



**National Institute for
Health Research**

**Patient and Public Involvement and Engagement:
NIHR Collaborations for Leadership in Applied Health Research
and Care Annual Reports 2016/17**

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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 and report on the following areas:

- Progress made in the delivery of your aims and objectives as detailed in your PPIE strategy/ies. What activities and outcomes are you delivering? What partnerships and collaborations are you involved in? What resources are you deploying? How is monitoring and reviewing of progress linked into the reporting and governance structures of the CLAHRC?
- Any significant changes or revisions to your PPIE strategy/ies.
- Examples of the impact that your PPIE activities are having. This could be in individual research projects and / or across research areas and / or in the governance and management structures of the CLAHRC itself. Please highlight any significant successes or challenges.

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 CLAHRC, and signpost them towards appropriate information about participating in research.

Each year, the NIHR makes the PPI/E sections of annual reports publicly available. All the reports in this series, both current and previous, can be downloaded from the NIHR website: www.nihr.ac.uk/ccf-ppie-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 2016/17 in delivery of their PPI/E strategies. 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@nihr.ac.uk using the subject header ‘CLAHRC PPI feedback.’

East of England CLAHRC

Annual Report 2016/17:

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
Contact Name	Lorna Jacobs
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Contact Phone	01223 465188

Progress in implementing the CLAHRC PPI/E strategy: good progress with the PPIE strategy.

Changes/revisions to our strategy: A revised PPI strategy (2016) and can be found [here](#).

Organisational PPI structure: We have three PPI representatives on the [CLAHRC Board](#), one PPI representative as peer reviewer on the Scientific Advisory Board, and one on the Capacity Building Committee. The [PPI Coordinating Group](#) includes three public members.

Partnerships and collaborations: PPI is embedded within each project, and themes have their own PPI partnerships and collaborations. An example is the [Mental Health Screening in Primary Schools](#) project, which worked with Healthwatch and primary schools in Cambridgeshire and Norfolk to set-up two PPI groups of parents. CLAHRC EoE also collaborates regularly with other regional NIHR infrastructure organisations and NHS Trusts on strategically driven PPI activities and events e.g. our [PPI forum event](#).

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

We have worked with regional partners to jointly deliver two PPI training sessions for researchers ([June 2016](#), and [April 2017](#)). We have drafted a 'PPI in Research' handbook in collaboration with CLAHRC researchers and representatives from PPI groups across the region (to be finalised in June 2017). We are working with the RDS East of England to deliver a programme of PPI training for service users and carers.

Monitor, review and report on delivery of the CLAHRC's PPI/E strategies:

All CLAHRC projects are required to have PPI as a part of the project protocol before being considered for funding. This is monitored through 3-monthly project reports and KPIs. The PPI Coordinating Group has responsibility for driving the initiatives and activities that will meet our PPI strategy.

How we make patients and the public aware of our research:

Information on CLAHRC research activities are posted onto our website e.g. researcher's [blogs](#), downloadable content such as [CLAHRC BITES](#), and our [newsletter](#). The themes hold a number of public engagement events throughout the year e.g. DeFEoL theme developed a brochure to present their work to stakeholders at an event in March 2017. Another example: researchers from the EDD theme, part of a programme of research relating to dementia in people with Down's Syndrome (DS), made a film with people with DS who were participating in research (['Together'](#)). This premiered to an audience of people with DS, their families and caregivers, clinicians, academics, and others at the Arts Picturehouse, Cambridge.

Examples of PPI activities and outcomes across CLAHRC research themes:

The [Transition from Child & Adolescent Mental Health Services \(CAMHS\) project](#) involved young people (YP) in the dissemination and implementation of research findings e.g. the YP co-presented findings to the Shadow Secretary for Health at Norfolk and Suffolk Foundation Trust (NSFT), to the CPFT Board and are part of a new transitions working group at HPFT. The [Frailty Trajectories: Understanding tipping points across care settings](#) project has established a PPI group with 6 lay members recruited to date and includes members of Healthwatch and the Citizen Senate. Service users, carers and members of the public were

also involved in discussing research questions and potential data collection. The Good Health Matters Workshop took place in Newmarket and was attended by 60-80 people. The group was composed of adults with learning disabilities, their carers, and health and social care commissioners. Dr Marcus Redley gave a 20 minute presentation about [HEALeD: Hospital Experiences of Adults with Learning Disabilities](#), a CLAHRC-related project. As part of the project [PROMISE: PROactive Management of Inpatient Services and Environments](#), the services users advisory Group (SUAG) were able to influence CPFT's Seclusion Policy, with the Trust amending their policy in a number of ways e.g. the design of the seclusion room has been changed to include a clock displaying both time and date, and more patient friendly furniture. The project [Developing an antenatal intervention to promote mental health \(development grant\)](#) held a PPI event for parents with children < 1yr. prior to recruitment of parents-to-be to this project. The parents were asked to comment on a presentation on 'My Baby's Brain – Antenatal', in terms of content, type of presentation and whether it is something that they would have benefited from during pregnancy. For the [Imaginator](#) study, a young persons' advisory group (YPAG) has been established and has had a beneficial impact on the design of the study, information sheets and posters, as well as for avenues for recruitment.

PPI engagement in the PPI Research theme:

[Patients as Partners \(PIPPIN\)](#) looked at what models work best to improve patient experience in services for long-term conditions. The project had a lay co-researcher, set-up an advisory group with three further lay members and worked with the [Patients in Research group \(PIRG\)](#) based at the UH for feedback on study design, materials and delivery. A new project [PPI feedback cycle](#), is investigating if, how and when, researchers should give feedback to PPI representatives, and is co-producing a tool to support the feedback process. PPI leads and representatives from regional NIHR organisations and six different PPI groups have been involved in the design and are participants in the study.

East Midlands CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-em.nihr.ac.uk/index.aspx
PPIE web pages	http://www.clahrc-em.nihr.ac.uk/public-involvement/index.aspx
PPIE Strategy	http://www.clahrc-em.nihr.ac.uk/documents/clahrc-em-public-involvement-strategy.pdf
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Contact Phone	0116 258 4318

NIHR CLAHRC for EM's PPI programme continues to develop and deliver its key priorities as identified and approved within our PPI strategy. PPI is embedded throughout the organisation. All CLAHRC projects report PPI as part of their Quarterly Updates which they produce as part of the performance framework of the organisation. Over an extended period these updates show how patient involvement and participation have shaped the project design and conduct, patient involvement in the co-production process, advising and participating in project team meetings, networks of practice and other events. There is further positive examples of how patients have helped shape project literature and publicity. PPI representatives sit on all of the major groups of the CLAHRC including the Governance Board, Partners Board and Scientific Committee where they are able to influence the strategic direction of the organisation and ensure that the patient voice is present when all major decisions are being taken.

There have been no changes to the PPI strategy for NIHR CLAHRC for EM. However, there has been a significant change in that our former PPI lead Dr Paula Wray has left the organisation to work for INVOLVE. She has been replaced by Vinod Chudasama who has an extensive background in community engagement and equalities work. Vinod also works closely with the Centre for BME Health.

Vinod's early work was to carry out a review of the function including arranging focus groups made up of PPI representatives. He reported a high and positive degree of engagement between the CLAHRC and patient representatives with PPI representatives having a lot of confidence in us and our work.

Participation

There are a number of excellent examples of patient participation in CLAHRC EM's work. These include:

- One of our PPI's representatives has now started a PhD on PPI as well as acting as a service user consultant on our REBOOT study.
- Two public involvement representatives have been integral to our Health Anxiety project. They have held advisory roles from the beginning of the study. Their contributions have included: attending monthly meetings and being involved in all study decisions discussed, creating the study name and providing input on the content and structure of study flyers, participation information sheets and adaptation of CBT booklets. In addition, one of the representatives Fred Higon has created cartoon images for study documents. The CBT manual containing images created by Fred is now being printed.
- Our Lets Prevent study which aims to develop a diabetes prevention programme in an area with a high BME community has been particularly successful at engaging the local community. PPI involvement has been integral to all aspects of the project. Patients helped to design the initial pathway. PPI engagement events were then held to inform the modification of the programme for BME communities. Finally, BME representatives were included as a member of the working group that meets monthly to discuss how the programme is being delivered and any issues that come up with the conduct of the project. The project has also benefited by GP practices consulting their PPI groups to inform them how best the programme can be delivered and advertised.
- Our MAP (Multimorbidities) study are working closely with PPI representatives. They are influencing the development of the education intervention, the design, format and delivery, including the setting and choice of facilitators (educators). They will also contribute to the adaptation/application of the intervention for future implementation.

