



***National Institute for
Health Research***

**Patient and Public Involvement and Engagement:
NIHR Collaborations for Leadership in Applied Health Research
and Care Annual Reports 2015/16**

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Background

All recipients of National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) funding provide the NIHR with an annual report detailing the activity and progress made in the previous financial year. Annual reports provide valuable information that allows the NIHR to review performance, enable decision making on future funding requirements, answer Parliamentary Questions, prepare briefings for Ministers, respond to other requests for information and share information amongst the [NIHR Coordinating Centres](#).

There is a patient and public involvement and engagement (PPI/E) section in the annual report that requests the following information, in no more than one page:

Please summarise your progress to date in implementing the NIHR CLAHRCs strategies for PPI/E reporting on the following areas:

- any significant changes or revisions to your PPI/E strategies
- your assessments of progress being made in the delivery of your aims and objectives as detailed in your PPI/E strategies
- the PPI/E activities and outcomes you are delivering. This is likely to include PPI/E in individual research projects and in your organisational structure
- the partnerships and collaborations you are involved in that support the delivery of your strategies
- the resources that are committed to delivering your strategies, for example, staff, training and development for researchers and members of the public and fees and expenses offered for involvement activities
- examples of the impact that your PPI/E activities are having. These could be in individual research projects and / or in the governance and management structures of the CLAHRC itself. Please highlight any significant successes or challenges. Any PPI/E 'Added Value' case studies are welcome
- how you monitor, review and report on delivery of your PPI/E strategies within the management and governance structures of the CLAHRC.

Please report on your involvement and engagement strategies separately. Please also describe how you make patients and the public aware of the research being undertaken within your NIHR CLAHRC, and signpost them towards appropriate information about participating in research.

Following the success of last year, the NIHR is again making the PPI/E sections of annual reports publicly available. All the reports in this series, both current and previous, are available from the NIHR website: [Download reports](#).

Collaborations for Leadership in Applied Health Research and Care (CLAHRCs)

The 13 CLAHRCs bring together a collaboration of the local providers of NHS services and NHS commissioners, universities, other relevant local organisations and the relevant Academic Health Science Network. CLAHRCs conduct applied health research across the

NHS, and translate research findings into improved outcomes for patients. They primarily focus on research targeted at chronic disease and public health interventions. For more information about CLAHRCs: [click here](#).

Purpose of this report

This report briefly summarises the PPI/E activities undertaken by CLAHRCs during 2015/16 in delivery of their PPI/E strategies. It repeats a process that was undertaken last year for the first time which was welcomed by many and saw more than 6,000 downloads of the nine annual report compilations. Following the submission of annual reports, all the PPI/E sections were compiled in a draft document that was shared with the CLAHRCs. This provided an opportunity to review and edit content; to add any necessary information about context, to explain abbreviations and acronyms and provide contact and website details.

The main aim of making this information publicly available is to support and promote the sharing of knowledge, learning and good practice across the NIHR and beyond. In addition, this report, along with others in the same series, begins to address Recommendation 9 of the [Going the Extra Mile](#) Report which followed a strategic review of public involvement in the NIHR:

Recommendation 9 – Coordination: All NIHR Coordinating Centres and infrastructure organisations should have a strategy, framework or plan that covers the promotion and advancement of public involvement, participation and engagement in research. Leadership, accountability and funding for this agenda within organisations must be clear and transparent. Progress should be reported annually, made publicly available and an overview included in the NIHR’s annual report.

[‘Going the extra mile: Improving the nation’s health and wellbeing through public involvement in research’ \(2015\)](#)

We believe this working document will be of interest and practical use to a number of different audiences including: all those who have responsibility for developing and delivering PPI/E strategies across the NIHR, the public, patients, service users and carers, researchers, research funders, all NHS organisations, Public Health England, industry and third sector organisations.

Further information and feedback

If you would like to know more about any of the specific PPI/E activities of the CLAHRCs please contact them directly.

The [NIHR Central Commissioning Facility](#) has produced this report and we welcome feedback from anyone who reads it. For example, it would be helpful to us to know who reads this report, whether readers find it informative and useful, or not and what we can do to improve it. To give your feedback, please email ccfppi@nhr.ac.uk using the subject header ‘CLAHRC PPI feedback.’

East of England CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-ee.nihr.ac.uk/
PPIE web pages	http://www.clahrc-ee.nihr.ac.uk/involvement/
PPIE Strategy	http://www.clahrc-ee.nihr.ac.uk/wp-content/uploads/2015/09/PPI-Strategy-June-2016.pdf
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Progress in implementing the CLAHRC PPI/E strategy: CLAHRC East of England (EoE) has made good progress with the PPIE strategy as detailed below.

Changes/revisions to our strategy: A PPI strategy workshop was recently held and some revision to our PPI strategy will follow in 2016.

Examples of PPI activities and outcomes across CLAHRC research themes: The project, [Transition from Child & Adolescent Mental Health Services \(CAMHS\)](#) involves Young People (YP) who are users and leavers of CAMHS in co-producing a Transition Preparation programme. A 2 day workshop was held with 5 young people who were leaving CAMHS, and arising out of this workshop were a number of clinician workshops which the YP co-hosted. At one workshop at Hertfordshire Partnership Foundation Trust (HPFT), 15 clinicians attended and a draft transition protocol/manifesto/list of recommendations was co-produced. For the [Cascade study](#), comments were obtained on the draft study documentation from 4 lay members of the public involvement group. This helped the researchers to devise a recruitment approach for the study. To broaden the discussion on ethical dilemmas, the researchers took this discussion to the larger "Public Involvement in Research into Ageing and Dementia" group at the University of Cambridge.

PPI research theme

The PPI research theme's projects - [Implementing PPI in an NHS research programme](#) (IMPRESS), [Patients as Partners](#)(PIPPIN) and [Understanding PPI in research with older people in residential home settings](#) (RREACH) are tackling important areas of PPI implementation, means of PPI inclusion of excluded groups and patient experience of managing renal conditions in hospital settings. One example of PPI activity by the PPI research theme is the stakeholder workshop for [RReACH](#) (Residents Research Active in Care Homes) to gain views and ideas about care-home residents' involvement in research, and to generate ideas to support people interested in involving residents in research in care homes. [This is one of the first studies to involve care homes' residents in research priority setting](#). Over 30 people attended the workshop including care-home residents, managers and staff, relatives, researchers, with many more involved through outreach follow-up. Guidelines were developed for 'involving residents in research as advisors or collaborators' and are available on the [ENRICH website](#).

Organisational PPI structure

We have 3 PPI representatives on the [CLAHRC Board](#), one as an external peer reviewer on the Prioritisation Group and one on the Capacity Building Committee. The PPI Coordinating Group is under review but currently comprises of CLAHRC researchers and 3 lay members.

Partnerships and collaborations

Each research project has PPI embedded within it, and each project and theme has their own range of PPI partnerships and collaborations, and its own approach to collaborating and partnership working. For example, collaborators in [Transition from CAMHS](#) project are all 3 mental health trusts in the region (Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), Norfolk and Suffolk NHS Foundation Trust (NSFT) and HPFT) and Cambridgeshire County Council Youth Offending Services. Healthwatch Cambridgeshire and Healthwatch Norfolk are partners in the [Delphi study](#). We also have collaborations with PPI organisations locally, regionally and nationally and run annual events in collaboration with the PPI lead for RDS East of England whilst collaborating regularly with INVOLVE.

Staff training and development for researchers and research training for members of the public

Literature Search training that was arranged for the 6 YP involved in the Transition project; this was provided by the Clinical School Medical librarian at the University of Cambridge. Another example are the 3 training events that were held for IMPRESS lay co-researchers, this included learning about focus groups and research methods.

Monitor, review and report on delivery of the CLAHRC's PPI/E strategies within the management and governance structures of the CLAHRC.

All CLAHRC projects have to have PPI as a part of the project protocol prior to consideration by the Prioritisation Group. We monitor PPI through 3 monthly project reports and 2 key performance indicators measuring patient and public involvement.

How we make patients and the public aware of our research

Information on our PPI activities, experiences, training outputs, projects and blogs are posted onto our website, often as downloadable pdf content (e.g. CLAHRC BITES) and contained in our newsletter. Occasionally we achieve a wider dissemination for example: Professor Simon Baron-Cohen was on the Today Programme (BBC Radio 4) talking about the [Red Flags for Autism](#) project and how early diagnosis of autism could help reduce the gap from referral to diagnosis. Valerie Dunn was invited to present at the Prince's Trust National Care Leavers Conference to show [Finding My Way](#), and [FMY Behind the Scenes](#), two CLAHRC funded films about YP leaving care. Two young people involved in the making of the films spoke to the conference. Prince's Trust fed back that they had received very positive feedback. We also involve our PPI representatives in the development of Plain English Summaries, for example the IMPRESS team (including PPI co-researchers) drafted a Plain English Summary using the INVOLVE guidelines; this was then further refined by the PPI members of the IMPRESS Advisory Group.

