied health services research, particularly those who wish to engage patients and the public at a strategic / programme level rather than within individual projects.

## 1.2 Background to CIS & KIS

The [Centre for Implementation Science](http://www.clahrc-southlondon.nihr.ac.uk/centre-implementation-science)<sup>1</sup> (CIS) is part of the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care ([CLAHRC](http://www.clahrc-southlondon.nihr.ac.uk/)) South London.<sup>2</sup> The CLAHRC South London is led by researchers from [King's College London](https://www.kcl.ac.uk/index.aspx)<sup>3</sup> and [St George's, University of London](https://sgul.ac.uk/).<sup>4</sup> The Centre for Implementation Science aims to develop the discipline of 'implementation science' (the science of identifying, understanding and overcoming barriers to the implementation of evidence-based interventions in healthcare) by investigating how best to help 'implement' evidence-based practice and clinical research within health services in south London and further afield. The team is looking at the role of healthcare professionals, managers, commissioners of services and policymakers as well as organisational structures and processes to try to understand how health services can put into practice the safest, most effective treatments and ways of working.

[King's Improvement Science](http://www.kingsimprovementscience.org/)<sup>5</sup> (KIS) is a sub-group within the Centre for Implementation Science. Improvement science is about conducting research that tells us how to improve and make changes in health services in the best possible way. KIS aims to help health professionals and NHS managers improve NHS services in south-east London. The specialist team of improvement scientists was set up in 2013 by [King's Health Partners](https://www.kingshealthpartners.org/)<sup>6</sup> and is funded until the end of 2018. Initially, KIS team members carried out quality improvement projects at the three NHS organisations that are part of King's Health Partners: [Guy's and St Thomas' NHS Foundation Trust](https://www.guysandstthomas.nhs.uk/Home.aspx),<sup>7</sup> [King's College Hospital NHS Foundation Trust](https://www.kch.nhs.uk/)<sup>8</sup> and [South London and Maudsley NHS Foundation Trust](http://www.slam.nhs.uk/).<sup>9</sup> The projects were instigated and led by health professionals. Now KIS is supporting the three NHS trusts' individual quality improvement and 'transformation' plans and proposals. In addition, the KIS team is developing resources and training to support quality improvement projects. KIS also has a group of research fellows working on a range of improvement and implementation science projects.

Researchers in CIS & KIS are also involved in training and education activities. They teach on the [MSc in Implementation and Improvement Science](https://www.kcl.ac.uk/study/postgraduate/taught-courses/implementation-and-improvement-science-msc.aspx)<sup>10</sup> and other short courses and organise monthly Implementation and Improvement Science seminars. They also offer expert advice to people planning quality improvement or

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<sup>1</sup> <http://www.clahrc-southlondon.nihr.ac.uk/centre-implementation-science>

<sup>2</sup> <http://www.clahrc-southlondon.nihr.ac.uk/>

<sup>3</sup> <https://www.kcl.ac.uk/index.aspx>

<sup>4</sup> <https://sgul.ac.uk/>

<sup>5</sup> <http://www.kingsimprovementscience.org/>

<sup>6</sup> <https://www.kingshealthpartners.org/>

<sup>7</sup> <https://www.guysandstthomas.nhs.uk/Home.aspx>

<sup>8</sup> <https://www.kch.nhs.uk/>

<sup>9</sup> <http://www.slam.nhs.uk/>

<sup>10</sup> <https://www.kcl.ac.uk/study/postgraduate/taught-courses/implementation-and-improvement-science-msc.aspx>

implementation science improvement projects through a specially developed '[Project Design Clinic](#)'.<sup>11</sup>

### 1.3 Background to PPI activities within CIS & KIS

CIS & KIS had carried out PPI activities separately until 2017 as PPI activities were largely at project level. After recognising that both teams wanted to improve the quality of patient and public involvement, they decided to merge efforts and funding to invest in activities that would develop an overarching PPI strategy for both the CIS implementation research team and KIS team.

The KIS projects team have carried out several quality improvement and evaluation projects and regularly contribute to teaching and training. Some projects closely involved patients and the public as project team members, other projects have involved patients through ad-hoc consultation, and some projects did not involve patients and the public.

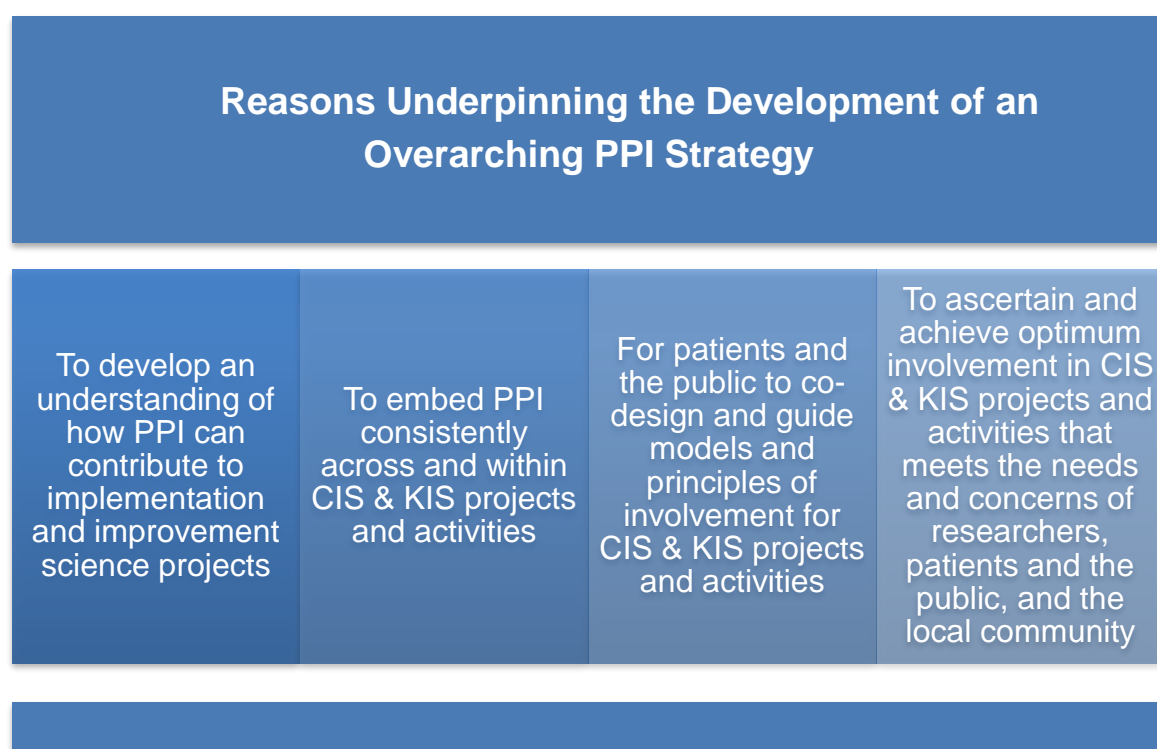
The CIS Implementation research team have also involved patients and the public on a project by project basis. Researchers have independently identified how PPI may best contribute to their work. This has varied from holding workshops to inform data collection and identify outcome measures to consulting patient advisory groups.

As such, both CIS & KIS identified the need for more consistent and continuous models of PPI, and agreed that an overarching PPI strategy, co-produced with patients and members of the public living and/or using services in South London would benefit the work carried out by CIS & KIS. Reasons underpinning the development of an overarching PPI strategy for CIS & KIS are detailed in Figure 1 below.

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<sup>11</sup> <http://www.clahrc-southlondon.nihr.ac.uk/training-and-education/advice-health-researchers-and-clinicians>

**Figure 1: Reasons Underpinning the Development of an Overarching PPI Strategy for CIS & KIS**



## 1.4 Background to PPI workshop

Initial discussions took place with KIS and CIS academic and theme leads, the CIS Scientific Advisory Panel, and members of the PPI theme in the CLAHRC South London, to discuss the development of a PPI strategy. Literature containing guidance for PPI in implementation and improvement science programmes and activities was sought but largely unavailable. Guidance of how best to involve patients and the public in research is readily available via, for example, [INVOLVE](http://www.invo.org.uk/),<sup>12</sup> but such guidance was found to predominately focus on PPI at a project level and did not address the specific challenges and opportunities of involving patients and members of the public in implementation and improvement science research.

Patients and members of the public needed to be involved in the development of the PPI strategy to ensure that it meets the diverse needs and concerns of multiple stakeholders to create meaningful involvement. It was decided that a collaborative approach, bringing together CIS & KIS researchers with patients and members of the public, would be the best way to co-develop a strategy that builds on principles and priorities of relevant stakeholders.

<sup>12</sup> <http://www.invo.org.uk/>

## 2. Workshop Planning

### 2.1 Planning committee/governance

The planning team consisted of individuals that have expertise in PPI and/or were interested and committed to developing a PPI strategy to inform the research and activities of CIS & KIS.

The core planning committee (in alphabetical order) consisted of:

- Lucy Goulding: Programme Manager, King's Improvement Science
- Savitri Hensman: CLAHRC South London PPI Coordinator
- Louise Hull: Deputy Director of the Centre for Implementation Science and Senior King's Improvement Science fellow (Strategy development lead)
- Zarnie Khadjesari: Senior King's Improvement Science fellow
- Barbora Krausova: Research Worker, King's Improvement Science
- Josephine Ocloo: Senior CIS Fellow, Health Foundation Improvement Science Fellow (Equality and Diversity lead)
- Konstantina Papoulia: Post-Doctoral Researcher and Deputy Lead of the CLAHRC South London PPI theme
- Sophie Wilson: Research Worker, PPI co-ordinator, King's Improvement Science (Strategy development co-lead)

In addition, Professor Diana Rose, Lead of the CLAHRC South London PPI theme and Professor Nick Sevdalis, Director of the Centre for Implementation Science, provided additional support and oversight.

Four planning meetings took place over an eight-month period. The meetings involved in-depth discussions concerning:

- Budget
- Recruitment
- Diversity and inclusion
- Access
- Venue
- Involvement approach/workshop format

In addition to the face-to-face meetings, several discussions took place over email and individual team members met ad hoc to discuss specific issues. A final de-brief meeting was held following the event to reflect on the workshop, discuss next steps and plans to produce this report.



## 2.2 Budget

In July 2017, the CIS Implementation Science Research theme and King's Improvement Science successfully applied for £3,300 (£1,650 per theme) of funding from the Patient and Public Involvement team of the CLAHRC South London to deliver a PPI workshop and three further PPI meetings (to take place between October 2017 and March 2018). The funding application submitted can be found in Appendix E. A total of £2,330 was budgeted to deliver the workshop and the remaining £970 was budgeted to deliver three subsequent PPI meetings. In line with CLAHRC South London recommendations, patients and members of the public were paid £60 (£15 per hour) to attend and contribute to the workshop.

Many decisions in the planning phase were considered and influenced by the budget.

## 2.3 Recruitment

### 2.3.1 Diversity and Inclusion (D&I)

When planning who to invite to attend the workshop, the planning committee was aware of longstanding criticisms about PPI in healthcare research. We tried to avoid falling into the traps of:

- Tokenistic involvement
- Involving only a small sub-set of the population. Patient and public representatives have often been found to be white and middle-class and there has been much criticism about the need to have a much wider section of the population involved. In his report 'Beyond the usual suspects', the author Peter Beresford highlights a number of groups that face barriers to their involvement
- Use of narrow methods not based upon partnership and inclusion that do not address power inequities and discrimination towards a range of groups

In relation to D&I, planning and organisation of the workshop included:

- Discussing how we defined equality and diversity, drawing predominately upon the definitions included in the [Equality Act 2010](https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)<sup>13</sup> [Peter Beresford's 'Beyond the Usual Suspects' research report \(2013\)](https://www.shapingourlives.org.uk/documents/BTUSReport.pdf)<sup>14</sup>
- Considering the makeup of our planning group in terms of equality and diversity and how this related to participation and leadership in the event
- Developing a recruitment and selection strategy to reflect our equality and diversity approach in identifying and involving patients and members of the public in the workshop

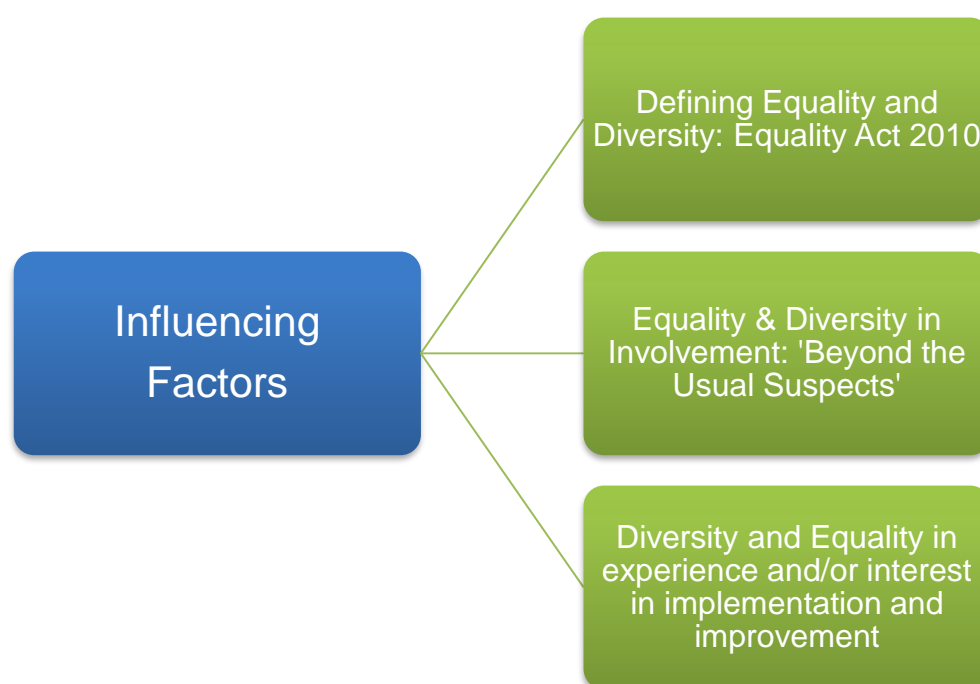
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<sup>13</sup> [https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)

<sup>14</sup> <https://www.shapingourlives.org.uk/documents/BTUSReport.pdf>

Our objective was to recruit an inclusive and diverse group of patients and members of the public that live or use health and social care services in South London. Patients and members of the public were initially eligible to apply if they either lived or used services in South London. A number of factors influenced our recruitment approach to try to involve a diverse group of patients and members of the public (detailed in Figure 2).

