

newsletter

Welcome to the Winter 2016/17 edition of the INVOLVE Newsletter



As reported in the Autumn INVOLVE Newsletter the National Institute for Health Research (NIHR) is launching a new set of newsletters that cover all of its functions.

This means that this is the last INVOLVE Newsletter that you will receive in this format.

One of these will be a new Patient and Public Involvement newsletter which the INVOLVE newsletter will become part of. If you want to continue to receive INVOLVE news and content in the new PPI newsletter, you will need to **sign up** to receive it. You can also choose to receive other NIHR newsletters if you want to.

We are always interested to hear about your experiences of active public involvement in research, whether you are a member of the public, a researcher or from a research organisation. If you would like to contribute to the NIHR PPI newsletter please contact us.

Also in this issue:

- Health Research: Better Together - an event report from the West Midlands Regional Public Involvement network, PILAR
- New PPI pages on the HRA website
- INVOLVE Coordinating Centre News
- Co-production: Old wine in new bottles or vintage PPI?
- NIHR Voices Event 2016
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- Noticeboard

We would love to hear your views on the new NIHR website Patient and Public pages - please fill in our **quick survey** to tell us what you think.

Friendly disclaimer: The views expressed in this newsletter and in any enclosures are those of the authors and not necessarily those of INVOLVE or the National Institute for Health Research. Articles are selected for the sole purpose of stimulating ideas and debate on public involvement in research.

Health Research: Better Together West Midlands Regional Public Involvement network, PILAR event



“Alone we can do so little: together we can do so much.”

The words of Helen Keller, which are included in the concluding paragraph of NIHR INVOLVE’s ‘Going the Extra Mile’ report, were the guiding principle for the West Midlands in planning the first community event for its regional network, **PILAR** (Public Involvement and Lay Accountability in Research and Innovation).

‘Health Research: Better Together’, was chaired by Professor Krysia Dzedzic from Keele University and was held at the University of Birmingham on 14 November 2016. 34 people attended the event, including 11 public members, and the ambition was to bring together individuals from across the region who share a passion for ensuring meaningful public involvement in health research. We know that effective PPI can lead to better quality research and PILAR’s event provided an opportunity for individuals in the region to make new contacts, build networks and share ideas and resources. PILAR’s ambition of organisations in the region working ‘better together’ resonates with INVOLVE’s strategic plans. A keynote presentation from INVOLVE’s Gary Hickey underlined one of INVOLVE’s key ambitions: to galvanise regional communities and partnerships to advance public involvement in each of the 10 Research Design Service (RDS) regions. Where no regional networks exist, INVOLVE would help to support the creation of new networks. INVOLVE would play a key role in ensuring that regional networks have a clear purpose and would provide support to address regional needs and issues. Importantly, INVOLVE would support regional networks in addressing PPI issues on the national agenda and help to identify and share effective practice across regions.

In the West Midlands, the regional network, PILAR, was established in 2013. Steven Blackburn from the Research Design Service and PILAR lay member, Andrew Entwistle, delivered a presentation explaining how PILAR is formed from professional and lay members and its overarching aim is to ‘Provide regional leadership and strategic direction for public involvement in the West Midlands.’ PILAR’s three overarching aims are:

1. To encourage patients, the public, researchers and health care professionals **to realise the potential of public involvement** in research and innovation
2. To ensure that public involvement is **embedded in all stages** of research and the uptake of innovations from research into practice
3. To **share best practice** for public involvement across the region.

Engaging presentations from some of PILAR’s organisations showcased examples of the diverse and innovative ways patients and the public help to deliver better health research. Mary-Anne Darby from the Clinical Research Network (CRN) talked about the value of Patient Stories in raising awareness of research amongst the public. Adele Higginbottom (PPIE Projects Coordinator, Research Institute for Primary Care and Health Sciences, Keele University) and Steven Blackburn presented examples of how patients and the public have helped co-produce research and also implement research in clinical practice. Keith Elder, lay advisor from West Midlands Collaborations for Leadership in Applied Health Research and Care (CLAHRC WM) spoke about the involvement of younger people in mental health research. Finally, Eric Deeson (PPI Panel Chair) spoke about his experience of developing clear participant information sheets for research at the NIHR Birmingham Liver Biomedical Research Unit.

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Effective public involvement is not an absolute. We can always improve and find better ways of working. Enthused by the ways in which public involvement is already being done effectively in the West Midlands and building on the work already achieved, attendees took part in an interactive session exploring how researchers and patients and the public in the West Midlands could work better together in three main areas:

- best practice and meaningful involvement of public members in research
- effective two-way communication
- involvement of different members of the community (diversity).

Within each theme, delegates discussed 1) what does good public involvement look like, 2) future possibilities, 3) challenges and 4) Solutions/actions.