East Midlands CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	NIHR CLAHRC EM
PPIE web pages	CLAHRC EM Public Involvement
PPIE Strategy	Public Involvement Strategy
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Patient and public involvement:

CLAHRC EM is on track to deliver its PPI strategy that was developed in its first year. Public Involvement (PI) is a fundamental component in health care research and delivery, to improve, quality and relevance. NIHR CLAHRC for EM has committed itself to a whole systems approach to PI linking it to all parts of the organisation. PI has a designated senior post and budgets for PI; Patient and Public Partners' Council (PPPC); the East Midlands Centre for Black and Minority Ethnic Health (EMCBMEH); and independent Scientific Committee as well as a system of robust reporting and monitoring systems and accountability measures. PI is an essential criterion for funding and PI representatives helped select our Phase 3 studies. As a result projects within the CLAHRC recognise PI as an integral component with multiple methods for involvement including; members on the project team; innovation networks; outreach public involvement and advisory groups. The PI strategies and the results of this lead to positive impacts beyond individual projects or the organisation, including positive lifestyle choices, awareness and improved self-management of long term conditions and an increase in health literacy.

All current projects have public involvement which is captured using an impact log that is part of the Quarterly Updates collected as part of the performance management of the organisation. Increased confidence and skills have been reported by PI representatives involved with CLAHRC projects. For example, one former PPPC member is now an RfPB reviewer and sits on the Scientific Committee whilst another works on projects in London.

Individual example of excellent PPI in our projects are:

AQUA – from the outset this project has involved patients, clinicians and health care providers through its innovation network. The patient and parent influences have been valuable in this project and they have gained knowledge as a result. The AQUA study recruited beyond initial targets and was able to coordinate sites across the country and has worked with commissioners and wider stakeholders to ensure that the outcomes of this study can be put into practice, benefiting patients and their families.

Health Anxiety – The study's network of practice has provided support and solutions to potential barriers, ensured that all stakeholders have a voice in the project design, delivery and potential implementation. The study was rolled out to Northamptonshire as a direct result of this network. The public representatives have spoken at the network meeting sharing their experiences of being involved, they have been instrumental in developing the website to ensure that people are kept informed about the study progress and also to assist

with recruitment. Testimonials from participants in the study will be recorded and will give a greater voice to those for whom the intervention could be beneficial.

E-DASH – This study is looking at delivery of remote Cognitive Behavioural Therapy to individual who self harm. The public involvement in this study has come from the local charity Harmless as individuals with lived experience and an inherent understanding of the target population. The study also used outreach methods to capture the perspectives of those out in the community with little knowledge of the support available. The study information was distributed by a contact from the PPPC and the comments returned to the study team, these resulted in significant amendment to the recruitment time scales and methods, justified the need for such a study and provided an alternative implementation plan.

Space for COPD – excellent example of involving patients in the design and conduct of the study. In particular, their views have been invaluable in developing the group self-management sessions for patients with COPD. They attend the fortnightly network of practice meetings alongside the research team, managers, CCG representatives and community healthcare professionals.

Public engagement:

NIHR CLAHRC for EM engages in a range of engagement activities including workshops and networks of practice. In particular, a number of our studies have developed Integrated Managed Innovation Networks (IMINs) where they engage with stakeholders providing information on the studies and opportunities to get involved. Many studies are now developing websites to support the engagement in the studies by providing updates on the study progress and general information.

In the last year we co-hosted (with EM AHSN) The Inclusive Involvement Conference on February 24th 2016 which was attended by over 150 people. Each presentation and workshop produced a top tips document which can be found here [Top Tips Guides](#). Our CLAHRC EM Partners Day was held on the 25th of February sharing the benefits of working with a CLAHRC and achievements to date. Event details and presentations can be found here [CLAHRC Partners Day](#).

Please also describe how you make patients and the public aware of the research being undertaken within your CLAHRC, and signpost them towards appropriate information about participating in research.

NIHR CLAHRC for EM uses a range of methods to ensure we communicate with patients and the public. We currently have 3 members of staff who work on Communications under the leadership of our Director of Partner Relations. We have a website that is updated regularly and has had more than 18,500 hits, an active twitter account with over 1,600 followers and we have published 34 BITEs (Brokering Innovation Through Evidence) which are short descriptions of our projects and their findings.

For the past year we have been working with a former journalist in placing stories about CLAHRC EM in the national, regional and local media detailing our work for public consumption. This has included stories about our projects in local newspapers where they

are being carried out through to getting a senior researcher an interview on the Today programme on BBC Radio 4 about their work.

In the next year we plan to refresh our Communications Strategy to reflect the fact that our projects will be beginning to complete and that we will be entering the implementation phase of this CLAHRC. However, our commitment to communicating our work to the wider public is undiminished.

Greater Manchester CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	www.clahrc-gm@nhr.ac.uk
PPIE web pages	
PPIE Strategy	
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Our PPI/E strategy remains largely unchanged from the last annual report, apart from reviewing to ensure it addresses the recommendations of the 'Going The Extra Mile' report of the 'Breaking Boundaries' review, which it now does.

Our PPI/E strategy and progress were assessed by our external review panel, which supported our decision to no longer carry out an academic research evaluation of the impact of our Patient Panel. This is due to the academic lead for PPI moving to another institution, and lack of coherence with our other research projects and resources. The external review confirmed that CLAHRCs were not required to 'research' PPI, and complemented us on the clarity of our strategy and the clear focus on carrying out effective PPI/E, rather than researching it.

The role and contribution of PPI/E across programmes and projects is already built into the individual projects and academic support for PPI (which is built into every project from its inception) is provided by links to the wider University of Manchester (UoM) PPI/E community, by our Enabling Network (stakeholder engagement) and CLAHRC staff and students with experience in different approaches to PPI/E.

Our CLAHRC Patient Panel (4 members), is now fully established, has an agreed remit and terms of reference, and meets every 6 months. At the meetings the Panel has formally reviewed projects at different stages of delivery and has provided feedback that has helped to identify lessons that can be learned across projects and applied to future projects, so that we continue to develop and deliver appropriate and useful PPI/E. The Panel members have regular input to the CLAHRC Programmes in between meetings, offering general advice to our team about how best to reach and use information gathered from patients and carers both individually and via established patient groups, and providing specific input i.e. advice re establishment of user groups and focus groups and development of lay summaries.

The Enabling Network facilitates interaction between the Panel and the rest of the CLAHRC team, to ensure that learning is shared across programmes via our learning and capacity building activities, producing resources to help programme teams in their PPI activities and bringing teams together to share experience and learning.

As described in last year's report, PPI/E is one of the key performance indicators (KPIs) measured across programmes and projects. Six monthly meetings between the Director and Executive Team and programme leads and managers review these KPIs and ensure a continued focus on PPI/E.

In terms of wider engagement, the CLAHRC team continue to engage with patients and the public through their project work, and Patient Panel members act as ambassadors to raise awareness of CLAHRC, using their own contacts and networks. We continue to participate in partner organisations' patient and public engagement forums, e.g. a presence at Salford Royal NHS FT's Research and Development 'Research Week', which engaged members of the public in various ways, including a presence in the local shopping centre and other events throughout the week.

All our projects now have appropriate PPI/E and have already built strong partnerships with patients and the public. The Panel will ensure that this carries through into future projects. PPI/E highlights include:

- **Mental Health THINKphysical Festival**

This took place between 14th-19th June 2015 and brought together service users, carers and the general public, academics healthcare and charity organisations in a series of events with the aim of determining research priorities and developing opportunities for engagement and research. A service user group was established and made a significant contribution to the development of an anti-psychotic medication side effects leaflet and a very successful theatre production ([Side Affect](#)) which is available freely on YouTube and being considered for use by a number of universities as part of the teaching curriculum. A research volunteer database was established and a PROM developed with the service user group, which will be developed and evaluated in 2016. The Festival was recognised at the NIHR Clinical Research Network Greater Manchester Awards in November 2015 winning the public engagement category.

- **Access to Primary Care PhD**

This project is utilising participatory research approaches and the PPI members are true partners in the research process. They have contributed to every stage of the research project so far, including the study design, the preparation of the ethics application and study materials, and ongoing data collection and analysis. Three PPI members have attended relevant seminars at UoM and 1 PPI member recently attended a qualitative analysis software training course with the PhD student (Dr Jennifer Voorhees) to further their skills in research. Following the student's attendance by at the International Collaboration for Participatory Health Research in June 2015, she formed a group of local academics and PPI members interested in better understanding the participatory approach to research. Through the work of this group, CLAHRC GM hosted the UK Participatory Research Network Meeting in October 2015. In conjunction with that meeting, we held a CLAHRCGM 90minute workshop comparing PPI and participatory

research, which was coproduced, cofacilitated, and attended by both academics and members of the public. We expect tangible impacts from this project over the coming year.

- **Uncovering the contribution, costs and economic value of family caregiving**

In the design of this national survey focussing on the economic impact of caring for people with cancer during the final stages of life, the involvement of local carer groups has been influential in ensuring a survey design which resonates and is understood by carers from diverse backgrounds. The survey was sent to 5272 carers, with 1504 (28.5%) completed surveys being returned. This high response rate is largely due to the extensive carer input into the survey design. We held initial discussions with 6 local carer groups about suitable and appropriate topics, followed by a more focussed discussion with a specific end of life research carer group about the acceptability of language, questions focussing on personal finances and retrospective recall of information; Cognitive testing was then done with 6 carers, followed by the survey being piloted with 20 carers, who provided detailed information about all aspects of the survey design.