**Figure 2: Factors Influencing our Equality, Diversity and Inclusion Recruitment Strategy**



## Diversity & Equality

In line with the [Equality Act 2010](https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)<sup>15</sup> we wanted to ensure that individuals were not selected (i.e. discriminated or positively discriminated) based on the nine protected characteristics:

1. Age
2. Disability
3. Gender reassignment
4. Marriage & civil partnership
5. Pregnancy & maternity
6. Race
7. Religion or belief
8. Sex
9. Sexual orientation

<sup>15</sup> [https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga\\_20100015\\_en.pdf](https://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf)

As part of this approach, the planning group discussed, on multiple occasions, whether to use an equalities monitoring form, based on the nine protected characteristics listed above, that applicants for the workshop could be asked to fill in. The workshop planning committee members had differing view on this, but decided not to use such a form for the following reasons:

- Call for personal information may be intrusive and whilst such information is commonly requested for monitoring purposes (i.e. after an involvement event) little guidance exists on how and whether this approach is appropriate in the selection of patients and members of the public that wish to be involved in research. Indeed, when used in the context of shortlisting potential candidates for employment, this information is not provided to individuals that shortlist candidates.
- No clear concept of how we would use personal information (i.e. would we select people based on diversity of south London's population? Would we positively discriminate to ensure diversity?)
- Concern about low level of interest in the event (i.e. we did not anticipate the high level of interest and as such did not anticipate that we would not be able to offer a place at the workshop to everyone that wished to attend, thus using a monitoring form for selection was deemed unnecessary).
- Simply selecting workshop attendees, based on the nine protected characteristics, would not ensure the diversity and equality that we hoped to achieve. For example, the nine protected characteristics would not allow us to ensure that people who are not usually involved (as identified in previous research) or people interested in implementation and improvement research would be involved.
- Concern that asking people to complete a monitoring form may be off-putting for some individuals (especially before an involvement event rather than at the end).

## Diversity in Involvement

We were conscious that some groups are seldom heard in healthcare research and purposively tried to reach out to these groups. We drew heavily upon the research report written by Peter Beresford: '[Beyond the usual suspects, towards inclusive user involvement](https://www.shapingourlives.org.uk/documents/BTUSReport.pdf)'<sup>16</sup> that identified a number of groups that are often excluded from user involvement. These groups are listed below.

- People with alcohol and drug problems
- Young people
- Elderly people
- People who communicate differently
- People with learning difficulties

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<sup>16</sup> <https://www.shapingourlives.org.uk/documents/BTUSReport.pdf>

- People with complex support needs
- Refugees and asylum seekers
- People from black and minority ethnic groups
- Travellers and gypsies
- Homeless people
- People living in residential services
- People in prison and under the penal system

The planning committee also aimed to include individuals who work alongside community-based groups in South London or have worked on projects around equality and diversity in the past. It was hoped that this would bring together individuals who may consider the broader community in discussions, and who may be able to reflect on the experiences of seldom heard groups in south London during discussions.

## **Diversity in Experience**

The planning committee agreed that it was important to invite people interested in improvement and implementation science and/or who have experience in related projects. This was to ensure that people that did attend the workshop did not turn up expecting something less abstract and more practical and feel uncertain of the topic area and therefore alienated.

In line with these interests, applicants for the workshop were asked the following questions:

1. What is your interest and experience in the area of healthcare improvement and implementation?
2. Are there any particular communities or services with which you have been involved, or with any work concerning equality and diversity?

### **2.3.2 Recruitment Strategy**

The following sections provide an overview of the strategy employed to recruit patients and members of the public as well as CIS & KIS staff. Patients, members of the public and community organisations were predominantly invited to the workshop via email (detailed in the preceding section).

### **2.3.3 Recruiting Patients and Members of the Public**

A multi-method and multi-stage approach was used to invite and include diverse patients and members of the public. We recruited patients and members of the public using three approaches detailed in Figure 3.

**Figure 3: Methods for Recruiting Patients and Members of the Public**



### **1. Engaging patients and members of the public at CLAHRC South London's Active Involvement in Research Day**

Patients and members of the public were recruited via the [Active Involvement in Research Day \(AIRD\)](http://www.clahrc-southlondon.nihr.ac.uk/events/2017/laehrc-south-london-invites-you-our-active-involvement-research-day-2017-saturday-18-marc),<sup>17</sup> an annual event organised and hosted by PPI theme of the CIS, which took place in March 2017. Awareness of the workshop was initially promoted through the AIRD, where the aim was for researchers to talk with interested service users, carers and community members and answer questions about CIS and KIS with a view to recruiting a broad diversity of people to the workshop. The PPI theme of CIS had made efforts to broaden the database of groups to be contacted and invited to AIRD, in part to reflect the diversity in South London (though the demography of the twelve boroughs varies considerably and is changing and statistics are not available for certain protected characteristics).

<sup>17</sup> <http://www.clahrc-southlondon.nihr.ac.uk/events/2017/laehrc-south-london-invites-you-our-active-involvement-research-day-2017-saturday-18-marc>

## 2. Together in research-patient and public involvement e-newsletter

The 'Together in Research' Patient and Public involvement newsletter is an e-newsletter that has been developed by the PPI theme of the CIS. The workshop was advertised in the [first e-newsletter](#)<sup>18</sup> (Summer 2017).

## 3. Reaching out to organisations in South London and wider London

We contacted organisations in South London and wider London via email and follow-up telephone calls. A conscious effort was made to identify organisations based in South London due as this is where CIS & KIS are based. Organisations were selected with the aim of communicating the invitation to individuals and groups that are seldom heard in healthcare research. We identified potential organisations to contact using the '[service user and community organisation map](#)'<sup>19</sup> developed by King's College London's Service User Research Enterprise (SURE) and by identifying suitable organisations for social groups outlined in Peter Beresford's 'Beyond the Usual Suspects' as often excluded from PPI in healthcare research.

Details of the organisations contacted can be found in Appendix A.

Selection was based upon the following criteria:

- Responses to questions detailed above (section 2.3.1)
- Taking into account the need to involve as broad a group as possible

### 2.3.4 Recruiting CIS & KIS staff

CIS & KIS staff were predominantly recruited via email invitation. A number of email reminders were sent to staff to ensure maximum participation. The workshop was also promoted by the workshop planning committee, formally at monthly CIS executive meetings and informally during face-to-face conversations with staff.

## 2.4 Access

Prior to the workshop, attendees were assured that every effort would be made to accommodate their access needs. Attendees were asked to inform the planning committee of any concerns about not being able, for any reason, to participate in the workshop and assured that we would work together to try and find a solution. Our aim was to accommodate access needs where possible (i.e. where it was possible to

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<sup>18</sup> <http://mailchi.mp/c09c6195eb60/together-in-research-patient-and-public-involvement-newsletter-from-nihr-clahrc-south-london?e=9bc24e9be0>

<sup>19</sup> <https://www.kcl.ac.uk/ioppn/depts/hspr/research/ciemh/sure/SUGroupsSouthLondon.aspx>

make practical arrangements to support people's participation within the budget available).

Considerations and adjustments for access needs included:

- Booking a community venue that would be accessible to people with a range of physical disabilities (e.g. ensuring venue was wheelchair accessible)
- Arranging for a Speech to Text Reporter (STTR) to provide real-time transcription of the conversation using specialist equipment
- Encouraging everyone present at the workshop to avoid using jargon and acronyms, to speak loudly, to write in large letters and inform CIS staff, KIS staff or the facilitator if they experienced any discomfort for any reason

## 2.5 Venue selection

The workshop took place at [Cambridge House](#)<sup>20</sup> in Camberwell, South London.

When selecting a venue, we had a number of priorities:

- a 'community-based' venue outside of our academic institution
- easy to access and public transport links for those within South London
- wheelchair accessible
- good value for money
- with a straight, even wall in the room for the use of a 'sticky wall' fabric

The venue was booked approximately six weeks in advance. Other options for venues were considered / shortlisted prior to deciding on Cambridge House.

We requested workshop tables with six to seven people around each one. We developed a seating plan to ensure that a mixture of researchers and members of the public were seated around each table.

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<sup>20</sup> <http://ch1889.org/>

# 3. Involvement Approach

## 3.1 Involvement approach

Members of the planning committee discussed how best to involve patients and members of the public in the co-production of a PPI strategy for CIS & KIS. During discussions it came to light that members of the PPI theme had previously used consensus based methods to facilitate discussions involving patients, members of the public and researchers in healthcare research and priority setting. Based on the previous success of these activities, members of the PPI theme suggested that a consensus based methodology would be a suitable and worthwhile approach to begin the development of a PPI strategy. Although two members of the PPI workshop planning committee were trained consensus workshop facilitators, it was agreed that an independent facilitator should facilitate the workshop so patients and members of the public and CIS & KIS researchers were 'equal' participants in the workshop, and that the facilitator was independent and unbiased throughout the process.

Key presentation were delivered to 'set the scene'. The presentations covered:

- CIS & KIS' organisational structure
- Aims of the research and activities that CIS & KIS do
- Definitions of implementation science and improvement science
- The context for PPI in healthcare improvement
- How we envisage PPI practice in the future

For full presentation slides, see Appendix B.

By covering these areas, the planning committee felt that attendees would be able to contribute fully to the strategy development during the workshop with the necessary context. Much thought was given to the content of presentations as well as diversity in presenters. For example, it was decided that both senior and junior members of the CIS & KIS team would present. Josephine Ocloo raised the importance of ensuring there was BME representation in the presenters. Furthermore, Josephine presented in the role of academic researcher and patient champion, sharing her personal experiences, in order to bridge the gap between academics and patients and encourage participation.

## 3.2 Overview and format of consensus based workshops

Consensus building workshops have been successfully applied in diverse settings internationally for over 40 years. They have a dual aim: firstly, they activate a fuller range of organisational resources than was previously available for a more effective



approach to perceived obstacles and intractable problems; secondly, they do so through an ethics of participation and shared decision making, so that every member of the team is able to make a meaningful contribution to the process and consequently claim equal ownership of the outcomes. Through judicious and structured use of consensus workshops, an organisation can begin to reflect on and address entrenched ways of doing things that may impede progress.

Overall, consensus workshops may generate a powerful dynamic which has the potential to fundamentally transform organisational cultures. The broader purpose of consensus workshops, therefore, is to help an organisation move from a hierarchical to a learning, collaborative model.

The facilitator is central to the success of the workshop. Their role is to regulate and contain the process so that it can run its course smoothly, while all members feel able to participate equally. The facilitator should never steer the workshop towards particular ideas or values. Ideally the facilitator should be external to the organisation. As this can be quite costly, training organisation members to facilitate may be a more cost effective solution.

Consensus workshops make use of a 'sticky wall': a large adhesive cloth stretched on a wall on which there is room for at least 60 cards for different proposals/ideas.

The workshop aims to answer a key question which will have been set by the facilitator after they have met the team and discussed their needs.

Additionally, a facilitator sets a 'rational' aim (*what the group needs to know by the end*) and an experiential aim (*how the group needs to be by the end*). While the rational aim may be spelled out at the beginning, the experiential aim may be implied, or only articulated at the end of the process.

Having set the question and aim, the facilitator directs and orchestrates the process through five, tightly regimented phases (detailed in Figure 4).

**Figure 4: Five phases of a consensus-based workshop**



### **1. Stage setting**

Context, presentation of method and initial discussions around the topic.