In total, 176 ideas and comments from attendees were expressed. Whilst PILAR has helped to shape and develop public involvement in the West Midlands, there is still much work to be achieved. Key aims to be achieved as PILAR developed included: **better communication** through local, regional and national campaigns and sharing best practice through an online resource; **promoting diversity** through creation of diversity champions and the promotion of diversity awareness; **sharing good practice** through joint organisational training in a variety of formats.

The key priority areas for PILAR moving forward chime with INVOLVE's five year aims to develop communities and partnerships, increase diversity and inclusion in public involvement and enhance learning and development opportunities for researchers and patients and the public. Although these aims are ambitious, surely organisations are best placed to tackle these challenges with the support of others. PILAR believes that organisations really are 'better together' and with mutual support and encouragement, we believe that we can help ensure public involvement continues to deliver health better quality health research, which in turn, delivers better care to patients.

HRA website has new patient and public pages

The Health Research Authority (HRA) has launched **new patient and public pages** on its website. The pages will be of interest to patients, service users, carers and members of the public who will find information on the research regulated and approved by the HRA, public involvement in research and how to become involved with the HRA's work.



The new pages have been developed by the HRA and 6 Public Contributors on its HRA Public Involvement Network who helped write the content, design the layout and feature in the videos made with them. You can access the pages by **clicking here** and please feel free to share the link with friends, family and colleagues.

This year, the HRA public involvement team is leading an ambitious programme of work to support and enable the spread of public involvement in research. As part of this work they will be looking at ways they can improve guidance and the information they ask applicants to provide on how they have involved the public in their research.

The HRA team are planning to work collaboratively with the research community to inform and shape this programme and will be developing opportunities for you to share your views to help determine how they take this work forward.

If you would like to talk to the team about their work on public involvement, please contact the HRA public involvement team via: hrapublicinvolvement@nhs.net or 020 7972 2545.

INVOLVE Coordinating Centre News



We are delighted to welcome Laura Young to the INVOLVE Coordinating Centre team. Laura is providing support and assistance to the Office Coordinator & Director's PA organising meetings and travel and to the Knowledge and Communications Manager editing and updating the INVOLVE and NIHR websites, and producing newsletters. Laura is a talented graphic designer, and she has also been refreshing and rebranding existing publications and creating infographics.

Co-production: Old wine in new bottles or vintage PPI?

Introduction

Co-production is a concept which has been used to describe a partnership between public and service providers as they jointly design and/or improve health and social care services.

For some the principles of co-production offers the opportunity to evolve and improve PPI in research. With its emphasis on equity of power in the relationship, and the blurring of boundaries between professional and public/patient, it may be vintage PPI. For others, however, it is just old wine in new bottles. A new word to describe collaboration.

This article reports on the outcomes from a round table event, attended by public and NIHR staff to explore various views, thoughts and opinions on the question of 'what is co-production in research?' The round table event forms part of a wider project.

The project

INVOLVE is leading on a project to identify how the discourse, elements and principles of co-production could be used to evolve and improve patient and public involvement in research.

This project has four phases. This round table event is part of phase 1. Phase 1 is about identifying learning points from co-production; the emphasis in this phase is on ensuring conceptual clarity between the discourses of co-production and PPI in research. The focus of phase 2 is on testing the application of these learning points in practice. Phase 3 will be about the implementation of these learning points across the NIHR. And phase 4 will be an evaluation of the project.

Capturing the 'essence' of co-production

Below are nine draft statements, which emerged from the round table discussion, and which are the beginnings of an attempt to capture the 'essence of co-production in research'. The statements are in no way an 'official' position on co-production – indeed, as the project progresses the statements are likely to be refined, lost and/or added to.

1. Co-production is more than 'good' collaboration

Co-production has a richer and more descriptive vocabulary than that associated with collaboration and consultation - and this provides us with an opportunity to evolve and improve public and patient involvement in research. At its heart some may say co-production of knowledge for practice represents one of the most powerful forms of involvement.

2. Co-production is about 'equality of power' between those involved in a research project

In collaboration it is often the researchers who determine when a member of the public should be involved. And usually this means at particular stages when the researchers think it relevant. It follows that in collaboration, and indeed consultation, the power still lies with the researcher. Co-produced research provides an opportunity to redress that power imbalance.

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3. Co-production is about 'joint ownership of key decisions'

Co-production does not require that all people are involved in every aspect/decision of the research. But it does require 'joint ownership of key decisions'. So co-production would involve a joint decision on who should be involved at any given stage or any given decision – it is not for the researchers to solely determine.

4. Co-production involves the public being involved at an early stage of a research project

Co-produced research is a joint venture. If there is to be joint ownership of a project then it follows that members of the public, ideally, need to be involved at an early stage of a project - not invited in to give views once a proposal has been developed but to be 'around the table' at the beginning, helping to design and shape the project. And it should not be forgotten that research ideas can originate from members of the public.