Organising Support for Carers of Stroke Survivors (OSCARSS) will evaluate a structured, carer-led process for the identification and support of carers' needs. A research users group (RUG) has been formed to help at all stages from the development of the initial study design through to the dissemination of results. The RUG meets once a month for 3 hours at a time. Members also receive additional information by mail, email or through phone conversations that require their input, comments and feedback. The RUG has provided the research team, all of whom have many years of experience in stroke research and/or care, with a far greater understanding of the experience and needs of stroke carers and provided specific input into the adaptation of an existing assessment approach to address the specific needs of carers of stroke survivors and reviewed participant information sheets and consent forms to ensure they are fit for purpose and understandable. They have also identified suitable media for staff training, identified scenarios for modules of staff training and participated in presentations on the study.

We work closely with other PPI networks and groups across Greater Manchester including the SRFT Citizen Scientist programme, PRIMER (Primary Care Research in Manchester Engagement Resource), which is part of the UoM Centre for Primary Care (CPC), and also works with researchers across the [NIHR School for Primary Care Research \(NIHR SPCR\)](#), and the Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network. We also have links to the UoM FMHS community engagement and involvement structures, with some CLAHRC researchers and PhD students accessing and training and advice offered by the Faculty.

We continue to gain a national perspective to inform our work and learn from others via the CLAHRC national PPI meetings and INVOLVE events.

In addition to the partnership working across GM described above, we continue to use newsletters, information leaflets and other CLAHRC materials disseminated via made

engagement events, email, and our website to involve and engage with patients and the public.

Expenditure on PPI/E related activities including associated salary costs, fees paid to PPI panel members (including payment of expenses), and events/ meetings amounted to over £33,000 in the past year.

North Thames CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-norththames.nihr.ac.uk/
PPIE web pages	http://www.clahrc-norththames.nihr.ac.uk/involve-2/
PPIE Strategy	http://www.clahrc-norththames.nihr.ac.uk/ppie-strategy/
Contact Name	Steven Towndrow
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Contact Phone	020 3108 3241

Patient and public involvement:

Significant changes or revisions to your PPI/E strategies, and assessments of progress being made in the delivery of your aims and objectives

- We have published our **PPI/E strategy** on our website, and our PPI/E Officer monitors the implementation of this strategy via the mechanisms outlined below.
- Our dedicated PPI/E Officer continues to engage with researchers across all our five themes, as well as our Academy trainees, advising on best practice relating to PPI/E. PPI/E is also a standing agenda item at our research theme meetings. An introduction to PPI/E is part of induction for new staff, students and researchers. Measures of progress include increased demand to work with our Research Advisory Panel (RAP) and document review panel. We are also working towards getting patients and public involved in more strategic discussions, and taking part in external events as ambassadors for the CLAHRC and to present our work.
- Our PPI/E officer has helped researchers to employ novel and innovative PPI strategies in their projects, (e.g. arranging graphic facilitation of a PPI event, asking laypeople to test and review study recruitment websites, adapting interview training for researchers for members of the public working with us).
- Our **virtual document review panel** has proved increasingly popular, and we have recruited 15 new people to the panel in year two (total n=20). Although not in our original application, this resource ensures that our research documentation and outputs are accessible. In line with good practice, we provide a small payment for each set of documents reviewed. Members of the panel have now reviewed documentation for nine CLAHRC research teams. Researchers accessing the document review panel have provided positive feedback: "*Comments made on the patient information sheet, consent form and letter have really helped in simplifying the language used to make it more understandable,*" and "*The information is very useful*

and I have amended some parts of Patient Information Sheet as a result of the feedback.”

- Our lay **Research Advisory Panel (RAP)** goes from strength to strength and there is high demand from across the CLAHRC to engage with this valuable resource. In place of a having a formal Chair, the panel decided that its meetings should be facilitator-led, which is proving a successful model. RAP members recently completed a first year review, and we are acting on the changes suggested (see section on monitoring and review). CLAHRC researchers engaging with the RAP are required to provide feedback to the group regarding how they have acted on and incorporated their advice. In addition, researchers are encouraged to revisit the Panel for advice later in the project, and continue the engagement through to dissemination.
- We continue to be proactive in raising awareness of the CLAHRC and opportunities for involvement, (e.g. our evaluation of the *Getting it Right First Time (GIRFT)* orthopaedic service improvement initiative, we utilised our partner’s networks, and are working with members of the British Orthopaedic Association’s Patient Liaison Group).

PPI/E activities and outcomes you are delivering. This is likely to include PPI/E in individual research projects, in research themes and in your organisational structure. Examples of the impact that your PPI/E activities are having. These could be in individual research projects and / or across research themes and / or in the governance and management structures of the CLAHRC itself.

- Examples of where we have involved patient/public in specific projects/events include: i) members of our RAP acting as peer reviewers for applications to our **Research Funding Competition** to help ensure that in addition to being scientifically robust, potential projects were for patient benefit, and had clear plans for PPI embedded within them; ii) a member of our RAP took part in a strategic “*Challenge and Build*” workshop established to refresh our engagement activities and independently facilitated by our industry partners SHM Productions Ltd. The individual offered the patient/public perspective during discussions with CLAHRC’s leadership and core team on the CLAHRC’s role, our position in the health landscape and the future direction of our engagement activity; iii) we convened a special meeting of our RAP exclusively for three health professionals on our Fellowship scheme to present their work and their plans for PPI, which supported the development of their applications for external funding to undertake further postgraduate study (e.g. NIHR PhD fellowships).
- We have taken part in a number of engagement events with a public audience, including presenting the work of the CLAHRC at UCLH research open day (June 2015) where we met staff, patients, visitors and schoolchildren, and at our host Barts Health NHS Trust’s *Better knowledge, better health* research evenings (August 2015).
- Our PPI/E activities have had significant impact. For example, the RAP had considerable influence on a CLAHRC project, where the team of researchers completely reconsidered a proposed grant application “*Based on the feedback, we realised that many Panel members had concerns about the viability and robustness*

(of the research). As such, we felt that an application would have a low probability of success, given the numerous concerns about the value of the design itself.”

- We produced a PPI case study outlining the innovative way we worked with children and young people impacted by diabetes; outlining how we trained them in research methods, supported their facilitation of public engagement events about local diabetes services, and advised them in analysing the results. The impacts resulting from this will include a peer education roadshow (via school and youth clubs etc), and a How to Guide for engaging young people in the NHS which will also influence the way commissioners involve children and young people in their processes.

Partnerships and collaborations that support the delivery of strategies.

- Building on our pan-London CLAHRCs Memorandum of Understanding around involvement and commitment to work together, youth commissioner collaborators from our ‘*Co-designing community-based diabetic services*’ project took part in a CLAHRC South London Active Involvement in Research (AIRD) showcase event in Spring 2016.
- We actively participate in the UCLP Involvement Leads Network, and our PPI/E Officer is part of the Network’s Steering Group. Our PPI/E Officer was invited to deliver a masterclass ‘*Evaluating and measuring the impact of involving patients, carers & the public*’ to network members (December 2015).
- We continue to have fruitful relationships with the Research Design Service (London) PPI leads, the PPI manager at the Joint (UCL, UCLH and RFH) Research Office, and UCL’s Public Engagement Unit, and work closely with our host Barts Health NHS Trust, including taking part in their series of Research Evenings aimed at the public.
- In the spirit of spreading good practice and supporting PPI more widely, we have shared our Research Advisory Panel’s supporting documentation (e.g. Terms of Reference and Ways of Working) with other elements of the NIHR who are at an earlier stage of PPI development.

Resources that are committed to delivering your strategies, for example, staff, training and development for researchers and members of the public and fees and expenses offered for involvement activities

- We provide a number of resources to our researchers to ensure PPI is an integral part of the research process (e.g. our RAP and document review panel described previously). We also provide training opportunities: delivering seminars in PPI/E to PhD students and fellowship trainees giving them an overview of good practice, and the CLAHRC resources available to them, to ensure good practice in PPI/E is fostered early in their academic careers. To our knowledge this is the first time that PPI/E advice is routinely delivered to fledgling researchers and is an example of how we are embedding a PPI/E culture across our partnership.
- With a service user, we co-designed / co-delivered a seminar on PPI in research at the CNMR Research in Clinical Practice Conference at UCLH (March 2016). The audience of nurses and midwives heard about what good involvement looks like and how to make a layperson feel part of the research team.
- Our PPI Officer and a member of our RAP met with BMJ Patient Editor Rosamund Snow, and gained an insight into how the Journal is involving patients, the required

level of lay involvement in articles for submission to the BMJ, and the channels by which the public can use the BMJ's reach to influence practice.

- We have recently recruited a CLAHRC training and engagement coordinator, who works closely with our PPI Officer, and whose responsibilities will include taking forward our more highly targeted engagement strategy.
- In line with recommended good practice from NIHR and INVOLVE we recognise the contribution of patients and public working with us, rewarding them for taking part in meetings, reviewing research documents, and reviewing grant applications.
- We signposted the research team working on the *Nurture Early for Optimal Nutrition* (NEON) project (which is using a volunteer-led model to investigate knowledge of child feeding practices in East London's Bangladeshi community) to qualitative interview training offered by UCL, which was adapted for the needs of these community researchers. We have also signposted laypeople working with us to learning opportunities: four members of our RAP registered to take part in the Massive Open Online Course (MOOC) *Improving Healthcare Through Clinical Research* delivered by the University of Leeds.

Please also describe how you make patients and the public aware of the research being undertaken within your CLAHRC, and signpost them towards appropriate information about participating in research.