### **2. Brainstorming**

The group comes up with ideas to answer the key question. This is usually done by moving from people working alone, to clustering in small groups by choosing among individual contributions, to presenting shared ideas for the large group to clarify and consider. The ideas are put on cards, gathered from each table and placed on the sticky wall.

### **3. Clustering**

The group gathers together to order the cards. Stages 2 and 3 overlap: typically, about a third of cards from all the groups are put up first, clustered, another third follows, these are also clustered and the final third completes the process. Throughout this time the clusters may change considerably. The point here is that all cards will be put up – none may be rejected as too obvious or irrelevant.

## 4. Naming

The group decide together how to name each cluster. While names can emerge through small groups, the overall group will reconsider these until consensus is reached

## 5. Resolving

All clusters/themes and their contents are read aloud (affirmed). Next steps are considered. A photograph or other visual record is made and distributed to all participants in order to validate the process and take it further.

The above overview is not exhaustive. Each of the five stages involves a further series of facilitation techniques. Depending on the time and resources available and on the skill of the facilitator these techniques can be used more or less extensively.

Finally, since the consensus workshop enables a participatory environment to come into being, it is not appropriate for members of the group to add new themes or ideas after the end of the workshop as the environment is not active at that point.

### 3.3 Possible next steps after a consensus workshop

- Work with the people in the group to develop the clusters further (the existing ideas)
- Use the clusters as a contents page for a report or paper (where appropriate)
- Create a chart to organise relationships between clusters (or potentially a graphic or poster)
- Do further consensus workshops on just one or some of the clusters

Further information on consensus based workshops is available at: <http://www.ica-international.org/top-facilitation/icas-technology-of-participation-top/> & Stanfield B (2002) The Workshop Book. Gabriola Island: New Society Publishers.

## 4. Workshop Overview

### 4.1 Workshop attendees and format

In total, 34 people attended the workshop; 17 members of CIS staff and 17 patients and members of the public attended the four-hour workshop. Members of staff from the CIS Implementation Research team, KIS, and the PPI theme attended.

Demographic and additional information relating to the patients and members of the public that attended the workshop (e.g. health conditions, interest and experience in healthcare improvement and implementation, and membership in community organisations) is not available as we did not systematically collect this information.

The rationale behind not collecting this information is detailed in Section 2:

Workshop planning & 7: Reflections, lessons learnt and recommendations. The workshop format, based on consensus based methodology [detailed in Section 3.2], is detailed in Table 1.

**Table 1: Workshop format**

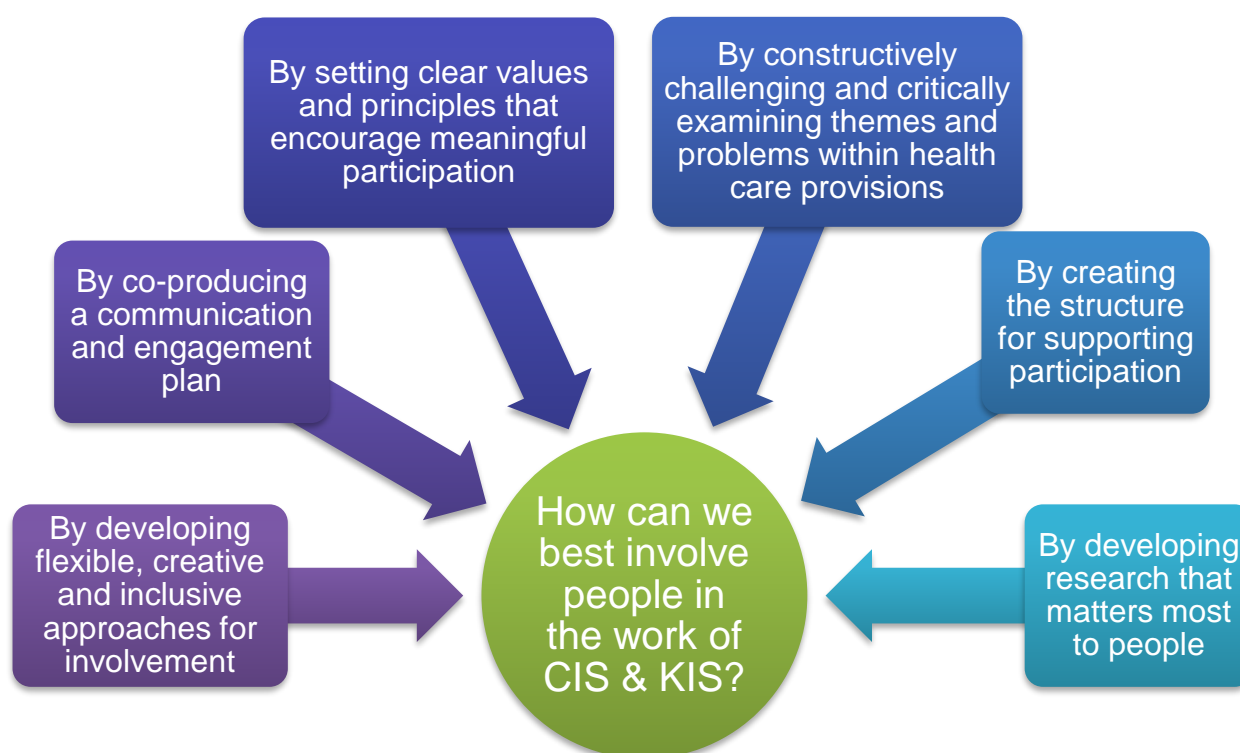
10 mins	Introduction to the day
20 mins	4x5 minute presentations from CIS & KIS staff <ol style="list-style-type: none"> <li>1. Centre for Implementation Science: What is Implementation Science and who are we and what do we do (Dr Louise Hull, CIS)</li> <li>2. King's Improvement Science: What is Improvement Science and who are we and what do we do (Dr Lucy Goulding, KIS)</li> <li>3. The Context for PPI in Healthcare Improvement: Diversity and Inclusion (Dr Josephine Ocloo, CIS)</li> <li>4. Foundations and Future Vision for PPI: Where we are now &amp; where we want to be (Sophie Wilson, KIS)</li> </ol>
10 mins	Presentation: Discussion and questions, for clarity
10 mins	Introducing the consensus workshop
15 mins	Individual brainstorming/mind mapping: How can we best include and involve people in the work of the Centre for Implementation Science and King's Improvement Science?
15 mins	Break
55 mins	Small group discussion and generation of ideas
15 mins	Break
60 mins	Clustering and naming the ideas, and whole group discussion
60 mins	Finish and lunch

Presentation slides and the workshop programme can be found in Appendix B & C respectively.

## 4.2 Sticky wall output

Six clusters, containing multiple items, emerged in response to *‘How best can we (CIS & KIS) involve people (patients and member of the public) in the work of the CIS & KIS?’* These themes are presented in Figure 5. A diagram of the sticky wall output can be found in Appendix D.

**Figure 5: How best can we involve people in the work of CIS & KIS?**



## 4.3 Sticky wall clusters

Each of the six clusters are presented below, including cluster items and a cluster summary.

### **By developing flexible, creative and inclusive approaches for involvement**

1. Better understanding of issues/concepts around improvement and implementation
2. How are patient reps recruited? Depends on public engagement teams at CCG (& also Health Watch) Quality varies!
3. Resources to support collaborative relationships
4. Joint co-production training and education
5. Continuous improvement loop, constant refinement as circumstances change
6. Clarify benefits/incentives for PPI
7. Consider and acknowledge representatives of communities
8. Working alongside but further than existing groups
9. Creative approaches to engagement (pub, gym, church)
10. Motivate and appreciate the participants
11. Methods for supporting and enabling participation
12. Embedding flexibility in research
13. Mentoring/buddying, education/training, payment incentives
14. Retention (training, pay, expenses) & recruitment of 'public voice'

## Cluster summary

In order for involvement approaches to be meaningful and inclusive, they need to be flexible and researchers need to be creative. There is no one-size-fits-all approach to involvement, and no research project nor individual is the same. Researchers should engage with community groups to share learning on improvement and implementation science so that individuals feel prepared for involvement and project work becomes more accessible. Furthermore, research itself should be more flexible so that patients and the public can be better positioned to steer processes and influence outcomes. This might mean breaking down institutional and professional barriers that sometimes can contribute to an imbalance of power, in order for decision-making in projects to be equitable. When recruiting people to become involved in projects, researchers need to consider diversity of the population they are working within. This means working with individuals, but also thinking about how to connect with representatives for community groups. It also means reaching outside of existing and formalised community groups, and being creative about how to establish relationships with individuals who have not been involved in healthcare research before, and are not in frequent contact with community groups.

## By co-producing a communication and engagement plan

1. Improving information and communication channels. System wide
2. Speaking in plain English, not using acronyms/jargon
3. Share learning to improve participation
4. Capacity building e.g. Black Thrive project with KIS
5. Proper dissemination of research results (communication hard/electronic)
6. Summary report of today with contact details)
7. Personal stories/experiences motivate engagement

## Cluster summary

This cluster represents the importance of, and need to, consider the way in which CIS & KIS communicate with patients and the public. Workshop attendees stressed that our communication plan should be co-produced to ensure that it is effective; delivering relevant and accessible information to patients and members of the public, and enabling CIS & KIS researchers to learn about local projects and activities in south London. Furthermore, workshop attendees identified the need to develop an engagement plan; the workshop was the first step in working together towards both identified needs.

## By setting clear values and principles that encourage meaningful participation

1. Kindness and care
2. Don't be paralysed by fear of getting it wrong
3. CIS & KIS reflection: external process
4. Being patient/carer centred
5. Sharing monitoring of contributions and working relationships
6. Wider participation through deliberate dialogue
7. Recognising diversity of and with social groups
8. Commitment to letting go of egotism
9. Be transparent but not expectant of research
10. Recognise and challenge power imbalances
11. It's not about me, it's with me
12. Consider and acknowledge representatives of communities
13. Recognise and value the significance of personal experience
14. Design with inclusion from the beginning
15. Breaking down professional barriers
16. Choose an inclusive environment

## Cluster summary

This cluster reflects the importance of clearly articulating the principles and values that underpin and encourage meaningful patient and public involvement in the research and activities of CIS & KIS. The scope of individual items suggests that we, as a research community, need to improve our approach to involvement and recognise the challenges that patients experience in involvement processes (e.g. due to the nature of physical and mental health disabilities and power imbalances between patients and the public and healthcare professionals and researchers). Identifying the principles and values, as well as understanding the challenges that patients experience, is a first step to addressing and tackling these issues.

## By constructively challenging and critically examining themes and problems within health care provision

1. Working across local sustainability and transformation partnership agenda
2. Making research part of services
3. Making monitoring really change health inequalities
4. 'Real cultural change' in the NHS, patients and clinicians (Drs 'know best!')  
\*Hierarchies
5. How funding arrangements impact health/social care provision
6. Unpicking 'better for less'
7. Influencing the decision makers

## Cluster summary

While most other clusters outlined the process and principles which might facilitate successful collaboration, this last cluster addressed some of the broader aims and desired outcomes of such collaboration. In particular, the seven items gathered here suggest that meaningful collaboration between academics, clinicians and the public could open the possibility of a broader cultural change in policy as well as research and service provision. This change might involve a closer integration between research and service provision, a willingness to recognise and address power relations within the NHS; and an openness to more collaborative approaches in higher level decision making (for example in decisions on local sustainability and transformation plans, on funding and defunding of services and on how quality improvements are monitored and measured).



## By creating the structure for supporting participation

1. Developing CIS & KIS infrastructure for PPI
2. Broad network of interested volunteers-research etc.
3. Harnessing of existing local expertise
4. Skills/experience matching (database)
5. Empowering patients at the GP level
6. Collecting and using patient experiences
7. PPI leadership & infrastructure embedded with research departments and acting as an ambassador for the centre
8. PPI liaison coordinator for services
9. Project focussed experience groups

## Cluster summary

Embedding PPI into CIS & KIS infrastructure would mean supporting a consistent and continuous model for involvement by ensuring that a broad network of patients and members of the public are frequently engaged and involved in ongoing work. Supporting an embedded group should mean that researchers are aware of the skills and experiences that individuals within the group hold, and therefore are able to find individuals who may be particularly suitable for, or interested in, involvement in their research. Ultimately, this cluster calls for greater recognition of the unique and/or diverse skills and experiences that patients and members of the public can hold, and for researchers to utilise these when setting up PPI in projects. The need for patients and the public to hold governance and leadership positions within PPI was an important outcome of this cluster. Individuals from patient and public group can be placed within the CIS & KIS organisational structure to advocate PPI activities throughout their work. It was also suggested that a PPI liaison coordinator role could facilitate relationships between CIS & KIS and patients, the public and the community.