Engagement

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 Assistant Director. We have a website that is updated regularly, an active twitter account with nearly 2,000 followers and we have published 34 BITEs (Brokering Innovation through Evidence) which are short descriptions of our projects and their findings.

We continue to work with Olly Jelley a former journalist, in placing stories about CLAHRC EM in the national, regional and local media detailing our work. In the reporting period he was able to place 138 stories about CLAHRC EM in the press ranging from national newspapers including The Times and The Sun; regional media like BBC East Midlands Today, BBC Radio Leicester and BBC Radio Nottingham; local papers like the Leicester Mercury and Nottingham Evening Post; media targeted as specialist groups like the Asian Voice and specialist magazines like the Diabetes Times.

In the past year we have relaunched our Communications strategy which underpins how we communicate with our partners, the local health economy and the wider public. The new strategy, which has the key message of “Health research today; improving lives tomorrow”, intends to strengthen our community engagement and identifies new approaches to maximising our wider message, with every objective linked to achieving a CLAHRC EM aim as set out in the original bid.

**Greater Manchester CLAHRC
Annual Report 2016/17:
Patient and Public Involvement and Engagement (PPIE)**

Website	http://www.clahrc-gm.nihr.ac.uk/
PPIE web pages	http://www.clahrc-gm.nihr.ac.uk/about-us/patient-and-public-engagement/
PPIE Strategy	
Contact Name	
Contact Email	
Contact Phone	

Our PPI/E strategy remains largely unchanged; the role and contribution of PPI/E across programmes and projects is 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 UoM PPI/E community, by our Enabling Network and CLAHRC staff and students with experience in different approaches to PPI/E. We now have a wide range of expertise across the CLAHRC in a range of approaches to PPIE, which is shared well for existing and new projects. Our CLAHRC Patient Panel (4 members) continues to meet every 6 months and has continued to formally review projects at different stages of delivery and provide feedback that has helped to identify lessons that can be learned across projects and applied to future projects. The Panel members have regular input into our programmes between meetings, offering general advice 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 about 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. We ensure our PPI/E representation is appropriate to the project e.g. working with stroke survivors and carers in projects across our stroke programme (PCC.S2, PCC.S3, PCC.S4) and arthritis patients in our REMORA project (PCC.ET2) and is wider than just our panel members. We now have a research fellow with expertise in PPI/E who has also been awarded an NIHR Knowledge Mobilisation Research Fellowship with a PPI/E focus, who will review our PPI/E activity to date within the Patient Panel and across the wider programme in May 2017. The qualitative data to be gathered from the Panel members will be analysed alongside our PPI/E performance data. PPI/E remains one of the KPIs measured across programmes and projects (see section 3). 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. PPI/E highlights include:

- OSCARSS (PCC.S.4) is a study in partnership with the Stroke Association evaluating the effectiveness of approaches to identify and support the needs of carers of stroke survivors. A research user group (RUG) was established to provide feedback on essential study documentation, recommendations for the choice of outcome measures and input into practitioner training packages. The RUG has 8 members and is made up of carers of stroke survivors. The group have ensured that documentation is suitable for the lay reader and the outcome measures meet carers' needs and are suitable for the target population. The RUG meets on a monthly basis and although they do not always agree on issues, they have bonded well and have always successfully managed to discuss differing opinions and reach a consensus. The group have also worked on the development of a script for Stroke Association staff training to deliver the project, which has been produced as a video. The RUG was recognised for their contribution at the Stroke Association NW Regional Life After Stroke Awards.
- REMORA (PCC.ET.2) involves the development of a smartphone app that allows patients to log rheumatoid arthritis (RA) symptoms regularly between appointments, which are sent directly to the patient's electronic hospital record, as well as to a research database. A PPI group of 7 RA patients was formed to contribute to the co-design of the app and the delivery of the study, and have met on a number of occasions in focus groups to discuss the findings. Their input has contributed to what services and features may be made available for the app in future to support uptake and implementation and the lead app developer will be attending one of the PPI meetings. The PPI members have agreed to be involved in a study video to be used for marketing the work that has been completed to date. Feedback from the group suggests that they feel valued as they can see how their input has contributed to the app and the project and [a blog about PPI in REMORA](#) has been produced.

We continue to work closely with other PPI networks and groups across Greater Manchester including the SRFT Citizen Scientist programme, and PRIMER (Primary Care Research in Manchester Engagement Resource). We also have links to the UoM community engagement and involvement structures, with some CLAHRC researchers and PhD students accessing and training and advice offered by FBMH. We continue to gain a national perspective to inform our work and learn from others via the CLAHRC national PPI meetings and INVOLVE events. As a result of a meeting with Dr Paula Wray, Senior Involvement Manager at INVOLVE to explore the potential for regional PPI/E networks, we have forged links with colleagues in other NIHR funded programmes in Greater Manchester, such as the newly established BRC (see section 8), to share learning and intelligence and explore opportunities for greater collaboration.

In addition to the partnership working across GM described above, we continue to use newsletters, information leaflets and other CLAHRC materials disseminated via engagement events, email, and our website to involve and engage with patients and the public. We participate in a range of events open to the public.

North Thames CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	https://clahrc-norththames.nihr.ac.uk/
PPIE web pages	http://clahrc-norththames.nihr.ac.uk/patient_and_public_involvement/
PPIE Strategy	http://clahrc-norththames.nihr.ac.uk/patient_and_public_involvement/our-involvement-and-engagement-strategy/
Contact Name	Steven Towndrow
Contact Email	s.towndrow@ucl.ac.uk
Contact Phone	0203 108 3241

In line with our [Involvement and Engagement Strategy](#), during the last year we have focused on involving our patient and public partners in more strategic discussions and decision making within the CLAHRC, as well as our day-to-day research work. In terms of Governance, we have created a public patient representative seat on the CLAHRC Management Board, which is shared by three of our PPI contributors.

- We continue to embed PPI/E across the CLAHRC, requesting all our studies to **report quarterly** on this, and including PPI/E as a standing agenda item at each of our theme's monthly research meetings. It continues to form an important element of our induction for new staff, students and researchers.
- Our **document review panel** (a virtual panel made up of patients and public) has increased to eighteen members, and seven sets of research documents have been evaluated this year. This included reviewing a manuscript for a BMJ paper – the Standards for Reporting Implementation Studies (StaRI) statement (<https://doi.org/10.1136/bmj.i6795>). This was an involved and demanding request due to the complexity of the material. The reviewers found the feedback provided to be very helpful, and their contribution was acknowledged in the final publication, which sets a good precedent for future PPI in writing academic papers.
- In terms of **engagement**, we continue to work with our public and patient partners to help spread the word about PPI/E in research. Members of our **Research Advisory Panel** have [participated in research events](#), [been part of discussion panels at national academic conferences](#), and have participated in training and development for researchers offered by the CLAHRC's successful academy. In Nov 2016, we ran a CLAHRC Academy seminar for PhD students and early career researchers, entitled 'Writing lay summaries'. Our PPI Officer was joined by one of our document review panel to offer top tips on how to write in a clear and accessible manner to a non-specialist audience or for the benefit of those unfamiliar with research.
- Our [Research Advisory Panel](#) (RAP) meet regularly (five times in the last year) and continues to have a direct impact on research design and the accessibility and acceptability of research. The RAP advises on projects at all stages of the research process – from grant applications to almost complete projects considering dissemination of results. The Panel's advice has led to stronger grant applications, improved research design, better dissemination, highlighted alternative sources of funding and opened up new networks to researchers to spread the word about their research. It has flagged up "real world" issues and practicalities that can make the difference between successful and unsuccessful research. The Panel and its members have developed knowledge of the CLAHRC and its work and are now experienced partners, taking a greater role in governance structures and decision-making. The Panel now also displays much greater confidence in offering challenge to researchers allowing it to flag up issues and potential problems with proposed research at an early stage.
- Our [Young People's diabetes project](#) (Child & Adolescent Health theme) has been successful in empowering and enabling young people with the condition to play a full role

in community engagement for service improvement, and commissioning of local services for their age group. Our work was integral in shaping new [NHS “how to” guidance](#) to help commissioners and providers think through and develop youth forums to support person-centred commissioning of children and young people in health and care services.