- In addition to the "usual channels" such as Twitter, our website and the NIHR *People in Research* portal, we have also approached specialist organisations - such as the British Youth Council and Association for Young People's Health to recruit children and young people, and the McPin Foundation and Shaping our Lives national user network to help publicise involvement opportunities in mental health research. In addition we take advantage of our partners' established communication channels and networks, publicising involvement opportunities on their websites and in their newsletters.
-

North West Coast CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-nwc.nihr.ac.uk/index.php
PPIE web pages	http://www.clahrc-nwc.nihr.ac.uk/be-involved.php
PPIE Strategy	http://www.clahrc-nwc.nihr.ac.uk/be-involved/PublicEngagementPolicy.php
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Contact Phone	01524 594 496

Any significant changes, or revisions to your PPI/E strategies.

We have made no changes to our [Public Engagement Policy](#) and [Engagement Strategy](#)

Progress made in the delivery of your aims and objectives in your PPI/PE strategy

Patient and Public Involvement

Public advisers formed a [Public Reference Panel](#) (PRP) in July 2015. Public advisers involved in theme or project activity become automatic members of the panel. The panel meets monthly and has strategic oversight of public engagement and involvement (PE) for CLAHRC NWC, supported by the PE Facilitator. Public advisers have formal governance positions on the Management Team, Steering Board and Subcommittee (which approves project proposals). In 2014-15, we reported a modest number of public advisers involved in our work and prioritised increasing this. 36 new advisers were registered in the 2015-16 period and the number of occasions that public advisers have contributed to CLAHRC NWC work in 2015-16 has increased by over 450% (to 216), compared to 2014-15. We anticipate a much greater increase in public involvement in our work over the next 12 months as the COREN recruits residents of our (Neighbourhoods for Learning (NsfL) as CLAHRC Champions. Each theme works with our PE policy to ensure widespread public and patient involvement from the concept stage through to the final dissemination and implementation of research. Themes report quarterly on their PPI/E progress (including in the management of their themes) to the Director of CLAHRC NWC. The PRP is responsible for PE training for CLAHRC NWC and has conducted a training needs audit and developed a training plan. A number of training sessions have taken place for staff and public advisers including Building your Team, health inequalities and training for advisers with governance roles. A shadowing system is in place to support public advisers holding governance roles and to build capacity in other panel members. There has been a delay with rolling out some training, this work will take priority in the year ahead and include the development of a mentoring scheme for public advisers holding governance positions.

The Health Inequalities Assessment Toolkit ([HIAT](#)) was created to help ensure activities have the potential to contribute to reducing health inequalities and that the public are consulted and considered when proposals for funding from CLAHRC NWC are being developed. At every stage of the toolkit the user is guided to question whether appropriate

and adequate public involvement is in place. We initiated the Community Research and Engagement Network (COREN), working in 10 'neighbourhoods for learning' across the NW coast. COREN works across research themes, with local authority, NHS partners and community organisations in disadvantaged neighbourhoods engaging residents in CLAHRC NWC work and contributing to evaluation. COREN residents acting as advisers have access to accredited training, support, learning events and a COREN Manager.

Public Engagement

A number of research themes delivered outward facing events sharing knowledge and resources, raising awareness of CLAHRC NWC activity and recruiting to specific projects. An interactive PE event is planned for mid-2016, based around a 'pop-up community' in Lancaster city centre. Engagement resources developed for the day will be available for CLAHRC NWC teams to use at events, talks and future conferences. We won funding from Research Councils UK (RCUK) to develop a resource for young people to introduce the concept of research to young people: a team is now coproducing a giant walk-on snakes and ladders game with young people, CLAHRC students and the public to help people explore the topic of health inequalities. The resource will be available to selected widening participation schools in the North West, partners and staff as well as to CLAHRC teams nationally. The PRP has developed a regular workshop to help communication, learning and engagement. The first ['Focus On' workshop](#) has taken place, investigating health inequalities. The workshops explore CLAHRC principles and activities to build public advisers' knowledge and understanding of some aspects of the collaboration. Sessions are filmed and are on our website as a resource to help the general public understand CLAHRC aims and activity.

The PPI/E activities and outcomes you are delivering.

Public advisers are integrated throughout CLAHRC NWC in theme management and projects as well as in the [PRP and governance positions](#). From the PRP, public advisers are also recruited to other opportunities, e.g. [coproducing materials](#), giving talks to CLAHRC NWC staff and advising on central groups and boards such as evaluation.

Theme management teams all involve public advisers in their programmes of work and on specific research projects. Examples include: the mental health theme's PE events "Research Have Your Say"; the aim was to initiate research into inequalities in mental health care and they were led by service user groups and the public across the NWC region. The evidence synthesis theme involved public advisers in two commissioned evidence reviews; the [Evidence for Change programme](#). The Lancashire County Council Team involved in this programme (including care home residents) created a video which is likely to feature in the NIHR 10 year celebration.

The partnerships and collaborations you are involved in that support the delivery of your strategies.

A learning exchange partnership has been established with NIHR Peninsular CLAHRC's PE Group (PenPIG). An exchange took place with public advisers and staff from the North West, visiting the team in Exeter with a full programme of talks, discussions, introductions to teams

and learning opportunities. The return visit is planned for 2016. It's intended that this will be an ongoing relationship to provide mutual learning opportunities and peer support.

Through COREN, we engage a variety of partners, including a number of third-sector organisations, who support the delivery of our strategies. Many public advisers are well connected to health and social networks within the North West coast. We're linked into a wide network of organisations interested in joint working and collaborations, including: Research Design Service, NHS research and Development North West and Academic Health Science Network, North West. A number of organisations have delivered elements of training to public advisers, teams and partners including Healthy Cities, COMENSUS and Shared Futures CIC.

The resources that are committed to delivering your strategies

A full time PE Facilitator, Jenny Irvine, part time assistant, Abigail Oyston (0.6fte), part time COREN manager, Paula Wheeler (0.2fte) and part time Engagement Director, Jennie Popay (0.1fte) are the PE team. Offering ongoing support for public advisers and teams, the team works with the PRP to deliver the PE policy. The PRP coproduced a variety of materials to support teams including [terms of reference](#), [code of conduct](#), [Welcome Pack](#), [induction checklist and induction and health inequalities films](#). A [payment policy](#) is in place, developed in consultation with INVOLVE and adhering to their guidelines. The team developed training for staff and public advisers covering an introduction to PE, PE event development, Building PE teams. CLAHRC NWC students are given information on PPI/PE, the PRP during their induction. £9k was allocated in 2015/16 to the local COREN organisations supporting Champions in the Neighbourhoods for Learning.

All project proposals include a budget for in-project PE activities. Pre-project development funds are available for projects in the pre-award phase to support teams to work with the public in developing a full application. A central protected budget for PPI/PE is in place. In 2015/16, a proportion of the central PPI/PE budget was allocated to themes to encourage and support engagement/communication/ dissemination with stakeholders, including the public.

Examples of the impact that your PPI/E activities are having.

A wide range of impacts have been reported on the value of PPI activities from research teams, students and public advisers themselves. This includes observations on the richness public advisers have brought when advising on early stages of projects, highlighting areas of investigation not previously considered. For example public advisers have provided invaluable contacts to a PhD project considering the inequalities in the access and utilization of genetic and genomic services across the North West Coast. Themes have also benefited, for example the Public Health theme consulted the group about their plans to improve their chances of being successful in their approach and take suggestions on how they could expand on public engagement already planned.

North West London CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-northwestlondon.nihr.ac.uk/
PPIE web pages	http://clahrc-northwestlondon.nihr.ac.uk/what-we-do/cross-cutting-themes/patient-and-public-engagement-and-involvement
PPIE Strategy	Action Effect Diagram – under revision
Contact Name	Rachel Matthews
Contact Email	r.matthews@imperial.ac.uk
Contact Phone	020 331 53047

- Our strategy is focused on enabling patients and the public to influence the programme. We continue to consolidate our PPEI aims and objectives building on our extensive seven year experience.
- We contributed to and led the analysis for ‘Going the Extra Mile (GEM): Improving the nation’s health and wellbeing through public involvement in research’ published by NIHR. This is the first strategic review of PPEI in the 10 year history of NIHR. It will influence strategic decision-making nationally and inform international dialogue in this field. We promote and support the vision, mission, strategic goals and recommendations of GEM in our programme.
- Ms Matthews published a narrative review of PPI, health and social care literature in the BMJ Quality and safety. Co-authored with the NIHR Patient Safety Translational Research Centre referencing healthcare improvement and 4Pi. The review recommends broader approaches to PPEI moving from simple consultation towards co-design and co-production[38]. The article achieved an Altmetric score of 111 (the top 5% of research outputs so scored), and was the second most read article in April 2016 (2884 downloads). 62% of 145 tweeters were members of the public.
- We use INVOLVE guidance and Benefits Helpline to test local reimbursement procedures. We will adopt the Imperial Biomedical Research Centre Reward and Reimbursement Policy.
- Our patient advisers act as ambassadors for the programme by describing the benefits of being involved at national events. For example, Ms Cameron recently reflected on her experience of being a CLAHRC NWL Fellow at a King’s Fund event on Patient Experience and contributed to the Imperial College London MSc in Health Policy.
- Ms Jayacodi, service user from the SHINE project described her experience of being involved through CLAHRC NWL to NIHR visitors in February 2016. She applied successfully for the Improvement Leader Fellowship.
- Our strategy is monitored by patient leaders in the core group and partnership forum of our governance structure. We report awareness, participation, engagement and involvement separately. We note these activities co-exist.