## By developing research that matters to local people

1. Implementation of NHS action plan on hearing loss
2. 'Anti-racism' as a health issue for research
3. 'Black box thinking' Matthew Syed<sup>21</sup>
4. Review successful models of PPI

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<sup>21</sup> For anyone unfamiliar with the work of Matthew Syed, you can find out more by visiting his website: <http://www.matthewsyed.co.uk/category/thinking/>

5. Evidence of impact of PPI
6. Apply scientific measures regionally to drive improvement/accountability
7. More research on mental-physical health interrelationship
8. More research on mental health and financial stress
9. More research on service quality variation

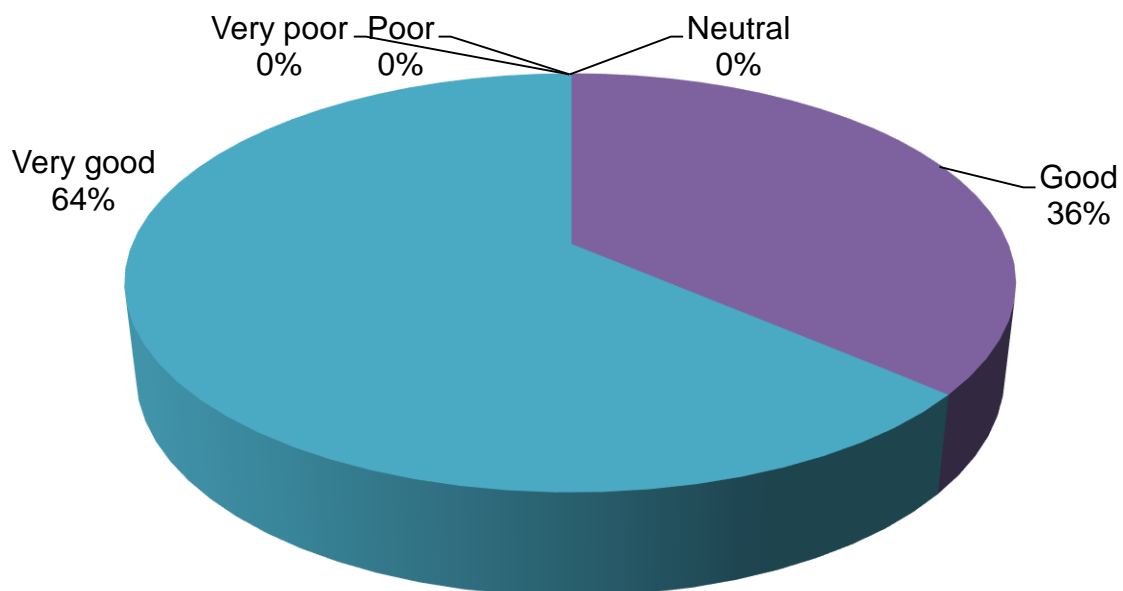
## Cluster summary

This cluster identifies a number of potential areas for future research. Some of the research ideas are more general in nature (e.g. more research on service quality variation) and some are very specific (e.g. implementation on NHS action plan on hearing loss). Taking these ideas forward requires further exploration and consideration and is reliant on numerous factors. For example, acquiring additional funding would need to be sought to take the ideas forward. This cluster reflects the importance, and acts as a reminder, of involving patients and members of the public at the earliest possible stage to ensure that the research conducted by CIS & KIS matters to patients and members of the public.

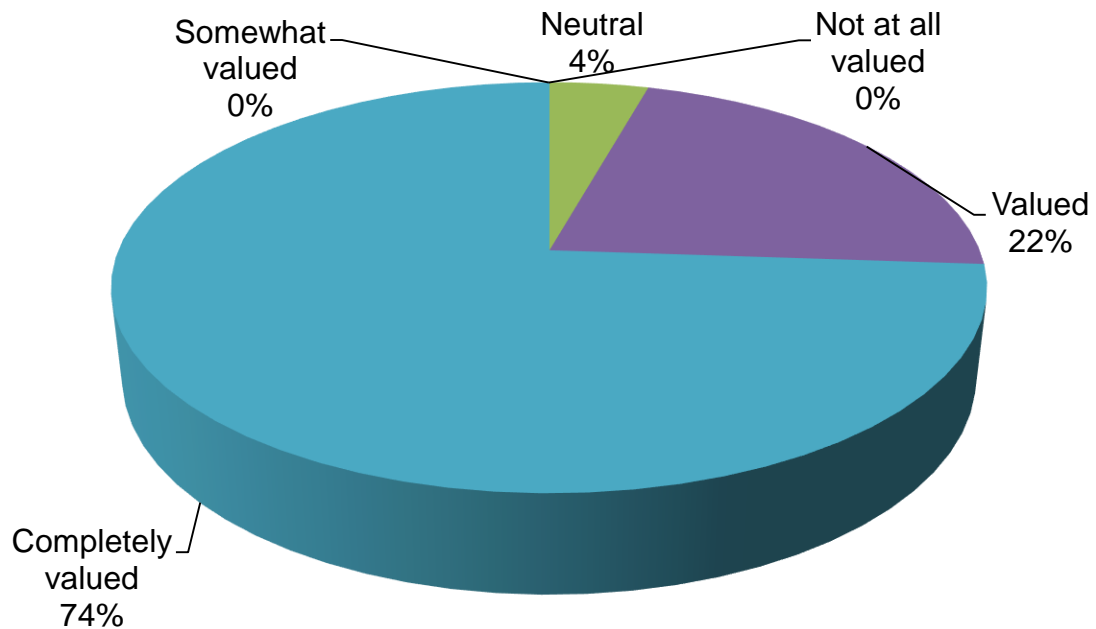
## 4.4 Evaluation and feedback

A short evaluation form was developed by the PPI workshop planning committee [for further details see Section 2.1 Planning committee/governance] that patients and members of the public as well as CIS & KIS staff were encouraged to complete at the end of the workshop. The evaluation form consisted of a number of statements that workshop attendees were asked to respond to by stating their level of agreement. There were also a number of open-ended questions that attendees were asked to respond to.

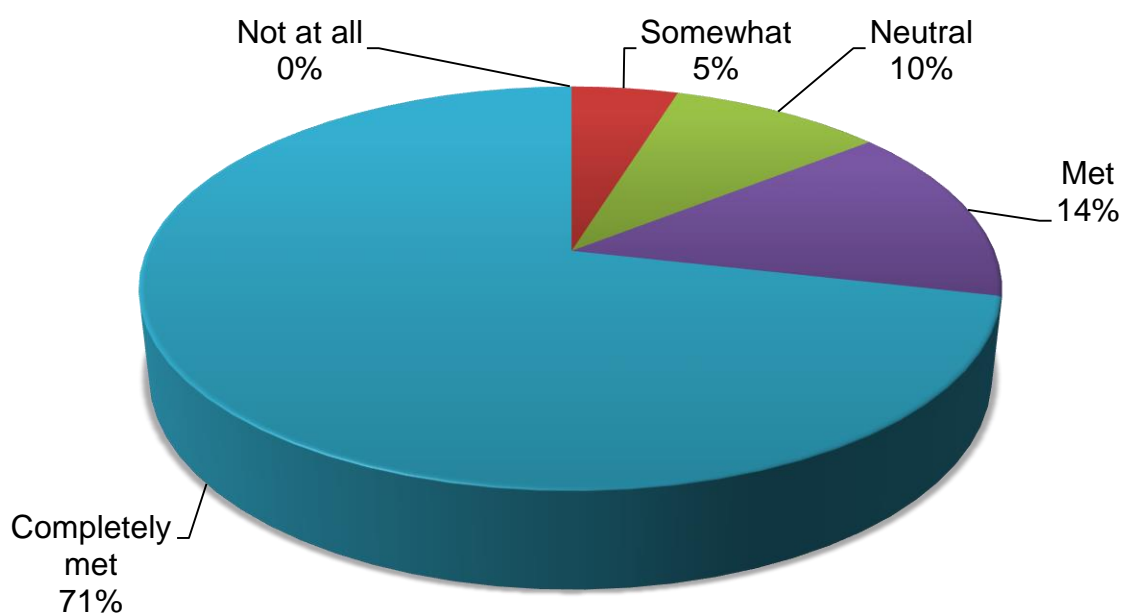
**Figure 6: What was your overall impression of the workshop?**



**Figure 7: To what extent do you feel that your contribution was listened to and valued during the consensus workshop?**



**Figure 8: To what extent were your access needs met?**



Workshop attendees were given the opportunity to provide free-text comments in relation to the above questions and two further questions: 1) Do you have any further suggestions for improving future workshops and/or involvement activities and 2): Is there anything else you would like us to know. All free-text comments can be found in Appendix F.

### Overall summary of feedback

- Workshop attendees had a positive overall impression of the workshop and felt that their contributions were listened to and valued during the workshop.
- The majority of workshop attendees felt that their access needs were met, however a number of workshop attendees felt their access needs were only 'somewhat met'.
- Many people commented that the workshop was very well facilitated but the venue was not suitable (room too small) and it was difficult to hear workshop discussions.
- Suggestions for improvement mainly centred around ensuring room size was adequate.
- Workshop attendees thought that the workshop was enjoyable, well-organised and well facilitated.

## 4.5 Finances

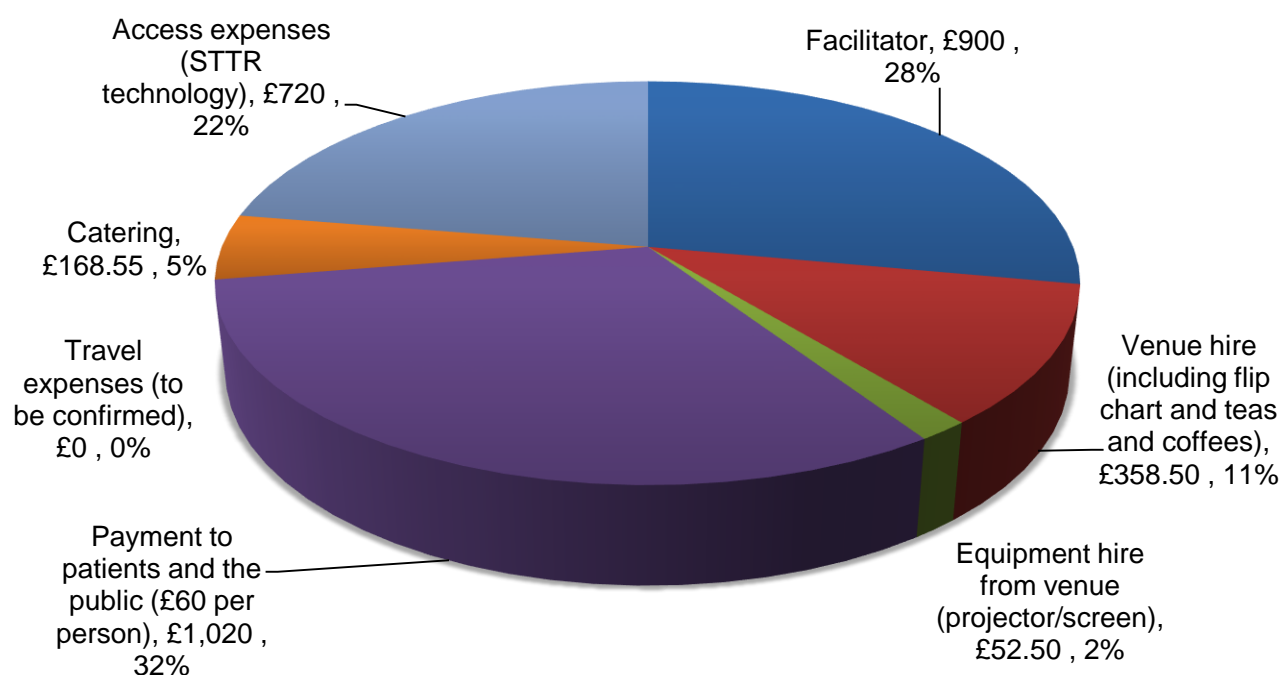
As detailed in Section 2.2, a total of £2,330 was budgeted to deliver the workshop. Table 2 provides details of anticipated and actual costs incurred delivering the workshop.

**Table 2: Anticipated and Actual Costs of delivering the workshop**

Details of Expense	Anticipated cost	Actual Cost	Difference
External facilitator	£900	£900	0
Venue hire (including flip chart and teas and coffees)	£300	£358.50	+£58.50
Equipment hire from venue (projector/screen)	£0	£52.50	+£52.50
Payment to patients and the public (£60 per person)	£840	£1,020*	+£190
Travel expenses	£140	(TBC)	
Catering	£150	£168.55	+£18.55
Access expenses (STTR technology)	£0	£720	+£720
<b>Total workshop expenses</b>	<b>£2,330</b>	<b>£3,220</b>	<b>+£890</b>

\*1 member of the public did not wish to receive payment for attending the workshop.

**Figure 9: Actual workshop expenditure**



In total, the workshop cost £890 more to deliver than anticipated. There were two expenses that accounted for the majority of the overspend:

- 1) Payment to patients and members of the public (£190 more than anticipated)
- 2) Access expenses (£720 more than anticipated)

### **Justification for overspend: Payment to patients and members of the public**

We planned to invite 14 patients and members of the public to attend the workshop. In the end, we invited 17 patients and members of the public to attend for several reasons:

1. Unexpected high level of interest and enthusiasm received to attend the workshop from both CIS & KIS staff and members of the public. Our intention was always to have an equal number of members of the public and CIS & KIS staff. 17 CIS & KIS staff expressed a strong desire to attend the workshop therefore a decision was made to increase the number of places available to members of the public.
2. We anticipated that a number of staff and members of the public invited to attend may have not been able to attend on the day and therefore invited slightly more people (+3) than we expected to attend. In reality, all members of the public that we invited did attend the workshop. Two members of CIS & KIS staff were unable to attend the workshop due to unforeseen circumstances.