- Collaborations included a partnership with PPI/E and communications colleagues from our host NHS Trust Barts Health and the local AHSN UCLPartners. As part of this work the CLAHRC’s PPI Officer planned, designed and delivered a seminar to professionals from across North Thames on developing effective communications strategies for Patient and Public Involvement and Engagement in Oct 2016. The session, delivered to an audience of involvement specialists, highlighted the importance of working with communication colleagues in an organisation to get the best of the support they can offer – in promoting, publicising and facilitating involvement in research (and other sectors).
- Our CLAHRC is making strides in contributing to the evidence base around PPI/E. PhD student Djellouli (Systems & Models theme), is conducting a project on [developing patient and public involvement \(PPI\) in large-scale change](#). Our PPI/E Officer (despite not having an academic background) was elected to be part of the PhD supervisory committee, providing expert practical knowledge on PPI.

In Nov 2016, we held our [CLAHRC showcase event](#) which gave our partners a chance to come and meet researchers in an informal relaxed setting. Crucial to the success of the event was the participation of our patient and public contributors. In total six attended, and they spoke to visitors about their involvement in our work, and met other CLAHRC researchers.

- We have taken part in a number of engagement events with a public audience. In July 2016 we were part of the Barts and Queen Mary Science Festival where an audience of secondary school children visited our stall and tried their hand at our [asthma board game](#) as well as testing their lung capacity. In the same month, we took part in a [UCLH research open day](#) where we met staff, patients, visitors and schoolchildren.
 - Our PPI/E Officer was invited to join the judging panel for the inaugural [Brian Turley Award for Patient and Carer Involvement](#) organised by our neighbouring CLAHRC North West London. He drew on his expertise in the field to evaluate entries in the award, which recognises early and credible involvement activity that allows seldom heard communities to take part in and lead research, as well as producing learning that can be applied in the field.
 - We actively collate ‘lessons learnt’ and hold “brainstorming” meetings with our PPI representatives, where future research and involvement priorities and projects are discussed.
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North West Coast CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-nwc.nihr.ac.uk/
PPIE web pages	http://www.clahrc-nwc.nihr.ac.uk/be-involved.php
PPIE Strategy	
Contact Name	
Contact Email	
Contact Phone	

Progress made in the delivery of your aims and objectives

Good progress is being made in delivering our aims and objectives as detailed in our public engagement (PE) policy, part of the engagement strategy. The Public Reference Panel (PRP) has strategic oversight of the policy (supported by the PE facilitator) and has been central in developments over this period. The PRP was formed by public advisers in July 2015 and meets monthly (but is currently undergoing a change to its model as the membership has expanded beyond the capacity of the current organisational working group structures). Public advisers involved in theme or project activity become automatic members of the panel. Public advisers have formal governance positions on the Management Team, Steering Board and Subcommittee (which approves project proposals). All projects require public engagement and involvement as a requirement of funding. Each theme works with our PE policy with the aim of delivering public and patient involvement and engagement (PPIE) from the concept stage through to the final dissemination and implementation of research. Themes report quarterly on their PPIE progress (including the management of their themes) to the Director of CLAHRC NWC (see public engagement in research to reduce health inequalities).

We prioritised increasing the numbers of public advisers and further developing training over this reporting period. Public advisers registered and actively involved in our work have contributed 1,146 hours of time, an increase of activity from the previous year, with advisers offered payment in line with INVOLVE rates, as set out in our [payment policy](#). There have been 44 public advisers registered and actively involved in the period and we have worked with many more members of the public who have not registered as advisers as well as a large number of patient and carer groups, regionally and nationally. We expect public adviser numbers to continue to grow as COREN continues to recruit resident advisers from our NsFL and as the Partner Priority Programme enters stage two, (which provides support for partner organisations and their public/university teams to develop and deliver evaluation plans for new models of care they are rolling out. We have engaged with 13,659 members of the public at [events and activities](#) within the NWC, including [Campus in the City](#) (Lancaster), Liverpool Mental Health festival and through screening 'The Divide' film on the causes of health inequalities at a number of NWC locations. Most of these regional events used the ['pop-up neighbourhood' coproduced materials](#) or our multiple choice [online quiz](#), both designed for public audiences to explore the topic of health inequalities. The public reference panel coproduced a number of materials to assist project teams to support advisers such as a [welcome pack, code of conduct, terms of reference, induction checklist and other materials](#). Theme Managers ensure advisers receive an [induction](#).

From a training-needs audit, the PRP developed a comprehensive training plan for advisers. The following training has taken place so far within this period: influencing skills, communicating and presentation skills, [health inequalities](#), research and evidence synthesis. A formal mentoring scheme was set up for public advisers holding governance roles, with

CLAHRC mentors (University and partner staff with experience of governance roles) and mentees taking part in formal training to support the pairings over a six month period. We also have a bi-monthly programme of training arranged for 2017. These formal sessions are coupled with a peer-led learning and development space for public/resident advisers to share experiences and reflect, linking back to the governance group. Over the next year, our priorities will move to capacity building with CLAHRC staff and partners around engagement and involvement as well as developing systems and support which will help public and NsFL resident advisers to have more influence and impact in the opportunities they are involved in.

What partnerships and collaborations are you involved in?

- Strong relationship developed with Peninsular CLAHRC public group PenPIG. [Second learning exchange](#) has taken place and a number of spin-offs have resulted from the connection.
- [Launched strategic network in the North West for PPIE leads](#). First event with over 60 attendees and 30 organisations represented. Discussions underway about co-delivery of the network.
- Close working with INVOLVE has involved Paula Wray in the NW network to share updates and reach the NW INVOLVE 'patch' to support 'Going the Extra Mile' report shared goals.
- Working with Public Health England on their strategy for promoting greater use of community involvement approaches in local practice to improve health and reduce health inequalities.
- Working with the NIHR School for Public Health Research to develop resources to support public health work in disadvantaged communities.
- The COREN network of local third sector organisations are partners in recruiting and supporting residents of our neighbourhoods to engage with the CLAHRC.

What resources are you deploying and signposting opportunities?

- Full time PE Facilitator, Jenny Irvine, part time (PT) assistant, Abigail Oyston (0.6fte), PT COREN manager, Paula Wheeler (0.2fte) and PT Engagement Director, Jennie Popay (0.1fte).
- £21,400 has been spent on public adviser fees in this period. This excludes staff and other costs.
- [Coproducted materials](#) including [terms of reference](#), [code of conduct](#), [Welcome pack](#), [induction checklist](#), [activities](#), and capacity building films.
- Training and capacity building for staff, students and interns is available and has been delivered on public engagement and involvement. Training for partners is in development.
- 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 2016/17, a proportion of the central PPI/PE budget was allocated to themes to encourage and support engagement/communication/ dissemination with stakeholders, including the public.
- COREN facilitators and Resident Advisers (RAs) form part of the wider Public Health Theme leads group that also comprises local authority partner members. This group acts as a knowledge exchange network, sharing insight from local activities and acting as a sounding board for specific local challenges.
- Resources have been deployed to develop core skills and resources pack for RAs in partnership with Sefton CVS. The aim of this is to support RAs to be more influential within their NsFL understanding how to actively participate in their community. This is co delivered through a 'train the trainer' model upskilling and building capacity with COREN facilitators.

- Opportunities for public involvement are advertised via NW networks and with support from the Communications Manager. Dedicated webpages with a [‘what’s involved’ film](#) and [contact details](#) are on our website to explain the role of the public working with CLAHRC NWC.

How is monitoring and reviewing of progress linked into the reporting/governance structures?