Public awareness and participation

- To improve collaboration and application of best practice, we agreed a Memorandum of Understanding with all London CLAHRCs. We collaborated with CLAHRC NT to advise

NHS England on a consultation to improving support for carers, which opened on the 18th March and [calls for further research](#).

- Patient Improvement Leader Fellows Ms Cameron, Ms Kingston, and Mr Silverstein were recognised in the group of 50 Health Service Journal (HSJ) Patient Leaders in 2015. They promote the value of involving patients nationally and internationally through speaking and social media and acknowledge the opportunities offered by their association with CLAHRC NWL.

Patient and Public Involvement: The Exchange Network

- The Exchange Network is a novel mechanism established with patient advisers that has evolved since 2013.
- The network provides regular opportunities for dialogue and learning about research, improvement and involvement. The growing pool of 54 members includes patients, carers, researchers, NHS managers and clinicians. We co-design and co-facilitate four meetings a year. This critical mechanism for engagement, involvement and awareness; strengthens the way healthcare professionals, patients, carers, and researchers work to improve care.
- It is designed and delivered in partnership with Mark Doughty (HSJ Patient Leader) from the Centre for Patient Leadership and network members including Improvement Leader Fellowship Alumni.
- Exchange Network Members are influential in encouraging clinicians to actively involve patients. Ms Augustine spoke about her experience of being involved as a patient at our Collaborative Learning event in February; this motivated a project manager from our new Alcohol Care research and improvement project to invite a service user to their team.

Formative evaluation shows the network:

- Allows patients, carers, and clinicians involved in CLAHRC NWL and other NIHR programmes to meet.
- Acts as an introduction to CLAHRC NWL for people interested in research and improvement to find how they could be involved by helping to identify their skills and attributes; there is scope to replicate in other settings.
- Leads to the recruitment of patients and carers to our Improvement Leader Fellowship Programme.
- Provides an ongoing link for Fellowship alumni to report their development, continue to contribute, and lead to employment opportunities. For example, Ms Augustine is part of our communications team, and speaks about her lived experience both nationally and internationally (Cincinnati Children's Hospital, 2015)

Programme and delivery themes:

- There is influential PPEI involvement in all delivery themes, e.g. in the project designed to improve outcomes and experience for people with oesophago-gastric cancer, 13 patients and carers met to explore how information, goal-setting, and the ward environment could be improved. This identified two topic areas not previously prioritised by the clinicians; impact of sleep deprivation in hospital and the inflexibility of mealtimes. The event highlighted the important role carers play in recovery and the psychological impact they experience.

- Five patient leaders are peer reviewers for improvement project applications, contributing to funding decisions.
- Patient Leaders and Fellows co-facilitate workshops at our Collaborative Learning events and MSc in Health Policy.

Public Engagement:

CLAHRC NWL, in partnership with Sickle Cell Society and the Picker Institute, delivered a comprehensive communication strategy, informing 722 people with Sickle Cell surveyed in the development of the validated Sickle Cell PREM and the 10,000 people who have Sickle Cell in the UK, regarding the research findings. This included the development of a Sickle Cell [infographic](#) and three Sickle Cell tweet cards: <http://bit.ly/scdmeds>; <http://bit.ly/scdpain>; <http://bit.ly/scdcare>. NIHR, University and NHS communications teams supported the plan and associated campaign. Dr Chakravorty was [interviewed by London Live](#) television on the Patient Reported Experience Measure (PREM) data and raising sickle cell awareness.

Oxford CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-oxford.nihr.ac.uk
PPIE web pages	http://www.clahrc-oxford.nihr.ac.uk/get-involved
PPIE Strategy	
Contact Name	Dr Sian Rees
Contact Email	sian.rees@phc.ox.ac.uk
Contact Phone	07761 045424

Infrastructure and resourcing: Continued the employment of a part-time PPI strategic lead (15% FTE), a fulltime Communications Manager and a PPI Coordinator.

Governance: Appointed two PPI contributors to the Management Board, who are paid for their time at INVOLVE rates.

Partnerships: We are part of the Thames Valley and Milton Keynes Patient Experience Operational Group led by Oxford AHSN and NHS England South (Central). This has broad stakeholder membership, including two lay members, one of whom jointly chairs with our PPI Lead. A major output from this group is the Leading Together Programme: <http://www.oxfordahsn.org/our-work/patient-and-public-engagement-involvement-and-experience/leading-together/>. A good example of how joint working can better develop support to the CLAHRC is that 3 partners from this group are funding and running another training programme aimed at an intermediary level of researchers and PPI Contributors.

Events: We invited PPI Contributors to the Stakeholder Symposium in Nov 15 and Dr Siân Rees ran a workshop on PPI entitled Leading Together.

Training – PPI Contributors have been offered basic research awareness training <http://www.clahrc-oxford.nihr.ac.uk/upcoming-events/ppi-seminar-series> . Researchers are offered a monthly PPI clinic where they can drop in to discuss any issues with the PPI Coordinator. <http://www.clahrc-oxford.nihr.ac.uk/upcoming-events/ppi-clinics-11>. The CLAHRC have also developed a PPI Guide for Researchers - <http://www.clahrc-oxford.nihr.ac.uk/get-involved/ppi/information-for-researchers>

Involvement Highlights

- On the early intervention in psychosis project patients and a carers review and contribute to writing newsletters and attend partnership meetings with clinicians and commissioners.
- The Better Outcomes for Older people with Spinal Trouble (BOOST) trial has actively engaged PPI representatives in the development of participant-facing intervention documents, both for the conduct of the intervention and the collection of outcome data.
- Within the Long Term Condition Questionnaire research team there are two PPI Contributors who have contributed to the development of the protocol and research design. Providing ongoing guidance, they attend every research meeting and comment in between meetings on documents and research outputs. There are also formal links with QORU Public Involvement and Implementation Group (PIIG)
- Theme 4 have involved 95 stakeholders (30 patients, 6 carers, 55 clinicians, 3 members of the public) in designing and planning research. This input changed the focus of the new way of working (Proactive Liaison Psychiatry) from reducing length of hospital stay to reducing time in hospital in the coming month due to patients and carers highlighting the importance of avoiding rapid readmission to hospital
- The CLAHRC has been integral to the James Lind Alliance Bipolar Priority Setting Partnership which received over 3,000 responses to the first survey in late 2014. 14,000+ questions were generated initially and we are now involved in a process of voting to reduce these further

Engagement Highlights

- Research publicised through CLAHRC website, Twitter and the BRC funded Patients Active in Research website which is a linking database. Publications from our research are placed on our website with an 'Altmetric Donut', a quantitative measure of the attention that a scholarly article has received <http://www.clahrc-oxford.nihr.ac.uk/oldpublications>
- Interested PPI representatives can sign up directly from our website. <http://www.clahrc-oxford.nihr.ac.uk/get-involved/ppi/information-for-patients-and-public>
- PPI Pulse - newsletter for our PPI contributors which can also be shared more widely. <http://www.clahrc-oxford.nihr.ac.uk/get-involved/ppi/information-for-patients-and-public>
- Care home staff participating in focus groups will be signposted to 'enrich' a website that aims to support care home staff by providing advice and guidance in

understanding what it means to support research in a care home and what the benefits might be for them participating in research. <http://enrich.nihr.ac.uk/>

- We have also made over 20 video clips in collaboration with the Oxford AHSN that can be viewed by members of the public and include information relevant to our work
- Leading Together: is a three-day programme that is supporting 120 health professionals and lay people develop real partnerships that make a difference to their local health organisations and communities. The aim of the programme is to create increasing numbers of lay partners and professionals who can work together strategically to build a culture of involvement

Total PPI Expenditure: £40,704

South London CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	www.clahrc-southlondon.nihr.ac.uk
PPIE web pages	<ul style="list-style-type: none"> • Involving patients, service users and their families: www.clahrc-southlondon.nihr.ac.uk/involving-patients-service-users-and-their-families • Jobs and opportunities to get involved: www.clahrc-southlondon.nihr.ac.uk/job-opportunities • Governance: www.clahrc-southlondon.nihr.ac.uk/what-is-clahrc-south-london/governance
PPIE Strategy	
Contact Name	Professor Diana Rose
Contact Email	diana.rose@kcl.ac.uk
Contact Phone	020 7848 5066

CLAHRC South London's PPI theme is led by Professor Diana Rose (King's College London). As well as undertaking its own research into PPI activities across the CLAHRC (see section 4), the theme is responsible for embedding involvement and engagement activities. Many members of our research team are long term users of health services. This ensures that our work is informed by service user perspectives. To find out more about our PPI work and current research on PPI, visit: www.clahrcsouthlondon.nihr.ac.uk/involving-patients-service-users-and-their-families

Patient and public involvement (PPI) strategy

As reported last year, the CLAHRC created a Strategic Oversight Group (SOG), comprising PPI representatives from health organisations and charities in south London, which is incorporated into the CLAHRC's governance structure. We continue to increase service user membership of this group – in addition to the service user researchers who are part of the PPI theme, the group includes service user representatives from six of our eight health

themes. We work with our lay members on the SOG to provide robust links between each individual health theme and the Strategic Oversight Group – this supports our strategic aim of embedding PPI in all health themes, and enabling good communication on PPI across the CLAHRC. Following this group's recommendations, in the first quarter of the year, the CLAHRC Executive included PPI sections on the progress reports that each theme submits quarterly, enabling us to monitor progress and identify any problems in implementing involvement.