### **Justification for overspend: Access expenses**

As detailed in Section Access 2.4, we wanted to be able to involve a diverse group of patients and the members of the public, this included meeting access needs.

## 5. Next Steps

The sticky wall output has provided the CIS research team and KIS project team with guiding principles and a foundational strategy for PPI in future work. Many of the guiding principles can be acted upon immediately by CIS & KIS staff to improve the quality and consistency of the way we engage and involve patients and members of the public in our work. However, more work will need to be done to ascertain how all clusters (and individual items) can be operationalised, adopted and implemented, and how they might work in practice under the organisational structure and constraints of CIS & KIS. A key step in operationalising and implementing the strategy is likely to involve elaboration of the cluster items identified in the workshop.

The six clusters will need to be reviewed and taken forward differently. For example, for some it will be necessary to consider infrastructure and capacity, whereas others will require thinking about priority setting and research focuses. Within these explorations, as was suggested above, we need to be realistic about the inevitable boundaries and challenges that result from institutional regulations as well as funding constraints.

At the time of writing, the sticky wall output has been shared with the workshop planning committee, patients and members of the public who attended, to ensure it is agreed with them as an accurate depiction of the day, and the CLAHRC South London and CIS executive groups and CIS Scientific Advisory Panel, to update on progress and allow constructive discussion about how the output can be operationalised into a PPI strategy.

It will be important to maintain regular and timely communication with members of the public and patients who attended the workshop, and to open up dialogue with new patients and members of the public who might be interested in co-developing the PPI strategy further. Regular and timely communication is especially important as many patients and members of the public that attended the workshop commented on the fact that they had previously been involved in involvement events/activities and that follow-up and communication had been either non-existent or lacking.

A challenge, but invaluable process, will be ensuring balanced and fair input from all stakeholders as the strategy is developed and refined. One method to evaluate whether we achieve this objective, or need to alter our recruitment strategy, is to develop and implement a form to monitor:

- Diversity (as defined by the Equality Act 2010, including the 9 protected characteristics: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation).



- Diversity of experience (in our case, diversity of interest and experience in improvement and implementation in healthcare)
- Inclusion of individuals and/or organisations representing seldom heard groups (as identify by Peter Bereford's report)

It is crucial to speak with as many individuals as possible; patients, the public, researchers, healthcare and academic management etc. to ensure a strategy is developed that is practical to implement within the work and activities of the Centre for Implementation Science and King's Improvement Science, but that also allows patient and public voices to be placed where they can be heard best, and indeed acted on. Again, the number of patients and the public that we can involve in the process will depend on the remaining budget.

Realities, abilities, opportunities and restrictions will be openly discussed between patients and the public and CIS & KIS staff members, as well as external stakeholders, in order to drive a strategy that can be embedded and implemented for PPI in CIS & KIS.

## 6. Reflections, Lessons Learnt and Recommendations

Throughout the planning and delivery of the workshop, the planning committee faced many challenges that resulted in lessons being learnt. We are confident these lessons will help us better plan future involvement events and activities. We strongly believe that these challenges are not unique to this workshop and as such are useful to share more widely with individuals and organisations striving to involve patients and the public in health services research.

### 6.1 Recruitment strategy & method

Our recruitment strategy relied heavily upon electronic communication (e.g. email and e-newsletter communication). We recognise this as a limitation in our recruitment approach as it could potentially have excluded individuals that do not have an email account, may not have regular access to the internet, or are not literate / computer literate.

We initially approached organisations in South London via email, although we did follow-up all organisations with a telephone call to ensure the email was received, sent to the most appropriate individual within the organisation and to answer any questions that the organisations may have had before distributing/forwarding the email to the groups of people that we were trying to include. We were informed that some organisations shared hard copies of the distributed email invitation.

Inviting individuals through community organisations may have also excluded individuals who are not affiliated with, or have membership in, such organisations or groups.

### Recruitment strategy & method recommendations

In order to engage a diverse and inclusive group of patients and members of the public, innovative and diverse recruitment approaches and strategies must be considered. This was highlighted in the Sticky wall output, suggesting that we should recruit via 'pubs, gyms and churches' and not solely rely on electronic communication. In order to capture whether our recruitment strategy is successful in recruiting a diverse and inclusive group of patients and members of the public, we plan to develop a monitoring form (to be used for monitoring NOT selection).

### 6.2 Access challenges

Although consideration was given to the potential access needs of individuals attending the workshop, the full spectrum of potential access requirements is very difficult to anticipate due to the wide variety of physical, mental and sensory

disabilities and associated access requirements. Meeting access requirement varies considerably in price. Some venues have built in equipment that meets diverse access needs and charge no additional fee (e.g. hearing loop and/or wheelchair access), whereas some technology requires one-to-one assistance, specialist expertise, and/or specialist technology (e.g. Speech-To-Text-Reporting), which can be expensive. The total access costs for the workshop was £720, which equated to a significant portion of the overall workshop budget (22% see Figure 9). A budget had not been set in advance to accommodate the diverse and substantial access needs that might and did arise.

High access costs cannot always be anticipated and/or met due to the diverse range of access needs and requirements. Some events will not require additional expenditure on access needs, whereas some will require a significant proportion of the budget. This raises the question about how much money should be reserved for access needs per event. If planning committees are to reserve a large percentage of the budget for access needs then other important expenditure is reduced, such as the number of people who can be invited and paid for their participation. The money spent to meet access requirements of individuals that attended the workshop, will unavoidably have a direct impact of future involvement activities. This is likely to have an impact on either the number of involvement activities that we can plan in the immediate future, the type of involvement activities, the duration activities, and/or the number of patients and members of the public that can be involved.

The process of organising the workshop enabled some of the planning committee members to learn about different access needs and the requirement to anticipate these and budget appropriately. We look forward to applying this learning when arranging future events.

## Access recommendations

Be aware that access requirements cannot always be anticipated. Solutions to meet people's access needs can be costly.

- 1) Consider allocating a portion of the budget to meeting access needs. We have shared this lesson and made recommendations to the CLAHRC South London executive (October 2017), CLAHRC South London PPI Strategic Oversight Group (September 2017) and also plan to share this learning across the CLAHRC South London PPI champions network.
- 2) Seek further sources of funding if access needs exceed the budget proportioned to meeting access needs
- 3) Explicitly request that access requirements are communicated at the first point of contact
- 4) Make individuals aware that access needs will be accommodated if possible, but that this not always be possible, due to budget constraints

## 6.3 Hidden disabilities

The format of the workshop required participants to write down their ideas and we asked attendees for written feedback on the event. We are mindful that this reliance on written communication will have reduced the accessibility of the event for some people. Secondly, despite hiring a room with disabled access, its small size may have created discomfort and stress for some members of the group.

A consideration raised in the feedback was hidden disabilities (disabilities that are not immediately apparent). For example, the need to write down thoughts/contributions during the consensus building activity was raised as difficult for individuals who are dyslexic. This highlights the importance of being aware of hidden disabilities when planning involvement activities and the need to clearly articulate to patients and the public what their involvement will entail. In the feedback form, one individual suggested that event organisers 'ask about hidden disabilities'. Disclosure of all hidden disabilities may not be necessary as some may not wish to disclose this information, requesting this information might be perceived as intrusive and/or individuals may not consider themselves to have a hidden disability. Furthermore, disclosing such information may not indicate what adjustments are necessary to maximise involvement and what the effect, if any, the hidden disabilities will have on involvement, and will also be dependent on the type of involvement activity. In future, we plan to provide workshop attendees with more information about what their involvement will entail and give patients and the public the opportunity to disclose any disabilities (hidden or not), if they feel this is appropriate/necessary.

## Hidden disabilities recommendations

1. Be aware of and consider hidden disabilities with equal weighting to 'visible' disabilities
2. Share a detailed programme for the event as early as possible with all attendees to enable opportunity to discuss adjustments to the schedule or planned activities
3. Create a supportive environment to enable all those that attend involvement events to feel comfortable to approach organisers and/or facilitators to disclose any disabilities (hidden or otherwise) that might affect their participation and/or wellbeing and specific access needs

## 6.4 Venue challenges

The venue in general was perceived as a good pick (especially in regards to its location), however many commented that the room was small for 34 people, raising problems with high temperature and cramped spaces (as noted during the workshop and in feedback forms). Although the room booked accommodated up to 50 delegates, workshop attendees felt that the room was too small.

## Venue recommendations

1. The venue and room should be visited and inspected in advance in order to ensure expectations and needs are fully met.

## 6.5 Diversity and Inclusion

As previously described, we plan to create a diversity and equality monitoring form to apply in future. There is consensus amongst the planning committee that this will require considerable thought. We wish to identify and invite a diverse group of patients and members of the public, however we are conscious that using a monitoring form has certain limitations. Application of a monitoring form that simply monitors equality, according to the 9 protected characteristics listed in the Equality Act 2010, will fail to monitor whether we are successful in including diversity in interest and experience in healthcare improvement and implementation and will not monitor the long standing concerns of inclusion in healthcare research (i.e. an equality form will not ensure that we are selecting individuals that represent all groups that have been identified as seldom heard in healthcare research). This simple example highlights the complexities of developing a monitoring form that satisfies multiple needs. Furthermore, there is lack of consensus amongst the planning committee whether it is appropriate to implement a monitoring form and use this information for selection in addition to monitoring. We have recently contacted [King's College London Diversity and Inclusion team](https://www.kcl.ac.uk/ioppn/diversity-inclusion/our-team/di-team.aspx)<sup>22</sup> to arrange a meeting to seek advice on how equalities monitoring forms should be used as many members of the planning committee were not confident whether monitoring information can be used as a way of selecting a diverse group of people to participate in a PPI events and activities or whether they should only be used for monitoring.

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<sup>22</sup> <https://www.kcl.ac.uk/ioppn/diversity-inclusion/our-team/di-team.aspx>

# 7. Output and Dissemination of Workshop

## 7.1 Report

This report will be shared with patients and the public that attended the workshop, CLAHRC South London Executive, PPI SOG and all members of CIS & KIS. This report will also be uploaded to the CIS ([www.clahrc-southlondon.nihr.ac.uk/centre-implementation-science](http://www.clahrc-southlondon.nihr.ac.uk/centre-implementation-science)) and KIS websites ([www.kingsimprovementscience.org](http://www.kingsimprovementscience.org)).

## 7.2 The CLAHRC South London Executive

The CLAHRC South London is governed by an executive that meets monthly and comprises representatives from all constituent parts as well as representatives nominated by each collaborating organisation. An overview of the workshop was presented at the CLAHRC South London executive monthly meeting that took place in October 2017. See appendices for presentation slides [Appendix G].

## 7.3 CLAHRC South London PPI Strategic Oversight Group (SOG)

CLAHRC PPI SOG is part of the governance structure of the CLAHRC South London. The PPI SOG comprises representatives nominated by each health theme and representatives from the Health Innovation Network, south-east London's two NIHR Biomedical Research Centres, the NIHR Clinical Research Network South London and voluntary sector organisations. The group meets three times a year and its job is to identify and advise on PPI activity within the research themes. The Group reports to the Executive and highlights any successes and achievements as well as any problems. An overview of the workshop was presented at the PPI SOG meeting that took place in October 2017.