Adding to information in the section on ‘progress’, an example of how the monitoring of progress is linked to governance structures is the PRP undertaking an exercise to develop metrics to help us understand how closely CLAHRC NWC is to living up to its PE principles. This resulted in a number of recommendations, approved by the steering board, changing, amongst other processes, the reporting requirements of all teams on PPIE metrics, and at the steering board, the adoption of a ‘you said, we did’ action log and the reporting of additional data to this group.

Any significant changes or revisions to your PPIE strategy/ies.

We are in the process of setting up topic specific governance groups under the umbrella of the Public Reference Panel. These groups will be made up of public advisers and will allow individuals to specialise within a particular topic area (which may relate to areas such as central governance, adviser experience and training or communications and engagement). The strategic responsibility for the public engagement policy will be shared between the groups.

Examples of the impact that your PPIE activities are having.

Public advisers have changed a number of processes within the governance of CLAHRC also, including additional PPIE reporting for projects to capture improved information on the activity and diversity of advisers involved. The PRP ‘metrics task group’ also identified qualitative metrics that will capture how closely we are to engaging and involving public advisers in line with our principles which will feed in to the CLAHRC NWC evaluation.

The Public Health Theme has made significant progress in terms of PPIE this year. We work with a network of partner local third sector organisations who recruit and support residents (resident advisers) to get involved in CLAHRC work and together these form the COREN. The evidence obtained from these enquiries is contributing to shaping the design of the Theme’s Resilience Initiative in each Neighbourhood for Learning (NfL). By taking part in these activities, this is supporting residents’ capacity and confidence to influence change in their locality.

The Evidence Synthesis Theme has engaged a multidisciplinary Advisory Panel to guide their Systematic Review. The Panel includes as equal peers: two members of the public, two healthcare practitioners, two academic staff, an administrator and a PHD student. [The panel has developed a tool to capture the degree to which the available evidence considers socio-economic health inequalities.](#) This tool is included within the evidence synthesis data extraction form. The group has also shaped the inclusion and exclusion criteria and supported the reviewers’ understanding of the discipline area with examples and experience from real life and professional practice. They will peer review the final report and dissemination materials.

The Improving Mental Health Theme has developed a project out of a series of three public engagement events called “Research Have Your Say” held in 2015/16. Ten members of the public are working together to develop a study to address inequalities in mental health care in the NWC area, particularly in relation to the psychiatrist patient relationship. The project commenced in November 2016 having been funded for 12 months by CLAHRC NWC and a RCF grant via Liverpool CCG. The main purpose is the development of public led mental health related research proposal suitable for funding through the NIHR RfPB.

The Delivering Personalised Health and Care Theme has developed a heart failure/renal patient group in collaboration with the SURE patient group and support from Liverpool Heart and Chest Hospital, funded by a Wellcome Trust public engagement grant and CLAHRC NWC. This group will contribute to the PERMIT project, relevant external grant applications and will help to shape associated industry collaborations.

[HIAT](#) helps ensure research 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*.

All projects within the PPP are actively encouraged to include public advisers in their teams and each initiative lead has received training to support them to achieve this. Advisers include individuals as well as representatives from service user groups attached to the partner organisation. The intention here is that, as well as improving the relevance of the project to service users, we build capacity in Partner organisations to mobilise their existing networks of patients and carers to be engaged in the research process. This is an example of the added value of the CLAHRC infrastructure to build new PPIE networks and capacity, and is now linking up with other PPIE groups such as those working with RDS and Future Hospital Programme pilots locally. This should raise the profile of, and empower step changes in public involvement in both research and service redesigns linked to STPs and Vanguard.

North West London CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-northwestlondon.nihr.ac.uk/home
PPIE web pages	http://clahrc-northwestlondon.nihr.ac.uk/what-we-do/cross-cutting-themes/patient-and-public-engagement-and-involvement
PPIE Strategy	Available on request
Contact Name	Rachel Matthews
Contact Email	r.matthews@imperial.ac.uk
Contact Phone	020 331 53047

CLAHRC NWL draws on extensive experience consolidated over eight years which reflects the ongoing and vibrant contribution of all our patient and carer leaders, advisers, and contributors. We build the capacity and capability of all those involved, to work together for patient benefit and actively support patient and service users to develop confidence and skills leading to paid employment (2 cases this year). Our strategy is unchanged and fully aligns with the '[Going the Extra Mile](#)' recommendations.⁶⁵ INVOLVE good practice guidance for payment and the Benefits helpline informs our strategy which is monitored by patient leaders in the Core Group and Partnership Forum of our governance structure. Five patient leaders were peer reviewers for improvement research studies in May 2016.

Engagement and Involvement: The Exchange Network

- The Exchange Network is an innovative mechanism, co-designed with patient advisers, which further moves practice away from tokenism and towards co-production. It actively incorporates the INVOLVE values and principles framework.
- We used a Quality Improvement approach to co-design and develop the network, working through explore and design phases in 2013/2014 and entering an ongoing test phase in 2015.
- This approach has enabled us to grow the pool from 54 to 72 members in 2016/2017, involve new participants in an inclusive way, and offers action learning in mixed groups of patients, carers, clinicians, and researchers.
- The strength of the networking and quality of the conversations in this network is proving influential across the programme and beyond with interest being shown in this approach by Imperial Healthcare NHS Trust, the Health Foundation, South London and West Midlands CLAHRCs. 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 relate to and understand each other and are complementary to our Improvement Leader Fellowship as it encourages people to apply to this and offers a place for alumni to meet.
- Exchange Network members are influential in encouraging clinicians and researchers to actively involve patients – see blogs from members [Ms Jayacodi](#) and [Ms Lawrence-Jones](#).^{67,68}

Involvement: Learning and Development

- Patient Leaders and Fellows co-facilitate workshops at our CL events and in postgraduate teaching at Imperial College London: Ms Cameron, Improvement Leader Fellow provided teaching on MSc in Health Policy; and Ms Augustine, Improvement Leader Fellow, is the first service user to co-present in the 'Improving Health Services' Module in the MSc in Public Health at Imperial College London on the March 2017.
- Ms Cameron presented her [abstract](#) at 'Medicine X' conference held by Stanford University, USA, on 22nd April 2017 to promote the benefits of inclusive medical education.

Involvement: The Inaugural Brian Turley Award for Patient and Carer Involvement

- This award was introduced to promote PPEI as integral to improvement research and share notable achievements and reflective practice in memory of Brian Turley, My Medication Passport Ambassador.
- The expert panel checked three indicators; involvement developed at an early stage, efforts to reach out to those who can be excluded and evidence of two-way learning and reflection.
- Seven nominations were received, three from improvement leader fellows and four from research improvement teams.
- The Award was presented to the 'PREPARE' Team from Imperial College Healthcare NHS Trust who have co-designed a pathway with patients and carers to prepare them for surgery for oesophago-gastric cancer.
- The 'PREPARE' Team worked with patients using a series of 'Patients as Partners' events to co-design a digital health companion; an online platform that enables the patient to access advice and support.
- Patients are involved at multiple levels; at strategic level in the development of the programme, in research funding applications, in delivery activities, and in their own care.
- The judges commented 'This is a superb example of integrated, meaningful, well planned patient involvement which is central to the project. While PPEI is often an afterthought to projects, collaboration with patients is at the heart of PREPARE. Individual contributions are clearly marked and recognised, while the ethos of collaboration is demonstrated throughout. This team were awarded the first BMJ (2017) Award for Patient Partnership.

Public Awareness and Engagement

- The WMH AF Team, including patients, used GIS mapping to inform target areas for community engagement in Hounslow where there was an increased risk of undiagnosed AF. Hounslow is a Borough with high levels of deprivation and there is concern about the impact of stroke on this population in terms of disability and quality of life.
- The team used outreach with community and faith groups to raise awareness of AF, and developed digital postcards to support those newly diagnosed in collaboration with "No Delays" NHS Grampian <https://youtu.be/1OvrE4irGg>.

Public Awareness

- Ms Jayacodi, service user and Improvement Leader Fellow, established discussion with senior clinicians and ministers in Malaysia with Prof Bell, to raise awareness of mental health research, care and public involvement.
- We collaborated with CLAHRC South London to contribute our experience of using 4PI National Involvement Standards at a public event 'Active Involvement in Research Day' in April 2016, and attended and promoted their 2017 event on March 18th.