Themes reported that they had difficulty in distinguishing between involvement, engagement and participation in qualitative studies, and wanted guidance on appropriate involvement strategies for different parts of the research cycle. In response, the PPI team produced detailed guidelines for involvement and set up surgeries and workshops to facilitate knowledge sharing across the themes (see below).

Working with health themes

We aim to embed PPI in the CLAHRC's range of research projects through sustained collaboration between the PPI theme and dedicated members of the health themes. This year, while continuing to offer support and advice on individual projects, the PPI team has developed foundations and shared tools to support PPI across the health themes. We have developed new practical guidelines, including:

- An abbreviated version of the guidelines for supporting active public involvement in health research produced by the national advisory group INVOLVE (June 2015).
- Payment guidelines, so that all health themes are aligned in the way that they recognise the contribution of service users and members of the public in involvement activity (September 2015).

Additionally, we organised a programme of knowledge-sharing events:

- In January 2016, the team organised an internal PPI learning event, bringing together 19 CLAHRC researchers with representatives from all health themes. The day was designed to help the themes find out more about each other's PPI work, and to work together to develop problem-solving strategies. In feedback collected, nearly all of the respondents said that they would think about how to include PPI in their work in new ways. A number felt more able to approach other themes for collaboration. The success of this event has led to the initiation of biannual action learning groups bringing researchers, clinicians and service users and carers together to address their current challenges in involvement in research. The first of these biannual events will be held in January 2016.
- In April 2016 the PPI team organised an Active Involvement in Research Day (AIRD). We collaborated with five other CLAHRCs (North Thames, Wessex, East of England, Oxford and North West London) in presenting examples of good practice in involvement to a mixed audience of service users and researchers. AIRD 2016 was the first of our annual outward facing events which seek to forge closer links between local communities, researchers and clinicians. Our aim is to embed meaningful community involvement in shaping and implementing research evidence into practice in South London health services.

Central funding for PPI activities

In September 2015, the CLAHRC Executive established an annual fund of £20,000 to actively support PPI activities within the CLAHRC. The PPI team has set up an application system, which helps guide researchers towards establishing meaningful involvement. This fund has already been used for a virtual community and research discussion board for patients and lay contributors in the palliative and end of life care theme; and payment of patients and service users involved in the health themes' work.

Partnerships

The PPI team is working collaboratively with its counterparts in CLAHRC Northwest London and CLAHRC North Thames to share knowledge and develop training opportunities and events.

Public engagement

Our diabetes theme held a Public Information Day in February 2016 attended by over 80 people in which we presented current and planned research on type 2 diabetes treatment and prevention, and provided opportunities for researchers and participants to interact and exchange views on research directions. The event was very well received, with 92% of participants who completed the event assessment rating the meeting as useful. This event was funded by the CLAHRC's PPI theme.

Making patients and the public aware of our research and opportunities to participate

During 2015 we undertook a mapping exercise, identifying around 100 service user groups across south London. We will use this resource to help disseminate CLAHRC activities and to consolidate community involvement in research in South London.

South West Peninsula CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-peninsula.nihr.ac.uk/
PPIE web pages	http://clahrc-peninsula.nihr.ac.uk/patient-and-public-involvement-in-research
PPIE Strategy	
Contact Name	Kristin Liabo
Contact Email	k.liabo@exeter.ac.uk
Contact Phone	01392 722895

Patient and public involvement:

The involvement of public advisors has been central from PenCLAHRC's inception, secured by commitment in the leadership group, reflected by the well-resourced team who work to implement and research involvement across PenCLAHRC. The team runs regular involvement clinics in Exeter and Plymouth, where researchers can book appointments to discuss their

involvement plans with a member of the involvement team. These clinics have resulted in several bespoke involvement workshops and meetings between researchers and patients to inform funding bids. Members of the involvement team continue to be co-applicants on research bids, and support members of the public to be so.

Public advisors are involved in all aspects of PenCLAHRC: training and recruiting researchers, disseminating and promoting our research, applying for research funding, as members of the PenCLAHRC Management Board, liaising with other involvement groups regionally and nationally, and informing research directly working with researchers or as members of study steering committees.

In 2015, two new researchers were recruited to the PPI team, with public advisors fully involved in the process. Their arrival prompted a revision of our strategy ([online](#)), focussing on 4 strategic areas: embedding involvement in PenCLAHRC, developing involvement through research and theory building, furthering collaboration with patients and members of the public, and expanding the work of the PPI team.

Involvement activities inform individual themes but also go beyond and cut across all of PenCLAHRC. Members of PenPIG (Peninsula Patient Involvement Group) presented their work on person-centred care at a meeting with researchers from the University of Gothenburg. We treat PPI as an integral part of research proposals in the same way as involving research methodologists. Recent examples with strong PPI involvement include design of a depression treatment trial, a mixed-method systematic review on rehabilitation for people with cognitive impairment, radiographer led diagnosis in A&E, an analysis of data sets to examine the link between environmental change and health, and training on how to involve members of the public in systematic reviews.

Examples of impact:

1. *Involvement of members of the public can impact on research training:* A member of PenPIG suggested the group could be more involved in informing our PhD research. As a result, the PenCLAHRC Training Lead worked with the involvement team on a communications day for PhD students, held in October 2015. Students first received advice from staff on how to present their research to a general audience and then presented to PenPIG members, who provided feedback on their communication skills. This engagement with PhD students helped identify broader needs within PenCLAHRC for training on involving patients with dementia. The PPI team developed training on this topic, in collaboration with the community interest company 'Innovations in Dementia' (<http://www.innovationsindementia.org.uk/>). The influence of this training on a particular PhD ethics application resulted in a request to from the University of Exeter Medical School Ethics Committee for a guide to ethical research and involvement of people living with dementia.

2. *Involvement of members of the public can impact on the outcomes of research funding applications:* After a group of researchers had a proposal rejected by NIHR-RfPB they approached the PPI team who ran a meeting with members of PenPIG and HEPE (Health and Environment Public Engagement group) to inform a revised version. This workshop re-shaped the bid which was then funded by NIHR-RfPB ([video clip](#)).

Challenges:

The involvement team of PenCLAHRC has helped ensure PPI is fully integrated into the ethos and practices of PenCLAHRC. This has enabled us to cascade knowledge and appreciation of involvement across the partner universities. As involvement expands into new areas, current structures are exposed in terms of their strengths and their weaknesses. We recognise that there are still gaps to be filled in defining the role of a group that primarily draws on its members' lived experiences. There are currently three involvement groups that inform the work of PenCLAHRC: the Peninsula Public Involvement Group (PenPIG), the Health and Environment Public Engagement group (HEPE), and the Peninsula Cerebra Research Unity (PenCRU) Family Faculty. Each of these sit between the professional and private spheres and this can present challenges in relation to responsibilities and expectations, for both researchers and members of the public. We have identified this aspect of involvement as one we want to research in greater depth in the coming months.

Public engagement: We have developed a close partnership between the Clinical Research Network and the PenCLAHRC involvement team. We collaborate with the CRN on public engagement through reciprocal distribution of information materials and co-run RDS Building Research Partnership training days. We also continue to run our [Miracle Cures workshops](#) for members of the public. We have worked to expand our engagement beyond our established groups: with members of the public who have registered interest with the Clinical Research Network's database, by building strong links to Devon- and Cornwall-based community groups, and by liaising with participation groups run by Somerset County Council. We are diligent about updating our website with information about our research findings and activities, and our website has a dedicated area for interested members of the public. In 2016 we have made a video clip about public engagement in PenCLAHRC, shortly to be released. We seek opportunities to speak about PenCLAHRC at public events. For example, in 2015 Kath Maguire spoke at a sold-out [TEDex event](#) in Totnes.

PPI expenditure over the period was approximately £150,000.

Wessex CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-wessex.nihr.ac.uk/
PPIE web pages	http://www.clahrc-wessex.nihr.ac.uk/patient-and-public-involvement
PPIE Strategy	CLAHRC Wessex PPIE Strategy
Contact Name	Dr Claire Ballinger
Contact Email	C.Ballinger@soton.ac.uk
Contact Phone	023 8120 3374

Our PPI strategy ([CLAHRC Wessex PPI Strategy](#)) is underpinned by an annual action plan.

The 2015/16 Objectives completed included to:

1. grow the numbers of public contributors and interested organisations across Wessex.
2. develop plans for learning and development for PPI, informed by INVOLVE and NIHR national schools
3. enhance public engagement via social media, communication and engagement with community groups
4. undertake PPI inclusive research prioritisation within two themes.
5. mobilise support to establish a group of experienced service user researchers, to plan for future developments
6. analyse and provide feedback about baseline involvement of PPI in themes via the 'Mapping PPI project'.

Patient and public involvement:

- CLAHRC projects continue to include PPI involvement coordinated by the PPI theme champions and the PPI lead. This includes input to project and protocol design, attendance at project management meetings, seminars and workshops. It has included input into project outputs including patient information, blogs and the NIHR CLAHRC Wessex website.
- CLAHRC project protocols have been independently reviewed by PPI reviewers not connected to the theme or project.
- We have delivered a Protocol Review training workshop for lay reviewers and potential PPI reviewers
- Our network of PPI/E leads and public contributors has been continuously expanding with a minimum of 10 people/organisations per theme resource.
- Groups representing "seldom heard voices" have been identified through the Fundamental Care in Hospital research prioritisation activity.
- Personal development reviews for PPI theme champions for 2014-5 have been carried out, and future development opportunities agreed
- Two models of PPI involvement in research prioritisation activity developed and tested and the work is being written up.