## 8. Appendices

### Appendix A: Organisations contacted

Groups	Organisation	Website
<b>Alcohol and substance misuse</b>	Blenheim	<a href="http://blenheimcdp.org.uk/">http://blenheimcdp.org.uk/</a>
	Wandsworth Service User Forum	<a href="mailto:WSUFINfo@gmail.com">WSUFINfo@gmail.com</a>
	Aurora Project Lambeth	<a href="mailto:support@auroraprojectlambeth.org.uk">support@auroraprojectlambeth.org.uk</a>
<b>Travellers and gypsies</b>	London Gypsies and Travellers	<a href="http://www.londongypsiesandtravellers.org.uk/">http://www.londongypsiesandtravellers.org.uk/</a>
<b>Refugees and asylum seekers</b>	CARAS (Community Action for Refugees and Asylum Seekers)	<a href="https://volunteerteam.london.gov.uk/organizations/906">https://volunteerteam.london.gov.uk/organizations/906</a>
	Hestia incl. a range of social groups	<a href="http://www.hestia.org/about/">http://www.hestia.org/about/</a>
<b>Homeless people</b>	Single Homeless People	<a href="https://www.shp.org.uk/">https://www.shp.org.uk/</a>
	Hestia incl. a range of social groups	<a href="http://www.hestia.org/about/">http://www.hestia.org/about/</a>
<b>LGBTQ</b>	Hear Us (project at SLaM)	<a href="http://www.hear-us.org/four-in-ten/">http://www.hear-us.org/four-in-ten/</a>
<b>Young people</b>	Young Lambeth Coop	<a href="http://www.younglambethcoop.co.uk/about-us/what-is-the-ylc">http://www.younglambethcoop.co.uk/about-us/what-is-the-ylc</a>
<b>Learning disabilities</b>	Croydon People First	<a href="https://www.croydonpeoplefirst.org.uk/">https://www.croydonpeoplefirst.org.uk/</a>
<b>Older people</b>	Link Age Southwark	<a href="http://linkagesouthwark.org/#about-us">http://linkagesouthwark.org/#about-us</a>
	Age UK Lewisham and Southwark	<a href="https://communitysouthwark.org/organisations-venues/organisations/age-uk-lewisham-southwark">https://communitysouthwark.org/organisations-venues/organisations/age-uk-lewisham-southwark</a>

	Indoamerican Refugee and Migrant Organisation (also for BME women and children)	<a href="http://irmo.org.uk/">http://irmo.org.uk/</a>
<b>BAME</b>	Ethnic Health Foundation	<a href="http://www.ehfl.org/index.php">http://www.ehfl.org/index.php</a>
	Helping Hands for Refugees and Disabled	<a href="http://hhfrd.webs.com/">http://hhfrd.webs.com/</a>
<b>Prisoners/ex-prisoners</b>	User Voice	<a href="http://www.uservoice.org/about-us/user-voice-centers/">http://www.uservoice.org/about-us/user-voice-centers/</a>
<b>Carers</b>	Southwark Carers	<a href="https://www.southwarkcarers.org.uk/">https://www.southwarkcarers.org.uk/</a>
	Alzheimer's Society	<a href="https://www.alzheimers.org.uk/">https://www.alzheimers.org.uk/</a>



## Appendix B: Slides presented at the workshop

### Presentation 1: Centre for Implementation Science: What is Implementation Science and who are we and what do we do (Dr Louise Hull, CIS)



KING'S  
IMPROVEMENT  
SCIENCE

Collaboration for  
Leadership in Applied  
Health Research and  
Care South London  
(CLAHRC South London)



National Institute for  
Health Research

# Centre for Implementation Science & King's Improvement Science Patient and Public Involvement Workshop



KING'S HEALTH PARTNERS  
An Academic Health Sciences Centre for London

## Overview

- Centre for Implementation Science**
  - What is implementation science?
  - Who are we and what do we do?
- King's Improvement Science**
  - What is improvement science?
  - Who are we and what do we do?
- The Context for PPI in Healthcare Improvement**
  - Diversity and Inclusion
- Foundations and Future Vision for PPI**
  - Where we are now
  - Where we want to be




Our various structures and acronyms can sound a bit like alphabet soup

## What is Implementation Science?

It's about **identifying, understanding, and overcoming barriers to the implementation of evidence-based interventions**—  
overarching aim to improve healthcare

## Value of Implementation Science

We spend a lot of time (and money) developing evidence...




...which then doesn't get applied into practice

## Centre for Implementation Science

### Who are we?

- Part of the **Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London**
- Research organisation funded by **National Institute for Health Research (NIHR)** funded – research arm of the **National Health Service (NHS)**



## A Collaboration



Guy's and St Thomas' NHS Foundation Trust

South London and Maudsley NHS Foundation Trust

King's College Hospital NHS Foundation Trust

St George's University Hospitals NHS Foundation Trust



## Collaboration for Leadership Applied Health Research and Care South London

Investigating the best way to make tried and tested treatments and services routinely available



## What do we do?

- Support research and other activities carried out by the CLAHRC South London & partner organisations
- We are investigating how best to help implement evidence-based practice and clinical research within health services in south London and further afield.
- Aim to improve health services and develop the discipline of implementation science



Presentation 2: King's Improvement Science: What is Improvement Science and who are we and what do we do (Dr Lucy Goulding, KIS)

KING'S  
IMPROVEMENT  
SCIENCE

## King's Improvement Science



KING'S  
IMPROVEMENT  
SCIENCE

## What is a quality improvement project?

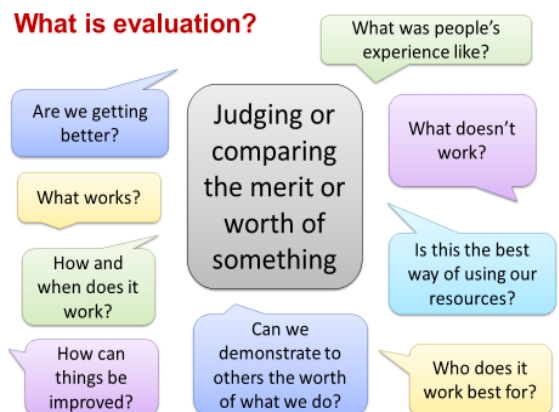
It is about **working together** with a range of people and using a **systematic approach** to make healthcare: safer or more efficient or more effective or more equitable or more timely or more patient-centred

## KING'S IMPROVEMENT SCIENCE

- We have worked on five Quality Improvement projects in collaboration with NHS staff and (sometimes) patients / service users



## What is evaluation?



## KING'S IMPROVEMENT SCIENCE

- We evaluate health services or improvement initiatives in collaboration with local partners



## KING'S IMPROVEMENT SCIENCE

### What is improvement science?

It is about conducting research that tells us **how to improve and make changes** in health services in the best possible way

## KING'S IMPROVEMENT SCIENCE

### Capacity Building Programme

- Developing research staff with expertise in healthcare improvement
- Post-Doctoral Fellows and PhD students
- They direct their work to the specific challenges identified by our partner NHS Trusts



## KING'S IMPROVEMENT SCIENCE

- We contribute to teaching and training



## Presentation 3: The Context for PPI in Healthcare Improvement: Diversity and Inclusion (Dr Josephine Ocloo, CIS)

### The Context for PPI in Healthcare Improvement

guardian.co.uk

Patient champion- Driven by a personal tragedy, Josephine Ocloo campaigns to give a voice to those who feel they have been wronged by the medical profession and to make healthcare in Britain safer.

Mark Gould reports.

[The Guardian](#)

Wednesday June 25, 2008



Josephine Ocloo: "I have lost my child in horrendous circumstances under an organisation that was supposed to be caring for her." Photograph: Tom Pengilly



Full article at: <http://qualitysafety.bmj.com/content/qhc/25/6/626.full.pdf>

### The Context for PPI in Healthcare Improvement

- Serious clinical/service failings increase calls for patients/public to be engaged in health to improve patient safety/quality.
- PPI in the organisation/delivery of healthcare/research considered central to health reform in the UK.
- Evidence shows PPI can make a difference to their treatment/healthcare planning/delivery.
- Despite this context, still uncertainty about how to do PPI & support individuals to genuinely influence decision-making.

'From Tokenism to Empowerment: progressing patient and public involvement in healthcare improvement' Ocloo, J. & Matthews, R. (2016) BMJ Qual Saf

### Context: the challenges for PPI, 'No decision about me, without me'

Partnership working **patchy** and **slow**;

- Evidence suggests patient rep's struggling to influence decisions/largely expected to work within existing systems;
- **Models of PPI too narrow/few organisations address equality/diversity in their involvement strategies.**
- Consultation rather than collaboration the norm, restricting ability to impact decision making
- **Building new partnerships based on co-production with diverse individuals/groups**

(Ocloo, J. & Matthews (BMJQS 2016) 'From Tokenism to Empowerment: Improving patient & public involvement in healthcare improvement')

### Equality and Diversity

- **Equality** is defined in line with the protected characteristics covered by the Equality & Human Rights Act & NHS Constitution & covers: age; disability; gender reassignment; marriage & civil partnership; pregnancy & maternity; race; religion or belief; sex; sexual orientation)
- **Diversity** literally means difference. When it is used as a contrast or addition to equality, it is about recognising individual as well as group differences, treating people as individuals, and placing positive value on diversity in the community and in the workforce.

Presentation 4: Foundations and Future Vision for PPI: Where we are now & where we want to be (Sophie Wilson, KIS)

## Foundations and Future Vision for Patient and Public Involvement

### Where we are now

Implementation and improvement science require **experience and local knowledge; experiential evidence**

**Contextual, cultural** and **local** knowledge is integral for **fair, equitable and meaningful** change across services and trusts

We need to know as much as possible about a certain **context and culture**, and how it is experienced, before we can understand how to change it

### Where we want to be

#### Create relationships that drive positive change

Research and projects should reflect the **experiences and concerns** of those around us

Our methods should reflect the **diversity** of people, organisations, healthcare conditions and more, in south London

Our work should aim to build shared knowledge **meaningfully and collaboratively**



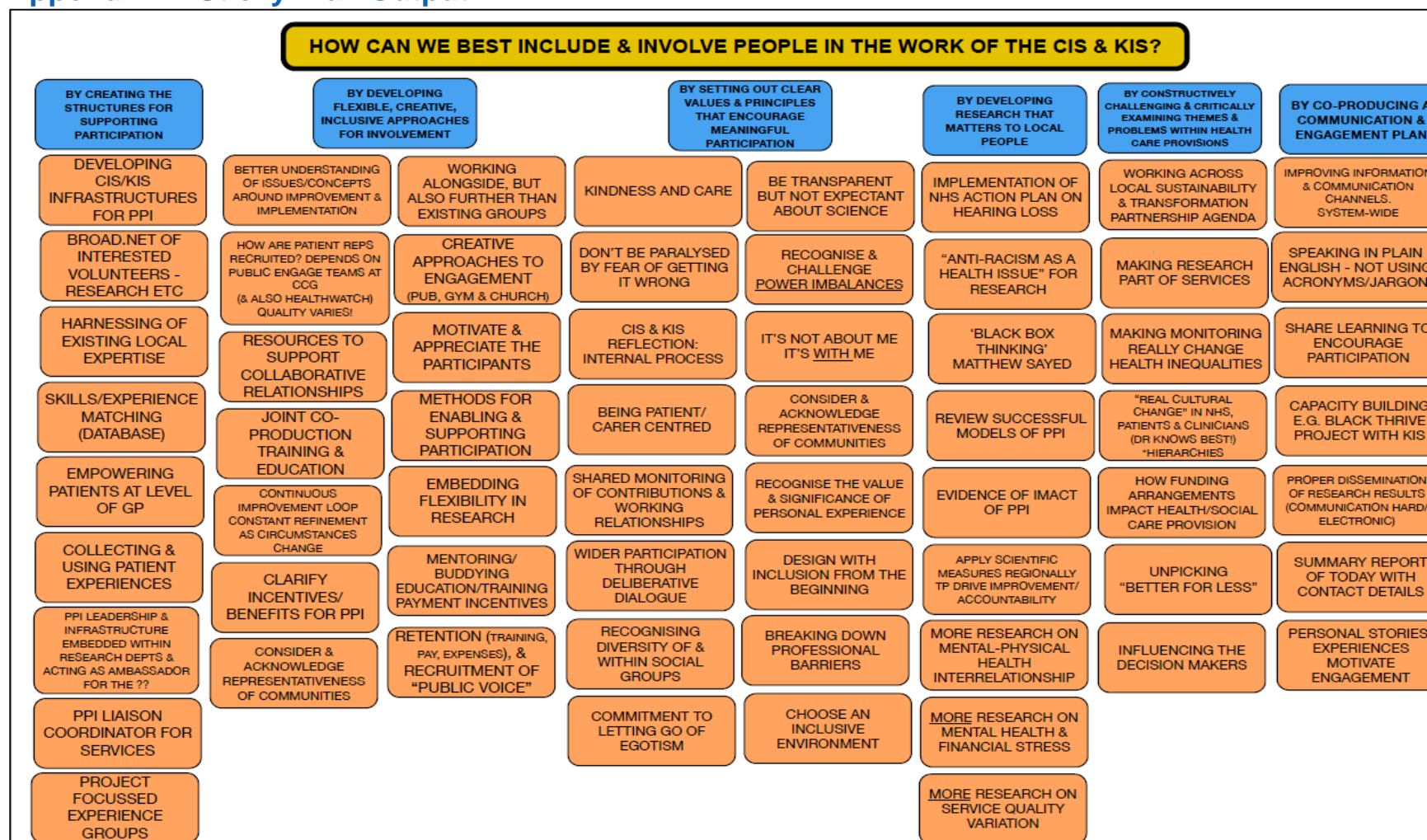
## Appendix C: Workshop Programme

### Centre for Implementation Science (CIS) and King's Improvement Science (KIS) Patient and Public Involvement Consensus Workshop

Wednesday September 27th 2017

Wednesday September 27th 2017	
09.30	Introduction to the day Mary Robson, Facilitator
09.40	Presentation: Centre for Implementation Science and King's Improvement Science ( <i>who are we and what do we do</i> ); What is Improvement and Implementation Science? Louise Hull, CIS & Lucy Goulding, KIS
10.00	Presentation: Discussion and questions, for clarity.
10.10	Introducing the Consensus Workshop Mary Robson, Facilitator  In a Consensus Workshop, all participants have their ideas, insights, perspectives and wisdom heeded.  It involves people working individually, then in small groups and finally all together in answer to our key question: How can we best include and involve people in the work of the Centre for Implementation Science and King's Improvement Science?  • Working agreement
10.20	Individual brainstorming/mind mapping
10.35	Break
10.50	Small group discussion and generation of ideas
11.45	Break
12.00	Clustering and naming the ideas, and whole group discussion
13.00	The Group Resolves to . . .
13.30	LUNCH (including feedback)
14.30	Close

## Appendix D: Sticky Wall Output



## Appendix E: CIS & KIS PPI funding application

### Request for funds for involvement activity

#### CLAHRC South London theme

Centre for Implementation Science (CIS) Implementation Research team and King's Improvement Science

#### Project title (if applicable)

Not applicable

#### Date

July 2017

#### Applicant's name

Louise Hull (CIS Implementation Research team) & Sophie Wilson (KIS project team)

#### Sum requested

£3,300 (to be split evenly across CIS & KIS PPI budgets)

#### 1. Briefly describe the study for which you seek public involvement funds

If this application is not for a specific study, please explain why CLAHRC South London funds are required – e.g. for a workshop/training opportunity involving members of the public.