Service users co-authored '[Service user engagement in quality improvement: applying the national involvement standards](#)', published in the Journal of Mental Health Training, Education and Practice.

Oxford CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	https://www.clahrc-oxford.nihr.ac.uk/
PPIE web pages	https://www.clahrc-oxford.nihr.ac.uk/get-involved/ppi
PPIE Strategy	
Contact Name	
Contact Email	
Contact Phone	

Following the retirement of the CLAHRC's Senior PPI Lead (Rees. S) a working group has been set up to steer the direction of PPI within the CLAHRC (chaired by Professor Ray Fitzpatrick). The PPI Working Group is embedded in Theme 3 and has an overarching remit. The group reports to the Executive Group and through this group to the Management Board and Trust Board. Following recommendations by the Management Board, a new PPI Strategy has been developed to include an element of PPI research (specifically requested by our PPI representatives) in collaboration with Oxford BRC, led by Professor Louise Locock. Management Board lay members were active in deciding the Phase 2 funded projects and are proactive in developing their role and making proposals to work with individual projects to enhance PPI. A PPI '[Guide for Researchers in working with PPI Contributors](#)' is updated regularly with input from research staff and PPI Contributors. A newsletter for patients and the public, [PPI Pulse](#) is being distributed and has increasing circulation. The CLAHRC acts as editor of new ebulletin that promotes PPI opportunities, events, training and news across the CLAHRC region on behalf of many partners and beyond research. The first 4 editions of [Involvement Matters](#) currently achieving opens of 50+% and ~10 new contacts per edition. The CLAHRC is developing a resource of innovative ways to conduct PPI to share best practice examples with researchers. INVOLVE have expressed interest in disseminating this across all CLAHRCs. Each CLAHRC Theme has a short video on the website introducing the work and videos can be accessed through <http://www.clahrc-oxford.nihr.ac.uk/research>. The CLAHRC PPI coordinator contributed a 'running PPI Contributor training sessions' to the CLAHRC [blog](#). CLAHRC has partnered with other Infrastructure organisations to develop a large database of PPI contacts. This work is being spearheaded by [Peter Knight](#) a new executive director at OUH. Ongoing recruitment to the 'virtual pool' of PPI Contributors means that over 135 people are available to CLAHRC researchers at any time to be recruited to specific projects. Due to its focus, Theme 1 conducts PPI with hard to reach groups i.e. care home residents; people with dementia and young people with psychosis. Jane Fossey was part of a Leading Together event organised by OHNHSFT to develop dementia services, with the aim of embedding patient input into service development. A young person's PPI coordinator (Evans.S) has been appointed and has coordinated young person's participation groups across the Thames Valley (Oxford, Aylesbury, Milton Keynes, Reading, Slough), and engaged over 20 young people in an ongoing participation group. They have taken part in individual research projects, and volunteered for the CRN: mental health national young person's advisory group; spoken at regional events about their experience; and sat on interview panels to recruit staff. There is a Facebook group to share events and activities and plans to organise patient facing information booklet about research opportunities for young people. CLAHRC funded development of a module in early psychosis for the award winning HealthTalk website. There are young people with psychosis on the steering group and as participants in the project, as

well as helping to disseminate the findings in collaboration with the charities YoungMind and Rethink mental illness. Themes 2 and 5 have shown how to offer mutual benefit to the VCS; Cynthia Sriksevan has presented to the Oxford National Rheumatoid Arthritis Society meeting on hand exercises for Rheumatoid Arthritis and James Sheppard presented on strokes to a day care group who provided PPI input for OPTiMISE. We developed a new Theme 6 in phase 2 – Diet and obesity. This has a 100+ strong virtual [PPI Panel](#) active in prioritising a range of research questions. Public engagement activities include: public lecture and discussion for the Royal Philosophical Society, ‘Knowledge, Nudge, Nanny; how can we improve the nation’s diet’ lecture, a panel discussion at Cheltenham Science Festival ‘Truth about fat’; and a presentation at University of Oxford Administration Conference about supporting healthy eating in the workplace. The Theme 4 application to NIHR HS&DR (*How can we best address prolonged acute hospital stays in older inpatients with medical – psychiatric multimorbidity?: A pragmatic multicentre randomised controlled trial to compare the effectiveness and cost -effectiveness of Proactive Liaison Psychiatry with usual care.*) was leveraged by CLAHRC funded pilot work and was successful due to the changes made to the protocol, as a result of PPI, ensuring the primary outcome was meaningful and important to both clinicians and patients. The Talking About Dying project has been substantially shaped by PPI. In our interviews with 35 stakeholders (doctors, nurses, patients and carers) the topic of discussing resuscitation came up frequently. Doctors told us that they found discussing resuscitation particularly difficult. Patients and carers told us that it was important that the NHS supports staff who look after patients at the end of life so that they can have these discussions with their patients. Theme 3 invited 6 patients/members of the public to help analyse a subset of patient feedback on mental health services gathered online by iWantGreatCare. This work was also conducted in workshops with clinicians and other academics. The PPI group were all self-reported users or writers of online travel and retail feedback, and some had used health feedback to make decisions about healthcare provision. The aims of the project were explained to them and they received instruction on how to analyse the feedback. The results were collated and used to validate the researcher’s analysis, which in turn was used to train innovative Artificial Intelligence software which uses algorithms to learn, in order to test its potential for analysing online patient feedback. This was an important example of involvement, as it ensured the software was trained based on the voices of patients and public as well as academics and clinicians.

Total PPI Expenditure: £45,335

South London CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.clahrc-southlondon.nihr.ac.uk/
PPIE web pages	http://www.clahrc-southlondon.nihr.ac.uk/involving-patients-service-users-and-their-families
PPIE Strategy	N/A
Contact Name	Professor Diana Rose
Contact Email	Diana.rose@kcl.ac.uk
Contact Phone	020 7848 5066

Our dedicated patient and public involvement (PPI) theme, based within the Centre for Implementation Science, and led by Diana Rose, professor of user-led research at King's College London, helps to embed effective PPI in the CLAHRC's research. As well as undertaking its own research to evaluate the CLAHRC's PPI activities, the PPI theme also works with the health themes to: establish infrastructure and produce guidance on good PPI practice; run the PPI Strategic Oversight Group (see 2014-15 and 2015-16 annual reports); develop training and education for service users, carers and academic researchers.

There is a range of PPI activities being undertaken across the CLAHRC led by the health themes. For example:

- In our diabetes theme service users worked closely with researchers and healthcare professionals on the development of the [T1 Resources](#) website, which brings together a range of resources and support that is available online. Researchers also regularly present at patient DAFNE study days.
- In the psychosis theme service user representatives come to every team meeting and feedback on the theme's work. Service users have helped to develop the tobacco dependence treatment e-learning course and contributed to the design of physical health plans.
- Our palliative and end of life care theme has worked closely with patients, families, and members of the public to develop the [first virtual forum for PPI in palliative care and rehabilitation research](#).
- Our alcohol theme also held an open event for service users, family, carers, and healthcare staff in March 2017 to discuss how services in south London can be improved through 'assertive outreach'. They organised a one-day conference in May 2017 with the HIN to promote the implementation of health innovations developed by the HIN and the CLAHRC.
- Our maternity theme PPI lead, Mary Newburn holds a meeting for services users every 2- 3months including a half day collaboration and planning meeting with researchers. She is a member of NHS England's Maternity Transformation Stakeholder Council, where she has recommended that the continuity of midwifery care audit, developed by Professor Jane Sandall, should be rolled out across England.

Patient and public involvement strategy

This year the PPI theme has delivered on the following:

- Monitoring and advising on PPI effectively across the CLAHRC: We have now put in place PPI 'champions' for each of our health themes, as well as for King's Improvement Science and the Centre for Implementation Science. These champions are full-time researchers/clinicians affiliated to the CLAHRC, rather than service users. Their role is to support the service user reps, attend our Strategic Oversight Group (SOG), feedback on and seek advice regarding all PPI matters from our PPI team. These champions will supplement and partly replace the quarterly reports providing more relevant and timely two-way communication on PPI across the CLAHRC. In October 2016, the PPI theme appointed a PPI coordinator who meets regularly with the themes' PPI champions and

conducts outreach work.