- Service User Researcher Insight (SURI) project successfully completed. Dissemination of both the project outcomes and the service user researcher model learning are currently underway.
- PPI Mapping Project – first round data collection complete and analysed. Individual theme summaries written and available to inform discussions with Theme Champions. Overall feedback presented to Scientific Forum, CLAHRC Management Group and PPI group.

Public engagement

- PPI supported the design of and attended Theme 3 'Fundamental care in hospital' and 6 'Complexity at end of life' research prioritisation workshops and events
- PPI lead and lay PPI Theme Champion Anya de longh have active Twitter profiles with over 470 and 2500 followers each, respectively.
- Regular engagement with public contributors registered on PPI database has continued.
- Five service user researchers involved in the SURI project (Service User Researcher insight into Commissioning) are now participating in disseminating this work, including poster accepted at national conference,
- Three learning and development events were offered to NIHR CLAHRC Wessex public contributors during this past year.

Future Projects

- PPI Champion Resource (PPICHR) project focuses on the development of guidance on how to recruit and work with lay PPI Champions at a strategic level within research organisations. It will provide experience based guidance planning, implementing and explore the impact of strategic PPI, including use of the personal development planning process with public contributors.
- Service User Researcher Insight (SURI) Follow-up. We are developing a resource to improve public involvement in health commissioning via dissemination to CCGs and developing research learning capacity with service users and researchers.
- Enhancing Patient and Public Involvement Capacity (EPPIC) is a project which will aim to develop a programme of PPI Learning and Development events with our NHS partners to support PPI in Wessex. This will enhance understanding of research and implementation with the aim of enhancing involvement in research and supporting NHS Trusts to meet participant recruitment targets.

Please also describe how you make patients and the public aware of the research being undertaken within your CLAHRC, and signpost them towards appropriate information about participating in research.

This is achieved through a variety of different media including: NIHR CLAHRC Wessex website; social media (eg Twitter, Facebook); workshops and training events; evidence briefs from NIHR Dissemination Centre; meetings (eg WISeRD); workshops, seminars, blogs and through a dedicated PPI mail box.

West CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-west.nihr.ac.uk/
PPIE web pages	http://www.phwe.org.uk http://clahrc-west.nihr.ac.uk/patient-and-public-involvement/
PPIE Strategy	PHWE website page with strategy link: http://www.phwe.org.uk/resources/phwe-resources-guides/ Link to 2015-19 strategy pdf: http://www.phwe.org.uk/wp-content/uploads/2015/05/PHWE-Strategy-2015-19.pdf
Contact Name	Rosie Davies
Contact Email	Rosemary3.Davies@uwe.ac.uk
Contact Phone	0117 3421248

The aims and objectives for PPI/E have been met, and we continue to develop new and expanded strategic and operational plans through our collaborative regional involvement initiative called People in Health West of England (PHWE) (<http://www.phwe.org.uk>). NIHR CLAHRC West shares the PPI/E strategy with the other PHWE partners – NIHR Clinical Research Network: West of England, West of England Academic Health Science Network (WEAHSN), and Bristol Health Partners. The strategy has five key principles: enabling a coordinated approach, developing capacity and capability for involvement, contributing to and sharing the evidence base on involvement, influencing policy and practice, and engaging the wider public in health research and health services. Two new partners have joined in 2015/16: NIHR Health Protection Research Unit (HPRU) Evaluation of Interventions and NIHR Cardiovascular Biomedical Research Unit. Andy Gibson, (AG) Associate Professor of PPI at the University of the West of England (UWE) joined the CLAHRC West team in May 2015 to lead PPI/E in CLAHRC West and joins Rosie Davies (RD) who continues as CLAHRC West Research Fellow (PPI).

Patient and public involvement

PPI activities this year included:

- Quarterly reviews of progress with strategy and projects with AG, RD, two public contributors from PHWE who focus on CLAHRC West, the CLAHRC West Director and at least two research team leads.
- AG and one of the public contributors attend the CLAHRC West Board to report on PPI activities and contribute to the strategic direction of CLAHRC West.
- PHWE website provides a single point of access for involvement regionally, to share resources, advertise involvement opportunities, and increase public accessibility.
- Nearly 100 people attended our regional involvement community event including many public contributors.
- Three public contributors, with AG and RD, contributed to the review process for the 2016 CLAHRC West call for research proposals including voting membership in the patient-

and partner-priorities advisory panel called RAP(p). PPI aspects of proposals were assessed, and topics of importance to patients and the public specifically identified.

- We ran four regional workshops attended by 28 people to generate research ideas from members of the public. Thirty-one ideas were submitted. They have been reviewed by the CLAHRC West Director, researchers and the public involvement team and three have been shortlisted for further development.
- PPI needs in all CLAHRC West research projects have been identified and prioritized.
- Research projects identified with high levels of involvement include: autism within the Somali migrant community, increasing participation in self-harm research, and a public-initiated topic on the prevention of post-operative urinary retention (co-production as the public contributor is joint lead and contributing to literature reviewing). More information on these examples is available from: <http://www.phwe.org.uk/resources/case-studies/>
- Capacity development has included four introductory workshops for researchers and members of the public, training three facilitators to run CRN Building Research Partnerships, and a networking event for PPI leads.
- PHWE team leads are continuing to engage with national collaborations including NIHR INVOLVE meetings, a joint regional response to NIHR's Breaking Boundaries review and the Extra Mile report, and a three-day Symposium for 16 PPI academics and public contributors to assess approaches to evaluating the impact of involvement.
- Publications: Gibson A et al. Exploring the impact of providing evidence-based medicine training to service users. *Research Involvement and Engagement* 2015, 1:10; Gibson A et al. Theoretical Directions for an Emancipatory Concept of Patient and Public Involvement. *Health* 2012; 16 (5), pp. 531-547.

Public engagement

Public engagement activities have included:

- Regional involvement event which was widely advertised and well attended.
- Conducting the research-idea generation workshops in Bath, Bristol, Gloucester and Swindon.
- Running two 'Using and Understanding Research Evidence' workshops (see Gibson et al. 2015).
- Collaboration with WE CRN to promote the Joint Dementia Research Register; and with CLAHRC West staff on Reach West, an innovative participatory research register.
- Plans for 2016/17 include improving reporting findings of our research studies for lay audiences, and working with the WE CRN to promote greater participation in research.

For more details of strategy and achievements, see (<http://www.phwe.org.uk>). PHWE strategy <http://www.phwe.org.uk/wp-content/uploads/2015/05/PHWE-Strategy-2015-19.pdf>

Please also describe how you make patients and the public aware of the research being undertaken within your CLAHRC, and signpost them towards appropriate information about participating in research.

We provide information about activities and opportunities for participation through the CLAHRC West website and our collaborative regional involvement initiative called People in Health West of England – PHWE (<http://www.phwe.org.uk>). We maintain a database of contacts, and regularly issue a digital newsletter called ‘Newsflash’ which reaches 586 subscribers and advertised 68 PPI opportunities in 2015/16.
<http://www.phwe.org.uk/news/newsflash/>

West Midlands CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	www.clahrc-wm.nihr.ac.uk
PPIE web pages	www.clahrc-wm.nihr.ac.uk/ppi
PPIE Strategy	www.clahrc-wm.nihr.ac.uk/ppi/resources/clahrc_wm_ppi.pdf
Contact Name	Magdalena Skrybant
Contact Email	M.T.Skrybant@bham.ac.uk
Contact Phone	0121 414 6026

Meaningful involvement of our 13 Patient and Public Involvement Advisors continues to enhance the quality of research undertaken by CLAHRC WM. Patients and the public are powerful agents of change and our PPI Advisors, embedded in all themes, continue to inform research design development and delivery, ask relevant questions, and help disseminate findings. CLAHRC WM is committed to further enhancing its PPIE strategy and developing and sharing areas of outstanding practice. A Patient and Public Involvement and Engagement Officer has been appointed to start in April 2016 to drive the strategy forward. Studies undertaken by CLAHRC WM, enriched by meaningful patient and public involvement, ensure better service design and delivery, bringing better health outcomes for patients (see also part 3 case study 10).

6.1 Patient and public involvement:

CLAHRC WM’s PPIE strategy is available on the PPI section of the website and is clearly signposted. Key points of the strategy include: involving patients and the public in the management of science; involving patients and the public in the design of service interventions; developing a programme for engagement in applied research; and ensuring the voices of ‘seldom heard’ groups are acknowledged. Working in close partnership with the PPI Steering Committee, the Patient and Public Involvement and Engagement Officer will develop our PPI strategy, making it clearer and ensuring CLAHRC WM’s vision is aligned to NIHR’s ‘Going the Extra Mile’ and local PPIE strategies.

In accordance with its strategy, there is PPI representation at all levels within CLAHRC WM. PPI Advisors were recruited to CLAHRC WM through a competitive selection process, and having been in post for one year, all representatives were re-appointed.

Themes: PPI Advisors are embedded in each of CLAHRC WM's themes, and a researcher within each theme fulfils an important liaison role, ensuring that the benefits of patient and public involvement are maximised. CLAHRC WM does not define how each theme should work with its representatives, but advocates a flexible approach to develop a model of working that incorporates Advisors' skills, knowledge, interests and experience. Researchers have worked with PPI Advisors at all stages of the research cycle.