This application is not for a specific study. Funds will be used to support the development of the Centre for Implementation Science (CIS) Implementation Research team and King's Improvement Science Project team strategy to integrate PPI into their research and activities. . Specifically, we plan to host a PPI workshop to bring together staff members of the CIS Implementation research team and KIS team, patients, and members of the public to collaboratively shape and develop the evolving CIS/KIS PPI strategy.

#### 2. Briefly describe your plans for involvement in the study

If this application is not for a study, briefly describe the activity/workshop (you may refer to the **Summary of INVOLVE briefing notes for researchers**, prepared by and available from the PPI team).

The initial workshop that we will host, on 27<sup>th</sup> September 2017, will bring together patients, members of the public and the CIS & KIS teams to discuss how best to involve patients and the public in our projects and activities.



We have been in contact with Mary Robson, an external facilitator that has worked with the PPI theme of CIS and CLAHRC South London, who has agreed to facilitate the workshop. Using a consensus building methodology, the workshop will explore how patients and the public can contribute to developing the CIS & KIS PPI strategy. All members present at the workshop will explore the ways in which patients and the public can be involved meaningfully in CIS & KIS work.

It is anticipated that the workshop will conclude with a co-produced proposal for a PPI strategy and agreed action points for future work. The workshop will be half a day in duration (approximately 3.5-4 hours). 14 members of the CIS & KIS teams have registered to participate in the workshop and we hope to recruit approximately 14 patients and members of the public (thus we specifically aim to involve an even number of CIS & KIS researchers and patients and the public). Patients and the public will be reimbursed for their time in line with the CLAHRC South London PPI payment recommendations.

### **3. How will you find people to involve?**

Please briefly describe how such people might reflect the south London population.

We will reach out to patients and the public in South London to participate in the proposed initial workshop via a number of avenues. Specifically, we will work with the CLAHRC South London PPI Strategic Oversight Group, the KIS community and the PPI team of the CLAHRC to identify and invite diverse patients and the public from south London to the workshop. We hope to involve patients and members of the public that reflect South London's diverse population in terms of gender, ethnicity, age, and social class and should also reflect diversity of physical and mental health conditions. To date, we have successfully recruited 4 members of the public to attend the workshop-these individuals expressed an interest in attending the workshop which was advertised at the Active Involvement in Research Day that was organised by the CIS PPI theme. We have also invited patients and members of the public who have previously been involved in KIS project work.

### **4. How will involving service users and the public contribute to the study/to the theme?**

Involving patients and the public in the development of the CIS & KIS PPI strategy will have a large impact on the way PPI is carried out with the CIS research and KIS project teams. Integrating PPI at an early stage should help to ensure that PPI is practised ethically and effectively and is meaningful for patients, members of the public and researchers alike. Patients and the public will contribute vital insight, perspective and expertise in how we can implement improvements into NHS health services.

As the CIS & KIS PPI strategy is at the very early stages of development, we feel it is vital to involve patients and the public at this very early stage when it can be most effectively shaped by PPI. Members of the CLAHRC South London PPI team, PPI experts within CIS, as well as experts in our CIS Scientific Advisory Panel, have also recommended that we involve patients and the public in the early development of the PPI strategy.

During the proposed workshop, we will be able to work with patients and the public to explore how best we can meaningfully integrate PPI into CIS & KIS projects and activities. This will contribute toward the development of our PPI strategy so that all CIS & KIS work can involve active input from patients and members of the public.

## 5. Briefly list any challenges/problems you can foresee

Recruiting patients and the public to be involved in implementation and improvement science research that might not specifically relate to a certain health condition is an anticipated challenge for a number of reasons, including unfamiliarity with implementation and improvement science as disciplines,

Implementation science and improvement science are new and evolving disciplines in healthcare and we anticipate that patients and the public will be unfamiliar with the subject. We therefore anticipate provision of appropriate training in implementation and improvement science for patient and public members involved in CIS & KIS projects. The potential need for training provision and introductory workshops will be dictated by discussions that will take place during the PPI workshop.

We are mindful that ongoing involvement requires adequate financial resource in order to be able to compensate patients and the public in line with the CLAHRC South London PPI payment recommendations. We are regularly discussing the need to budget for this. Within this application we have budgeted for three additional PPI meetings following on from the initial PPI workshop (to be held between October 2017 and March 2018).

## 6. What are your estimated costs for involvement in this study?

(break down costs wherever possible)

<b>Initial workshop</b>	
Venue hire	<b>£300</b>
Catering (teas & coffee)	<b>£150</b>
Facilitator	<b>£900</b>
Patient and public payment	<b>£840</b> (£60 x 14)
Travel expenses	<b>£140</b> (£10 x 14)
<b>Three further PPI meetings (Oct 2017 – March 2018)</b>	
Patient and public payment for meeting attendance	£160 (£20 X 8) per meeting ( <b>£480</b> for 3 meetings)
Travel expenses	£70 per meeting ( <b>£210</b> for 3 meetings)
Light refreshments	£40 per meeting ( <b>£120</b> for 3 meetings)
Patient and public payment for reviewing documents in between meetings	<b>£160</b> (£20 X8) (estimate across 3 meetings)
<b>Total estimated cost</b>	<b>£3,300</b>

The completed form should be sent to Savitri Hensman ([Savitri.hensman@kcl.ac.uk](mailto:Savitri.hensman@kcl.ac.uk))

## Appendix F: Feedback free text comments

### What was your overall impression of the workshop?

- Good workshop for thinking about PPI
- Would have been a '5' [very good] if in a more inclusive environment not squeezed in
- Structure of the day and the facilitator were brilliant. Learnt a lot. Felt confident to speak and be listened to
- Good workshop although the room was a little cramped
- I feel like the day was very well facilitated
- It brought people from different backgrounds, not matter their [*unable to decipher handwriting*] to participate
- Mary was a good facilitator. Room was not conducive to my overall wellbeing
- Started and finished on time
- Great facilitation approach-inclusive and productive
- Engaging
- Collaborative approach
- Very useful, [*unable to decipher handwriting*]
- Allowed for significant & meaningful interaction between facilitator(s) and audience

### To what extent do you feel that your contribution was listened to and valued during the consensus workshop?

- Breaking into groups allowed me and I would like to think others to have a fair say
- Good group
- My contribution was considered and discussed
- Good combo of small group work and collective work-plus with written cards you can remain anonymous if you would like
- Give & take
- Because Alex and Steve were very inclusive, kind, and made it a very pleasant experience
- When put on cards
- Even when I came up with a thought at the end of a phase it was acknowledged/respected
- It has been a very productive day!
- Mary Robson facilitated the workshop very well
- Small groups yes was beneficial and sharing of experiences listened to
- It was and [*unable to decipher handwriting*] of number of participants

## To what extent were your access needs met?

- Hearing difficult because of the size of the room and the ambient noise. Was able to access Orla's equipment. I would not normally need this if there was less local noise
- Though I did not have any significant need, am sure if I had they would have been met
- Written on the cards
- No special access requirements
- N/A
- Dyslexia-being asked to scribe
- Very good and accessible venue
- Room a bit tight, even after presentations table was done away with. Consider a larger room
- The reason I circled 3-4 is because as a room it was totally unacceptable to work in as a workshop the acoustics noise of everyone talking around such squeezed in tables was poor for conversations. The big tick is thank you for providing STTR as I definitely would not have been able to actively participate without it. I needed to follow the talks/conversations on text screen I am also aware chatting to others they would have benefited if it was also shared on large screen text over top. Hence 4-5 for this as its of benefit to others too inclusive and wasn't made available to all.

## Do you have any further suggestions for improving future workshops and/or involvement activities?

- A room that is not squeezing us in as already said
- The workshop ran well. Maybe earlier lunch
- Consider role play, case study etc. activities. Invite one or two reps from Southwark council-public health arm, Southwark Clinical Commissioning Group, Forum for Equalities and Human Rights
- Not an improvement as such: I'd like to follow-up this event; would be useful to consider different means of doing that.
- Larger venue-more space/less background noise
- Venue with a little more space
- Brain food snacks-dates, nuts etc.
- Examples/background/methodologies of current/past projects (good and bad!)
- I thought the process of this workshop was a blue-print for great sharing and engagement
- More consensus workshops of this kind for particular issues/research questions
- I would like to get involved in any future event
- No it really was great-make future workshops more like this!
- Was very well run and kept to schedule whilst not feeling at all rushed. Very interesting and informative.
- Ask about hidden disabilities

- A clear explanation of possible next steps/where do we go from here would be good
- Mary is really excellent. Needs to be a bigger or quieter room
- Perhaps switch groups around so people get to know each other better
- No-excellent-do it again!
- Better venue/facilities-by this I mean a bigger room
- Good facilitation really helps
- Smaller groups for the consensus workshops. 38 people was a lot of people
- [unable to decipher handwriting] engage with different forums in the Borough and get them to nominate appropriate/suitable people who are willing to participate

### Is there anything else you'd like us to know?


- The rethinking opportunity was fantastic. I was able to promote a [unable to decipher handwriting] event so people get to know what I do-already a participant on my table is going to invite me to an event they are organising.
- I enjoyed myself!! Good number of people and group sizes
- What happens next
- Thank you for the opportunity to contribute to the day!
- The artificial lighting and small room with noise volume made it a little 'challenging' in the sense that my disability means I experience sensory overload
- I will feedback to the PPG I go to and it has really helped me to consider improving ways to develop our patient group. Thank you.
- Room slightly too small
- Well organised, well facilitated. Achieve [unable to decipher handwriting] Can easily [unable to decipher handwriting] and trigger for further PPI events in the future. Thank you.
- Have/will you provide a community newsletter for members of the public in the [unable to decipher handwriting] Southwark?

## Appendix G: Slides presented at the CLAHRC Executive meeting, October 2017



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Collaboration for  
Leadership in Applied  
Health Research and  
Care South London  
(CLAHRC South London)



National Institute for  
Health Research

### Centre for Implementation Science & King's Improvement Science Patient and Public Involvement Workshop: Report to CLAHRC Executive

Louise Hull & Sophie Wilson



KING'S HEALTH PARTNERS  
An Academic Health Sciences Centre for London

### Background

- High-level exploration of How best can we involve patients and members of the public in the work of the Centre for Implementation Science and King's Improvement Science?
- 34 people attended (17 researchers from CIS, KIS and PPI themes & 17 members of the public living or using services in South London)
- 27<sup>th</sup> September 2017, half-day workshop, hosted at Cambridge House





### Why?

- Aim for meaningful and inclusive PPI strategy for implementation & improvement research
- Create open dialogue to inform strategy
- Build relationships in local community
- Enhance C.I.S and K.I.S work going forward

### An introduction to C.I.S and K.I.S

- The **Centre for Implementation Science** was introduced by Louise Hull
- **King's Improvement Science** was introduced by Lucy Goulding
- Josephine Ocloo spoke about the importance of **diversity and inclusion** in patient and public involvement
- Sophie Wilson spoke about why we should **collaborate on healthcare improvement** and implementation by working with local and diverse groups

### How can we best include and involve people in the work of the CIS & KIS?

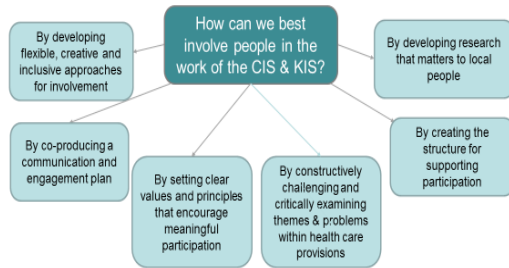


Facilitated by Mary Robson, external facilitator, using a consensus based approach (Sticky wall)

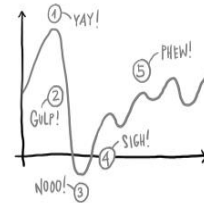
### HOW CAN WE BEST INCLUDE & INVOLVE PEOPLE IN THE WORK OF THE CIS & KIS?