Materials to assist public and research community

- Our PPI team has initiated biannual Action Learning Workshops for PPI champions and service users working with the CLAHRC. These workshops provide an opportunity for research teams in different health areas to address challenges together in a supportive environment. The first workshop (after a pilot in January 2016) was held in January 2017 and received excellent feedback. We acknowledge the role of the Exchange Network for PPI at CLAHRC Northwest London for inspiring this innovation.
- We are aiming to provide training on PPI for service users/public and (separately) for researchers. A short course for service users/public has been developed by our partners at St George's, University London and will be offered to CLAHRC service user collaborators in June 2017.
- We continue to provide seed funding for PPI activities across the CLAHRC.
- Our payment guidelines are being revised so that they can be fully aligned with INVOLVE guidelines.
- We continue to expand and consolidate our SOG for PPI.

Knowledge-sharing and public engagement events

Last year the CLAHRC held an outward-facing event in April 2016 with four other CLAHRCs (North Thames, Wessex, East of England and Oxford) presenting their PPI work. This first Active Involvement in Research Day (AIRD) was a success with 60 people attending. This year, we held a second AIRD event on 18 March 2017, with an emphasis on outreach to the public, service user groups and on reflecting the diversity of the local population. Around 100 people came to find out more about the CLAHRC's research and to discuss how to improve health services in south London. The event received excellent feedback.

Partnerships

We have ongoing collaborations with CLAHRC Northwest London and CLAHRC North Thames ([see section 8](#)).

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

Our database of service user groups across south London now contains details of 300 groups and will be integrated on our website in the coming months. We use this resource to help disseminate CLAHRC activities. We have also enhanced our website to highlight public events and news, and opportunities to get involved.

South West Peninsula CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-peninsula.nihr.ac.uk/
PPIE web pages	http://clahrc-peninsula.nihr.ac.uk/get-involved
PPIE Strategy	http://clahrc-peninsula.nihr.ac.uk/uploads/attachments/PenCLAHRC%20PPI%20Strategy%20170704.pdf
Contact Name	Tanya Hynd
Contact Email	piexeter@exeter.ac.uk
Contact Phone	01392 726042

The involvement of patients and public has been central from PenCLAHRC's inception, secured by commitment in the leadership, reflected by a well-resourced team who work to implement and research involvement across the programme and amongst our partners. Patients and members of the public are involved in all aspects: recruiting and training researchers, selecting topics and designing studies, applying for research funding, helping to conduct studies, disseminating and promoting research, as members of PenCLAHRC management structures, and liaising with other involvement groups regionally and nationally.

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 PenCRU (Peninsula Cerebra Research Unity) Family Faculty (<http://clahrc-peninsula.nihr.ac.uk/meet-penpig>). Each has an emphasis on different areas of work but share learning and some members.

Our strategy has been adjusted to account for changes in the team, but our aims remain unchanged (<http://clahrc-peninsula.nihr.ac.uk/patient-and-public-involvement-in-research>):

Embedding involvement across PenCLAHRC:

Our aim is that PPI is integral to all PenCLARHC activities and is as normal a part of research design as statistics. A range of experiences and conditions are held by members of our longstanding groups. We expand activities beyond these groups for individual projects, as we see direct experience as important for meaningful involvement. This includes so-called hard-to-reach groups: young people, the very elderly, people in full-time work, children with disabilities and others. We have involved people by advertising in a local paper, in GP surgeries, through the local NIHR and clinical network, public engagement activities and community groups. The PPI team runs "clinics" for staff from PenCLAHRC and partners to help them work out how best they can incorporate PPI into their projects. We have been keen to find "champions" amongst the research and clinical community, people who have worked with us and then go on to promote this way of working in their own communities. For instance, a local orthopaedic surgeon who worked with us on one grant application has become an enthusiastic and effective proselytiser across the discipline.

Developing involvement through research and theory building:

The PPI team (in collaboration with PenPIG) has generic research ethics approval for a programme of research into our activities. An abstract based on early work has been accepted at the Health Technology Assessment International Meeting in 2017 and another on the role played by ethnography in developing PPI has been accepted to the 12th Annual International Ethnography Symposium in Manchester.

Furthering collaboration with patients and members of the public:

We train members of the public to boost their confidence in their roles. For example, Dr

Maguire and Family Faculty member Jane Ring co-produced and delivered joint training for researchers and public advisors consisting of activities that prompted discussions between members of the two groups, highlighting different and converging perspectives in research collaborations. In October 2016 members of PenPIG and the PPI team went on a learning exchange visit to North West CLAHRC.

Expanding the work of the involvement team:

The PPI team has local, national and international networks. Kate Boddy advises ExeCTU on PPI. Kristin Liabo delivered PPI workshops in Norway, and colleagues from Norway observed co-produced teaching with PenPIG member Nigel Reed in Exeter. Nicky Britten and Helen Burchmore are members of the Patient and Citizen Involvement in HTA Interest Group. The PPI team advised the establishment of the University of Exeter Medical School PPI steering group, and Malcolm Turner of PenPIG is a member. Dr Maguire was awarded NIHR funding to examine the role of PPI in knowledge mobilisation. Members of the Family Faculty delivered a plenary, two workshops and a poster at the 2017 European Academy of Childhood Disability meeting in Amsterdam in May. They are flooded with requests for advice on how to build PPI around research and services for disabled children and their families and have provided input for a range of research projects being led from other universities and internationally.

Public engagement:

Many members of our involvement groups have established their own networks with researchers and services in the South West, contribute to other community groups and speak about PenCLAHRC’s work. This illustrates how involvement impacts on engagement when supported over a sustained period of time. In turn, some people become involved through research engagement activities. Individual study teams and the communications team of PenCLAHRC do a great deal to liaise with the wider public about applied health research. The PPI team has worked to engage senior citizens through contact with care homes and Devon Senior Voice. The team provides further networking opportunities for research-interested citizens through research training advertised to community networks.

PPI expenditure over the period was £170,000.

Wessex CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	https://www.clahrc-wessex.nihr.ac.uk/
PPIE web pages	https://www.clahrc-wessex.nihr.ac.uk/patient-and-public-involvement
PPIE Strategy	http://bit.ly/2xJbZvA
Contact Name	Martin Simpson-Scott
Contact Email	mdss1m17@soton.ac.uk
Contact Phone	02380 589211

Progress made in the delivery of your aims and objectives as detailed in your PPIE strategy/ies. What activities and outcomes are you delivering? What partnerships and collaborations are you involved in? What resources are you deploying?

- Our PPI strategy is available on our NIHR CLAHRC Wessex PPI webpage: (<http://www.clahrc-wessex.nihr.ac.uk/patient-and-public-involvement>) and all our strategic aims for 2015/16 have been met.

- We continue to develop our PPI database and network and have been able to meet both individual project, Theme and central CLAHRC PPI needs from our network (Strategic Aim 1).
- Our Guidance for Embedding Patient and Public Involvement Champions within Applied Health Research Programmes - termed 'PPICHR' - has been finalised. This has been co-produced with our PPI champions (all public contributors) and is available on our website: <http://bit.ly/2zcDpWV>. This work has been disseminated widely, and has received very positive feedback. Simon Denegri (NIHR National Director for Public Participation and Engagement in Research) has written the foreword for it. We are currently developing a shorter, more accessible version (now available here: <http://bit.ly/2sTcBbL> (Objective 2).
- We have shared the findings from our research prioritisation exercise through a number of different outputs including a publication (<https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0045-8>); a PPI blog (<https://nihrclahrcwessex.wordpress.com/2016/12/12/prioritising-the-fundamentals-of-care-with-patients-professionals-carers-and-the-public-anyadeiongh/>); a forthcoming Evidence Brief; and a conference paper (accepted, to be delivered by our PPI Champion / public contributor, Anya de Iongh) at the Royal College of Nursing Annual Conference 2017 (Objective 4).
- Findings from the Service User Research Insight project have been included in a publication (<http://bmjopen.bmj.com/content/6/7/e010853>) and were the focus of a poster presented at the Health Services Research UK conference 2016 by PPI Champion / public contributor Mark Stafford-Watson, where it was awarded best poster (Objective 5).
- A paper focusing on the baseline data collected as part of the 'Mapping PPI' project has been submitted to 'Health Expectations' (Objective 6 above).
- PPI continues to be monitored via the CLAHRC Board, Scientific Committee, Management Group, Quarterly Monitoring Meeting and the PPI group.
- Our PPI Strategy has been reviewed and updated but there are no significant changes to the CLAHRC Strategic Objectives.