Steering Committees: The PPI Steering Committee has met three times over the last year and has developed and approved its own Terms of Reference. Committee meetings are an effective forum to discuss the breadth and depth of patient and public involvement within CLAHRC WM: advisors have shared their experiences of good practice with regard to involving patients and the public in applied health research and discussed strategies to ensure that involvement is more meaningful. Steering Committee meetings have also provided an opportunity for researchers to discuss research ideas in their embryonic stage and gain valuable feedback from the Advisors. The Steering Committee maintains a strong link with researchers on the Implementation and Organisational Science theme. Researchers investigating PPI and implementation, Lee Gunn and Alison Hipwell, have presented their progress to the Advisors, which has generated valuable discussion and debate. Researchers at Keele have recently published their work on PPI good practice and sustainability.^(22,23)

CLAHRC Steering and Executive Committees: In accordance with the CLAHRC WM PPI strategy, there is patient and public representation on CLAHRC WM's Steering and Executive Committees. The elected Chair of the PPI Steering Committee, Revered Barry Clark, sits on both Committees to ensure continuity. In response to feedback from Advisors and in alignment with NIHR's 'Make it Clear' campaign, theme leads now provide lay summaries for research projects discussed at meetings. Advisors ensure that the patient voice is heard, and there have been valuable contributions from advisors at the Steering and Committee meetings.

6.2 Public engagement:

CLAHRC WM is continually exploring ways in which involvement and engagement with patients and the public can be enhanced. Moreover, CLAHRC WM is working to raise the profile of patient and public involvement in applied health research and share knowledge and experience of good practice.

PPI Internships: This new initiative is designed to provide support to PhD students and early career researchers to better understand the role of patients and the public in health service delivery research. There are three types of opportunity available through the Internship:

- 1) An opportunity to shadow PPI professionals to offer insights into coordinating patient and public involvement;
- 2) To access feedback from the PPI Advisors through theme/Steering Committee;
- 3) To 'buddy' a PPI Advisor and gain an understanding of the Patient and Public Advisor role.

Although in its infancy, PhD students have expressed an interest in the Internship and some PhD students have requested feedback from PPI Advisors through theme/Steering

Committee meetings. We hope to generate more interest and take up of the scheme through promoting positive testimonials through the CLAHRC WM blog.

PPI in implementation: In November 2015, the Implementation and Organisational Science Theme hosted a workshop on how patients and the public can be involved in research implementation, *Making it Happen: Involving Patients and the Public in translating research into practice*. The planning and facilitation of the workshop benefited from input and involvement from CLAHRC WM's PPI Advisors.

6.3 Raising awareness of research and implementation activity

In the past year, there have been significant revisions to the PPI section of CLAHRC WM's website and there is a prominent link to the PPI pages from CLAHRC WM's landing page.

There was significant input from CLAHRC's PPI Advisors regarding the design and content of the website and a PPI Advisor was recruited to work on incorporating the suggestions to the final pages. The PPI section of CLAHRC WMs website is now structured around three key areas: involvement, engagement and participation. The website also links to resources, news and events sections.

Lay summaries on the website provide information about CLAHRC WM's research projects and there is information about the ways in which patients and the public have influenced research design and implementation. Development of the website is ongoing with further enhancements planned. These include: detailed profiles of PPI Advisors; a diagram illustrating the breadth of networks our PPI Advisors are linked to; and case studies highlighting areas of outstanding practice with regard to patient and public involvement and engagement.

CLAHRC WM is committed to ensuring that information about PPI reaches a wide and diverse audience. Central to raising the profile of PPI is the dedicated PPI section to the CLAHRC WM blog (see also part 3 case study 11). With contributions from PPI Advisors and PPI leads in each theme, the section has raised awareness of PPI within CLAHRC WM and shared examples of good practice. In particular, contributions from PPI Advisors (Ray Fiveash) and researchers (Jennifer Cooper) have helped blog readers contextualise how the PPI strategy is implemented within CLAHRC WM's themes.

The CLAHRC WM blog PPI section also provides a valuable opportunity to promote opportunities for involvement, participation and engagement not just within CLAHRC WM, but through organisations such as NIHR; HTA and Healthwatch. CLAHRC WM has developed a template for researchers to use when recruiting patients and the public to their studies, ensuring that the recruitment process is transparent and that prospective representatives are informed of expectations and obligations.

In addition to the CLAHRC WM blog, the twitter feed has promoted patient and public involvement and engagement. Through social media channels, CLAHRC WM promotes NIHR campaigns such as 'OK to ask', 'Make it Clear' and it has also promoted 'Going the Extra Mile'

CLAHRC WM is committed to ensuring that researchers are aware of the benefits of meaningful Patient and Public Involvement and are informed about best practice.

Presentations on PPI were delivered at the following events:

- Presentation on involving PPI in Qualitative Research studies to Leadership and Diffusion Fellows – 6 October 2015
- Presentation on PPI to Postgraduate/Early Career Researchers – 19 November 2015
- Presentation on PPI in CLAHRC WM to Annex U (University Hospitals Postgraduate Training Skills – 23 February 2016

All presentations involved input from a patient representative and all events received positive feedback. Participants valued the opportunity to learn about the benefits of involving patients and the public in research projects and appreciated the practical advice and support. Several researchers attending the workshops have contacted CLAHRC WM regarding involving patients and the public in their projects.

Yorkshire and Humber CLAHRC

Annual Report 2015/16:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-yh.nihr.ac.uk/
PPIE web pages	http://clahrc-yh.nihr.ac.uk/ppi
PPIE Strategy	
Contact Name	Dr Christine Smith
Contact Email	christinesmith@nhs.net
Contact Phone	0114 226 5518

Public Involvement and engagement is a focus of activity inherent in the Coproduction principle underpinning our CLAHRC work. In response to the 2015 NIHR Going the Extra Mile report, the match funded PPI Working Group undertook a full revision of our [PPI Strategy](#) in collaboration with the Executive and the Consumers in Research Advisory Group (CRAG). During the year we have focussed on operational delivery of this strategy within themes, whilst continuing to build on our regional collaboration with the Yorkshire and Humber NIHR PPI Community group (YHPPIC), reported previously as the Strategic Localism PPI Group. This is reflected in our achievements against the objectives detailed in our strategy and illustrated below.

The full range of PPI **activities** undertaken this year are demonstrated in the Finance and Activities report with themes reporting 49 activities that described engagement, participation and involvement in members of the public in research. At programme level the CRAG group now acts as the PPI oversight group for CLAHRC YH in addition to advising on eight individual projects this year.

Our working Group continues to build **partnerships and collaboration** at both regional and national levels, a key objective in the PPI Strategy; through the PPIC network and as active partners in the Yorkshire and Humber NIHR PPI Community group. This regional team,

representing NIHR infrastructure in Yorkshire and Humber hosted a 'Patient Voices' PPI event in November, which was part funded by CLAHRC YH. At this event 30 lay representatives from 16 PPI regional groups, plus 10 NIHR PPI Leads used a world café approach to explore some of the key issues from the NIHR 'Breaking Boundaries' report. A follow up event is planned in November 2016 and the team are planning an online 'Tour de Yorkshire' **signposting** guide to PPI in the region. Additionally, the manager of our Public Health and Health Inequalities Theme has been appointed to the Board of Healthwatch Sheffield.

PPI is resourced through a combination of our NIHR budget and match funds including participant reimbursement e.g. PPI Lead and Coordinator, CRAG, regional YHPPIC. The PPI Working Group **reports this PPI activity** at each CLAHRC YH Executive Group, which meets 9 times per year. In addition, it provides regular reports to the regional NIHR PPI Community group and the national Patient Involvement in CLAHRCs (PPIC) group.

We have held a number of events to consult people with **lived experience** for example we held a TK2A Design Challenge for people with Parkinson's Disease and a mental health and co morbidities event with patients suffering both mental and physical health problems to identify areas of success and failure in their care. We also held a 'Lego Serious Play' event to explore the lived experience of peripheral neuropathy(PN) in order to begin understand how technology might be integrated into their lives and promote self-managed rehabilitation.

Patient and public involvement in CLAHRC YH is enacted in many ways within projects and Themes e.g. as oversight group members: the DIAMONDS project (MHC Theme) included 2 PPI members as co-applicants on a **successful** NIHR Programme Development grant; as a consequence of the high value placed on the CRAG group input into a HEOM Theme PhD study two CRAG members will join an advisory panel for the project.

Examples of public involvement in specific projects include:

- Members of our frailty oversight group (FOG) have been undertaking observations of the assessments by staff on the CARE cohort study, which **resulted in improvements** to the assessment and consent processes. In addition a FOG member helped design and facilitate a workshop on the use of oversight groups in cohort multiple Randomised Controlled Trials (cmRCT) at the HSRN Symposium. This model of oversight has been written up and **submitted for publication**
- The PRASE project (EBT Theme) has recruited a cohort of trained hospital volunteers, across three regional NHS Trusts, who have been collecting feedback from patients on wards on patient safety. This information directly feeds into action planning cycles to drive improvements in patient care and experience
- As part of a knowledge translation project looking at how we deliver improvements to the experience of people attending Hep C services to reduce the amount of Do Not Attends (DNAs) the TK2A Theme delivered co-design sessions where current and ex-users of services worked with service providers to **co-design** a new intervention which will be piloted as service improvement.

- Within the ReQoL projects (HEOM Theme) on governance groups and as part of external service users' organisations providing advice on how to tailor interviews for older adolescents

Expert user groups in HEOMs and PHI Themes testing face validity of questionnaires