OF IMPROVING THE STRUCTURES FOR INVOLVING PATIENTS AND THE PUBLIC	OF RESEARCHING, DESIGNING, IMPLEMENTING AND EVALUATING RESEARCH	OF RESEARCHING, DESIGNING, IMPLEMENTING AND EVALUATING RESEARCH	OF RESEARCHING, DESIGNING, IMPLEMENTING AND EVALUATING RESEARCH	OF RESEARCHING, DESIGNING, IMPLEMENTING AND EVALUATING RESEARCH
DEVELOPING CLEAR, INFORMATIVE, ACCESSIBLE, AND EASY TO UNDERSTAND INFORMATION FOR THE PUBLIC	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
BROADENING THE SCOPE OF INVOLVEMENT TO INCLUDE A WIDER RANGE OF PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
HARVESTING OF EXISTING LOCAL EXPERTISE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
SKILLS/EXPERIENCE BUILDING (EDUCATION)	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
EMPOWERING PATIENTS AT ALL LEVELS OF GP	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
COLLECTING & USING PATIENT EXPERIENCES	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
PROVIDING A STRUCTURED APPROACH TO INVOLVING PATIENTS AND THE PUBLIC	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
PPI LEADERSHIP COORDINATOR FOR SERVICES	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE
PROJECT FOCUSED EXPERIENCE DESIGN	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE	BEING TRANSPARENT ABOUT HOW WE INVOLVE PEOPLE

## Foundations for C.I.S & K.I.S PPI Strategy

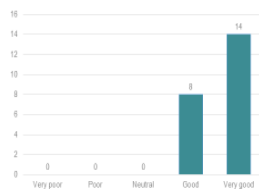


## Feedback, Lessons Learnt and Recommendations



## Feedback

What was your overall impression of the workshop?

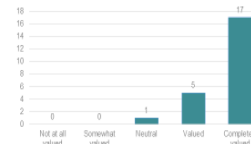


'Structure of the day and the facilitator were brilliant. Learnt a lot. Felt confident to speak and be listened to'

'Allowed for significant & meaningful interaction between facilitator(s) and audience'

## Feedback

To what extent did you feel your contribution was listened to and valued during the consensus workshop?

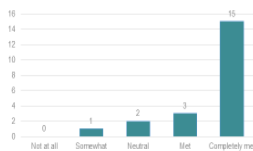


'Breaking into groups allowed me, and I would like to think others, to have a fair say'

'My contribution was considered and discussed'

## Feedback

To what extent were your access needs met?



'The big tick is thank you for providing STTR as I definitely would not have been able to actively participate without it.'

'Dyslexia-being asked to scribe'

## Diversity, Inclusion & Accessibility

### Challenges in planning & delivery

- Much discussion but lack of consensus/agreement how to **define & monitor diversity**  
Defined in line with the protected characteristics covered by the Equality & Human Rights Act & NHS Constitution (age; disability; gender reassignment; marriage & civil partnership; pregnancy & maternity; race; religion or belief; sex; sexual orientation)
- Lack of consensus on how to **identify and invite a diverse group**
- **Accessibility** (facilitator, room hire, location, time, catering, sensory equipment, invisible illness)



## Unanticipated Costs & Consequences

- Access costs for the event were £600 (+VAT)
- Costs impact future events: number, duration, number of delegates, etc
- Recommendation: budget for access costs



## Sustainability

### Time and expertise to organise PPI workshop

- Planning team: CIS, KIS and PPI theme; regular team meetings and discussion

Based on current funding model (£1,650 per theme), this type/scale of workshop is **NOT** feasible for individual themes to deliver

- CIS & KIS pooled their resources (£3,300). Does this make sense for CLAHRC themes?
- Capacity building and cost reduction: investment to train staff to facilitate (Stan & Savi have agreed to facilitate future PPI workshops/activities)



### Staff engagement

- Good engagement and attendance from C.I.S and K.I.S staff
- Important to emphasise that workshop aimed to build PPI strategy for CIS and KIS rather than develop PPI practice for an individual project
- Working with external facilitator very helpful to 1) engage effectively and 2) have no bias during consensus building



### What next?

- Write up **report** of workshop and C.I.S and K.I.S PPI strategy foundations
- **Share** draft report with patient and public attendees for input
- Configure how principles may translate into an **action plan and model** for involvement within C.I.S and K.I.S
- **Implement model** and test within a C.I.S-K.I.S project





## Appendix H: CIS & KIS PPI Report Feedback from CIS & KIS Staff and Members of the Public

### CIS Staff

#### S1

This is nicely presented and generally reads well (though I've not read in very close detail – minor stylistic point but I think reports look better justified, but that's a personal preference).

I may have this wrong (not read in forensic detail) but in the lessons learned section there seems to be a lot of emphasis on diversity and equality with respect to PPI selection/recruitment (and particularly in relation to population characteristics identified in the 2010 legislation referred to) which almost seems to put a premium on achieving certain “quotas” with respect to specific population groups listed. Is this linked to NIHR requirements with respect to equalities legislation – or was it agreed on at the session that that this should be the guiding principal covering recruitment/section efforts? I raise this because this might compromise or compete with other legitimate aims around selection and recruitment too – e.g. proportionate representation by age, gender, illness severity etc. with respect to specific patient groups. I also wondered why recruiting as many people as possible should be an aim when this may make things more challenging from other perspectives (reaching decisions, consensus etc.) – again a possible trade-off?

CIS & KIS PPI planning committee response: Thank you for taking the time to review the report. The comments and thoughts you have are extremely helpful and highlight the complexities of developing a diverse and inclusive approach. These comments will be shared with the CIS PPI planning team and also with members of the public at the next PPI event.

#### S2.

This is a very useful way forward, many thanks indeed for the production of the report and also of the short piece around the clusters and how to operationalise them. I am very conscious that the clusters, and wider report, suggest interactive participation from the group who attended the event last year and indeed in the future. We should have an actionable (and affordable) manner to achieve this – let's touch base when possible regarding how to do this to ensure we maintain the group engagement and goodwill. Thank you and indeed everyone again for all the contributions that got us to this point. This is a team effort, as I'd like to believe all we achieve through the CIS and the KIS is. Well done all!

**By developing flexible, creative and inclusive approaches for involvement:** So in order to achieve the various elements mentioned within this cluster, **we need to practically set up a patient reference group for CIS/KIS** – and a mechanism to maintain it, keep everyone informed, engage people with the work and so on. I would practically propose that we start with the group copied into this email. The group

needs to be able to interact, physically or virtually, to take forward some of the ideas expressed here (and also within other clusters below)

**Workshop attendees stressed that our communication plan should be co-produced:** So we do need a few people to be directly involved in this activity; see my suggestion to have a standing reference group, as above

**Engagement plan:** The CLAHRC South London Active Involvement in Research Days (AIRDs), which are mentioned in the more detailed report, may offer an existing route to directly engaging with patients and the public. It would be good to align the various activities that the CLAHRC South London (which include CIS and KIS) supports, as this makes things more easily achievable in practical terms

**By setting clear values and principles that encourage meaningful participation:** This is a critical cluster to me, as a workshop participant. I would actually think this is the cluster that underpins or encloses all the other clusters – as this is about values, and not practicalities. I'm very glad this has come out as a clustered principle from the workshop – it is so important!

**By constructively challenging and critically examining themes and problems within health care provision:** As above, an important value-based approach for us to take. I do like the fact that specific NHS policies are mentioned (eg the transformation agenda). As the value cluster this one too cuts across projects and practicalities and offers a lens for the CIS and KIs to take; this is a broad lens, by necessity. Last but not least, one thing to bear in mind is the scope and reach of CIS and KIS: ie how much we can expect to influence national policy. I would think the aspiration and vision should be there, as stated. But we need to align this with some of the more operational clusters, so as to be able to do a few meaningful things in the short to medium term within the resources that we have.

**By creating the structure for supporting participation:** This is an important cluster for pragmatic implementation and us all going forward. Some ideas exist here in terms of how to use the role of the PPI coordinator to facilitate better links with the group who attended the workshop – and indeed others and CIS/KIS. I feel this cluster starts to present some deliverables and actions to us to pursue.

**By developing research that matters to local people:** Taking the perspective of someone involved in the decision making of CIS and KIS research proposals, what I see here is that we need the mechanism to involve better the people who attended the workshop and potentially the wider group called for (above) to the research prioritisation process. We did discuss at the workshop some of the boundaries within the CIS and the KIs function – including for example the requirements of our funders; and the issue of aiming to generate more funded research to address some of these new research priorities. I would propose that having a reference group could assist us with the process of proposing research and designing it.

**The sticky wall output has provided the CIS research team and KIS project team with guiding principles and a foundational strategy for PPI in future work:**

This is a key sentence in my personal view as participant – I absolutely agree and would second it (and its implication for future actions)

**The six clusters will need to be reviewed and taken forward differently:** It would be helpful to have representation of the people who attended the workshop and are not core CIS/KIS members in the review process.

**Realities, abilities, opportunities and restrictions will be openly discussed between patients and the public and CIS & KIS staff members, as well as external stakeholders, in order to drive a strategy that can be embedded and implemented for PPI in CIS & KIS:** It would be useful to have a brainstorm about potential for a to achieve this. For example, the AIRD event in March 2018 – see my earlier comment?

CIS & KIS PPI planning committee response: Thank you for your comments and suggestions of ways to practically move forward in embedding the PPI principles that were co-developed as part of the workshop into the work of CIS & KIS. We plan to share your comments and suggestions with members of the public at the next PPI event.

Public members

P1

**Commented on ‘By developing flexible, creative and inclusive approaches for involvement’ cluster summary text:** This means working with individuals, but also thinking about how to connect with representatives for community groups. It also means reaching outside of existing and formalised community groups, and being creative about how to establish relationships with individuals who have not been involved in healthcare research before, and are not in frequent contact with community groups.

“It needs to be clear to patients & public reps that they are also made aware of the dynamics of group decisions & consensus. Knowing that we will not always get our way and knowing when to compromise on strongly held feelings & beliefs”

**General comment:** It might be just me, though I feel that it is a rather inward sounding document, that is that it reads as if communicating with academics/researchers, rather than general public. I found some of the concepts difficult to see translating from thought experiments into real life, so I would like to see more details on how KIS/CIS intend to excite and engage the public in their future projects.

CIS & KIS PPI planning committee response: Thank you for taking the time to reflect and comment on this report. Acknowledging the role of group dynamics in decision making is vital for our collaborative practice. CIS and KIS PPI work so far has aimed to reach consensus on important strategic directions across our diverse stakeholder group, including staff and members of the public. This will continue to inform the co-production of the CIS KIS PPI strategy as well as CIS KIS PPI activities going

forward. This report was produced with CIS KIS staff and public members who attended our workshop in mind. In future reporting, we will consider further options to improve open and accessible communications.

Finally, we hope that our most recent PPI workshop on 27<sup>th</sup> March helped to translate abstract concepts outlined at the first workshop into real life action plans to inform the strategy. We welcome all suggestions for how CIS and KIS can further engage and excite the public for successful collaboration.

## P2

The main question we were trying to address was 'How can we best involve people in the work of CIS & KIS'. Before trying to develop frameworks to operationalise what we came up with we must think through:

- Who are the 'people' we want to get involved?
- Where are they?
- Have they had previous experience in this type of work? How would we know?
- How do we reach out to them? Our marketing processes must be clear and simple and attractive including translation services if necessary.
- Do you want to work with all of them?
- If not what selective processes are we going to use to satisfy equal opportunity?

The next step will be to develop a profile of each group understand fully what they are about and what motivates each of them

We would then use those details to 'develop flexible creative and inclusive approaches for involvement' as one size does not fit all. Followed by co-producing a communication and engagement plan as understanding on 'involvement' and 'engagement' could mean different things to different people

Once these extensive pieces of work are carefully done we would explore putting other themes into practice if necessary. Yes I say if necessary because we may not be doing everything with all the 'people'. Some for example may just want basics like regular newsletters to update them more. The greatest challenge would be how to sell this piece of work so the extensive details do not scare people off. Would be helpful to find out how similar exercises have been done by other credible partners and learn from their lessons.

CIS & KIS PPI planning committee response: Thank you for taking the time to reflect and comment on this report. Considering who may want to be involved in the work of CIS and KIS and to what extent is vital for our PPI strategy. The CIS KIS PPI planning team are currently developing an Equal Opportunities monitoring form to think critically about 'who' we are involving, who we are aiming to involve, and whether we are achieving this. We plan to share a draft version of this form to our public members group who may find time to advise us on its development. From there, we hope to gain information that will allow us to know what groups we are and are not reaching, and how we might reach out further to more diverse groups to be

involved in our work. We also hope that our follow-up PPI workshop held on March 27<sup>th</sup> 2018 helped us to think more around the importance of contacting different groups of people in south London and setting up PPI structures and opportunities that are meaningful to them. This may differ substantially for different individuals and it is vital that we have structures to support this type of participation.