Examples of the impact that your PPIE activities are having.

One of our major strengths organised on behalf of NIHR infrastructure in Wessex. The CLAHRC has developed very good working relationships with other local NIHR infrastructure and as a result a Wessex Public Involvement Network (Wessex PIN) is being created which will support PPI development and engagement across Wessex. The network is being financially supported by the CLAHRC, NETSCC, CRN and RDS and the CLAHRC's PPI lead will lead the network.

Please also describe how you make patients and the public aware of the research being undertaken within your Centre, 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). PPI lead Claire Ballinger and lay PPI Theme Champion Anya de Iongh have active Twitter profiles now with over 700 and almost 3000 followers each, respectively.
- workshops and training events;
- evidence briefs from NIHR Dissemination Centre;
- meetings (eg WISeRD); workshops, seminars, blogs and through a dedicated PPI mail box.
- Regular engagement with public contributors has continued through emails to those registered on our PPI database, blogs posted on our NIHR CLAHRC Wessex website and also tweets from our NIHR CLAHRC Wessex Twitter account.

Opportunities to participate in our NIHR CLAHRC Wessex projects have been promoted through our website.

West CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.phwe.org.uk
PPIE web pages	
PPIE Strategy	http://www.phwe.org.uk/wp-content/uploads/2015/05/PHWE-Strategy-2015-19-Up-dated_8.6.17.pdf
Contact Name	Dr Andy Gibson
Contact Email	andy.gibson@uwe.ac.uk
Contact Phone	

Progress made with the delivery of aims and objectives

We are continuing to deliver the main aim of the PPIE strategy of effectively involving and engaging patients and the public in CLAHRC West activities through our partnerships and strategy, and have made considerable progress in relation to our objectives of ensuring that patient/public views are considered at all levels in the CLAHRC, developing PPIE methodology, advising and supporting the research themes, identifying and meeting the support needs of research partners, engaging the wider public in the work of the CLAHRC, embedding PPIE across the research lifecycle, and beginning to evaluate PPIE. We have reviewed our strategy and it is in line with the principles of 'Going the Extra Mile'.

Activities and outcomes delivered. All research projects have been reviewed by public contributors and the PPIE team, and appropriate PPIE initiated. We have run 'Using and understanding research' and 'Research question generation' workshops to engage with the public. We run a PPI learning and development programme that is open to all our collaborators, and this year, 94 people attended seven sessions, with one third originating from the geographical area outside Bristol. We also provided information about research for children and young people, and supported pupils' research projects. Public contributors are involved in two groups to help us with key aspects of PPIE: a 'Plain English panel' to help simplify and make clearer information posted on the website, and material for CLAHRC Bites and research abstracts; and a 'Health systems panel' with some training to provide PPIE on projects related to broad health systems' issues such as patient safety, workforce initiatives, optimal care and system integration.

This year we have supported two projects based on research ideas generated by public contributors on urinary retention and rehabilitation after stroke. Our PPIE lead has published a paper on PPI evaluation methodology (Gibson et al. in press, Health Expectations 2017). We have begun work on evaluating PPIE undertaken under the umbrella of People in Health West of England (PHWE), with a documentary analysis to clarify the underpinning theory and to define key parameters for a larger-scale evaluation. We are supporting several projects engaging with 'easily ignored groups', for example street sex workers, members of the Somali community, and self-harm service users.

Partnerships and collaborations: Our work in CLAHRC West is delivered through our regional PPI network, People in Health West of England (PHWE), including WEAHSN, CRN West of England and Bristol Health Partners, and a new joint appointment with the Bristol NIHR BRC.

Resources: PPIE resources include part-time research fellow, PPI facilitator (jointly appointed with the BRC) and administrator (jointly appointed with CRN WoE. Academic leadership is provided by Assistant Professor Andy Gibson, UWE. We also use resources to pay public contributors for their time and expenses, and to organise events and workshops.

Monitoring and review: Progress in embedding PPIE in CLAHRC projects is monitored by quarterly meetings with the CLAHRC Management team, including the director. The core PPI team meets on a monthly basis to check progress. The CLAHRC West Board has a public contributor and PPIE-lead as members. Two public contributors represent the CLAHRC on

the PHWE Strategy Group. We also meet formally with our partners annually to review progress and sustain our regional commitment to PPI/E.

Significant changes or revisions to PPIE strategy

None.

Examples of impact

The 'Plain English panel' of public contributors who review and revise lay summaries of project findings has improved the readability and accessibility of our outputs and material posted on the website.

Telephone calls for NHS health checks: public contributors advised that it was important to state that researchers would not access medical records, and that telephone calls should be made from a number that did not create a 'withheld number' (i.e. not directly from the University or Trust).

Reducing drug use in female street sex workers: public contributors advised that a poster about the research would be more likely to be read in the format of a night-club flier, and that recruitment should be directly to the women rather than by letter as many women lack secure accommodation.

Making public and patients aware of research undertaken in CLAHRC West

Patients and the public are made aware of CLAHRC West research via our website <https://clahrc-west.nihr.ac.uk/research-and-implementation/>, the PHWE website <http://www.phwe.org.uk/involvement-opportunities/> and a monthly email 'newsflash' to over 600 people across our region.

West Midlands CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	https://www2.warwick.ac.uk/fac/med/about/centres/clahrc/
PPIE web pages	https://www2.warwick.ac.uk/fac/med/about/centres/clahrc/ppi/
PPIE Strategy	https://www2.warwick.ac.uk/fac/med/about/centres/clahrc/ppi/resources/clahrc_wm_ppi.pdf
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Introduction Meaningful involvement of patients and the public is the cornerstone to CLAHRC West Midlands (CLAHRC WM). CLAHRC WM recruited **14 Advisors** who are service users, carers, and members of the public from a range of backgrounds that are *already involved in influencing the service*. The partnership between our advisors, researchers and NHS staff ensures our research focuses on issues important to patients and the public. This partnership also ensures that the insights and direct experiences of patients and the public involved across our projects are used to shape research design and delivery and influence how services need to change.

CLAHRC WM PPI/E Strategy As set out in our strategy, the public are:

Involved in the Management of Science – Our Advisors are allocated to research themes according to their interests/experiences and meet together three times a year as a **Supervisory Committee**. The Supervisory Committee elects its own Chair and representatives to CLAHRC WM's **Steering Committee** (2 advisors) and **Executive**

Committee (2 advisors) ensuring a strong patient/public voice at all decision-making levels. A PPI report is delivered by Magdalena Skrybant, CLAHRC WM's PPI Lead, at each Steering Committee and Executive Committee meeting.

Involved in the design of interventions – In CLAHRC WM, we strive to co-produce knowledge with our public partners. Public Involvement, throughout the research cycle, ensures that CLAHRC WM's research is relevant to patients, uses appropriate and acceptable methods that have the best chance of success, and is shared in accessible formats to a range of audiences.

Recruited Systematically Recent recruitment of an additional Adviser provided an opportunity to revisit our recruitment and selection process, which included completion of a short application form and participation in a short, informal interview. Applicants reported that they felt supported throughout the process and that it was a positive experience.

Partnerships and collaborations- Building on existing relationships and developing new networks has been a major achievement for CLAHRC WM in the last year. CLAHRC WM's PPI/E Lead has worked with PPI structures in its partner Higher Education Institutions to ensure that appropriate mechanisms are in place to facilitate meaningful public involvement in research activities.

Through its PPI/E Lead, CLAHRC West Midlands has been instrumental in developing the capacity for PPI in the region. The PPI/E Lead was involved in developing the role description and recruitment of a PPI/E Lead at University Hospitals Birmingham, our host partner. A strong working relationship has been established with this post, which will ensure that our PPI/E is linked directly to research priorities in the Trust.

CLAHRC WM is also a committed member of Public Involvement and Lay Accountability in Research (PILAR). PILAR brings together organisations in the West Midlands that involve patients and the public in research and its members include various NIHR organisations including: Clinical Research Network (CRN), Academic Health Science Network (AHSN), Research Design Service (RDS) and Biomedical Research Centre (BRC). Gary Hickey from NIHR INVOLVE attends our meetings, which take place every 2 months. The focus of meetings is to share best practice and develop strategies to overcome barriers to effective involvement of patients and the public in the region.

Resources for Advisors Our Advisors receive support from a dedicated PPI/E Lead and PPI Liaisons in each of the themes. Regular communications from the PPI/E Lead (including a monthly newsletter) ensure our advisors are updated on CLAHRC WM research, opportunities for further involvement, and regional and national developments on PPI. All our Advisors receive reimbursement for expenses/time in accordance with INVOLVE guidelines.

Our Advisors are also supported to become involved in research projects. In 2016, all Advisors were offered a Learning Needs Analysis, which identified topics for development. A session on 'Everything you want to know about the NHS but were afraid to ask' was popular, with follow-up sessions planned. Our Advisors have also been supported to attend a number of conferences and workshops.

Resources for Researchers Workshops on public involvement have been delivered to PhD students, Clinical Academic Interns, Masters to Doctorate students and Masters in Public Health students, which included contributions from public advisors. Practical support is also provided to facilitate public involvement in research, such as the **Research Design Service (RDS)** to support public involvement in developing new grant applications. CLAHRC WM provides opportunities for researchers to pitch research ideas or challenges to PPI in their research to our Supervisory Committee. This initiative has been well-received by researchers, who have 'buddied' PPI Advisors to provide support in developing public

involvement in their research, and to PPI advisors, who have welcomed the opportunity to get to know researchers across the CLAHRC and the range of projects.

Examples of impact

[Shout Out for Youth Mental Health](#) – PPI Advisors in the Youth Mental Health Theme were involved in the planning and delivery of an event about our research which underpinned the design and delivery of an integrated care pathway for 0-25 year olds. This involved people from the Young Persons’ Network and provided opportunities for commissioners in the region to learn about the service and its implementation. Further ‘Shout Out’ events are planned in the region with a view to implementing the successful care pathway (see also impact case study).

Lay Involvement in the Implementation of Knowledge Group (LINK) –Keele University’s Patient and Public Involvement and Engagement Team has set-up a group, which works with patients and members of the public to mobilise the implementation of research evidence into practice. Task/Finish groups on two projects, [JIGSAW](#) and [STarT Back](#) have produced resources for patients empowering them to incorporate the best evidence into managing their conditions.

Research into PPI CLAHRC WM is researching the PPI Advisor role, how it develops over time, and how patients and the public can implement research evidence. This longitudinal study aims to examine the development of PPI advisor role and identify how PPI advisor could better contribute to all stages of research from grant application to implementation of research evidence. The research also looks at what motivates PPI advisors to be involved in research, so as to provide them more suitable training and personal development opportunities. Moreover, the study identifies barriers and facilitators for PPI advisors’ full participation in all stages of research and offer practical solutions to how to better embed the PPI advisor role into WM CLAHRC.

Engagement In addition to its website, CLAHRC WM uses social media platforms (Facebook and Twitter) and has a popular Newsblog, which features regular items about Patient and Public Involvement activities.

Yorkshire and Humber CLAHRC

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://clahrc-yh.nihr.ac.uk/about-us
PPIE web pages	http://clahrc-yh.nihr.ac.uk/ppi/1-ppi-home
PPIE Strategy	https://docs.google.com/a/nihr.ac.uk/viewer?a=v&pid=sites&srcid=bmloci5hYy51a3xjbGFocmN5aHxneDozMjlzNzgyMTlwOGYwZjM1
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Yorkshire and Humber has a long tradition of public involvement (PPI) in research. In 2016/2017 there is a wide spectrum of successful PPI at project and Theme levels. In particular, our focus on cohorts and participatory research methods represent the diverse, flexible, and multifaceted approaches embodied in our Co-production principle, and it is evident that our research teams highly value the public's knowledge and their contributions to research. We have recruited a total of 25,344 participants into our research projects.

Specific involvement highlights include:

- actively involving service users to support impact on services and research: This includes 1) co-design of services, reflecting patient and public experiences and delivering locally driven proposals to Sheffield Clinical Commissioning Group (CCG) in the Translating Knowledge to Action (TK2A) Theme; 2) developing wristband equipment and testing the rehabilitation gaming system (RGS) system for patients with poor mobility of their arms after stroke in the Telehealth and Care Technologies (TaCT) Theme; 3) developing PPI training package for service users and carers. This will be offered to all NIHR infrastructures in YH from Year 4.
- PPI members as research team members: PPI Mental Health and Comorbidity (MHC) Theme team members have helped to develop funding bids and interventions e.g. the development of Diabetes and SMI intervention for an NIHR Programme Grant bid. Service users were steering committee members for an Health Services and Delivery Research (NS&DR) bid, and a PPI was also co-applicant on this bid.
- Providing advice to improve the quality of projects. For example 1) in the TaCT Theme ADHD work; 2) with parents and governors in HCHF to develop measurement tools and study materials 3) As a Frailty Oversight Group (FOG) member and co-author in a Frailty Theme publication about oversight groups in cohort studies

Public engagement forms part of our wider communications strategy, including regular Twitter and Mailchimp messages and newsletters e.g. the HCHF Born in Bradford newsletter (<https://borninbradford.nhs.uk/news-events/bib-newsletters/>) was distributed to 13,000 families this year.

A range of events has been held with the aim of making our work more accessible to the public e.g. with stroke survivors and carers; older people and the Alzheimers Society; the University of Sheffield's Festival of Life (<https://www.sheffield.ac.uk/life/2016>) and Festival of the Mind (<http://festivalofthemind.group.shef.ac.uk/yorkshire-health-study/>) showcased the PHI Theme Yorkshire Health Study through a video coproduced with an industry partner, Human Studios, and a Q&A session with the project Lead; the HCHF Theme contributed to a Wellcome Trust Engaging Science theatre project that toured school in Leeds in June 2016 (http://www.leeds.ac.uk/forstaff/news/article/5468/public_engagement_at_leeds_shines_at_national_award_ceremony?notags=true).

The Health Children Health Family (HCHF) and Frailty Themes held celebratory events e.g. the Born in Bradford Family Festival in October 2016, which were organised in collaboration with their PPI groups. The TaCT theme have set up a PPI database to hold a list of those who have consented to be contacted for either participation in research projects and/or PPI input into the development of projects. There are currently over 50 members to date. Professor Ade Adebajo, the programme's Strategic PPI Lead, spoke at the regional NIHR Voices event in September 2016 (<http://clahrc-yh.nihr.ac.uk/ppi/nihr-voices>). This event, attended by over 30 members of the public and an equal number of researchers, focussed on Equality and Diversity.

PPI is resourced through a combination of our NIHR budget and match funds, including participant reimbursement. During Year 3 (2016/2017) the working group has experienced a significant reduction in capacity, due to long term sickness, changes in substantive roles and the loss of our dedicated PI coordinator. In response to these challenges, whilst the overall PPI Strategy (<https://drive.google.com/file/d/0B3-SF4FxenwJZF10Vmw2ejl1aG8/view>) will remain unchanged, the PPI Working Group will undertake a refresh of the action plan in Year 4 (2017/2018).

PPI is now led by the Senior Programme Manager Dr Christine Smith, and Professor Adebajo brings his wealth of experience to the Strategic Partnership Board. The working group continues to successfully collaborate and contribute with colleagues to both the

regional (Yorkshire and Humber NIHR PPI Community group 'NIHR Voices') and national PPI agendas through Involve and Patient, Public Involvement in CLAHRCs (PPIC). Monitoring and review of progress in PPI is now timed to coincide with the quarterly PPIC reports. These reports are also submitted to the NIHR CLAHRC YH Executive board.