5. Co-production involves creating a 'level playing field'; it requires investment in, and cultivation of, public members

Creating a 'level playing field', so that all actors can contribute, will usually require an investment in and cultivation of public members. Patients/public need to be supported and enabled to contribute.

Sometimes this will be beyond the means of a single research project. For co-production to occur then it is likely that research organisations need the appropriate architecture in place in terms of the culture on the one hand and processes and procedures on the other that will underpin co-production. The processes in place to support people and enable them to get involved might include training and payment processes. The culture requires that the knowledge and assets of all people in the team are respected and valued.

6. Co-production is not just about patients and the public – it includes all members of the team

Co-production involves the inclusion of all the relevant stakeholders/agencies involved in a piece of research.

7. Co-production is about respecting and valuing the knowledge and assets of all those involved.

If there is to be a level playing field, in terms of the power relationship, it follows that the different knowledge bases and perspectives of all those involved in a co-production team must be given equal respect and value.

8. The processes and culture must support and enable all stakeholders to be involved.

Co-produced research should be proactive in promoting diversity and inclusion. The processes and procedures used in a research project must facilitate the involvement of different stakeholders.

9. Co-production involves all members of the research team taking ownership of the production of knowledge

The interpretation of findings and knowledge however is usually developed by the researchers. Co-production, as well as involving patients/public in the research process, also involves patients/public in the development of knowledge.

What next?

Colleagues from the RDSs in London and East of England will be looking at literature and interviewing researchers and public involved in co-produced research to develop further the key elements/principles of co-production in research. If you have any comments or would like further information please contact: Gary Hickey. Email: gary.hickey@nihr.ac.uk

Roundtable attendees: Gary Hickey, Senior Public Involvement Manager (SPIM), NIHR INVOLVE; Doreen Tembo, Senior Research Manager (PI) NIHR NETSCC; Prof Gill Green, Director RDS East of England; Kate Sonpal, SPIM, NIHR INVOLVE; Dr Sophie Staniszewska, RCN Research Institute, University of Warwick; Dr Kati Turner, researcher Population Health Research Centre, St George's, University of London; Katalin Torok, PPI Senior Programme Manager, NIHR Central Commissioning Facility.

Additional contributors: Sharmila Soekhoe, Senior Programme Manager, NIHR Trainees Coordinating Centre; Tina Coldham, NIHR INVOLVE Advisory Group public member.

NIHR Voices Event 2016

The second NIHR Voices event took place at Weetwood Hotel, Leeds on 10th November 2016. The Voices project is supported by INVOLVE, the Yorkshire and Humber Improvement Academy (AHSN) and NIHR Voices.

The topic of the day was the importance of diversity and inclusion in the future of Public Involvement.

Simon Denegri, the NIHR National Director for Patients and the Public and Chair of INVOLVE opened the event, which was attended by 62 people, with a presentation on the subject of Public Involvement in Research.



During the meeting the group worked together to gather the different perspectives and present them as poems to help shape future inclusion in public involvement.

The full report from the day will be in the NIHR PPI Newsletter - you can sign up to receive it and other information from the NIHR at www.nihr.ac.uk/sign-up

Involvement training for researchers Shared Learning Group on Involvement in Research Training Group

The Shared Learning Group on Involvement in Research brings together UK-based charities that are committed to patient and public involvement (PPI).



**Shared Learning Group
on Involvement**

An increasing number of our members are asking applicants to actively involve patients in the design, delivery and dissemination/implementation of their funded research. There is recognition, however, that the guidance we offer on how to do this was limited, and so we came together to jointly develop training for researchers about PPI.

In order to inform this training, and make it as useful and valuable to researchers as possible, we designed a survey to assess their PPI training needs; this was distributed to all those funded by our member charities. We received 494 responses, from researchers carrying out different types of research (from basic to applied health), at all stages of their careers and from many different disciplines.

Whilst many respondents rated their knowledge of PPI as high, more than half expressed an interest in accessing half-day or web-based training, and shared what they thought the training should cover. The respondents wanted help to develop a broad knowledge of PPI, but were particularly eager to understand the methods for involving people, and practical tips for planning PPI in a particular project.

We understand that this is the largest response to a survey about researchers' PPI training needs that has been collected, and believe this to be an invaluable resource for those looking to justify the need to develop involvement in research in their own organisation.

Developing the training

We brought together staff, researchers, patients and carers on a development day. We used the rich information that came from the survey to plan a half day, face-to-face training course, and to develop guiding principles to support it. This was held in November 2015 and was attended by 15 people.

During the day we:

- Discussed the results of the training needs survey and about the training that is currently available for researchers about PPI
- Developed messages and underpinning principles about how the training should be run. This included a requirement that the training should always be co-facilitated by a patient or carer
- Prioritised the topics that the training should cover and developed ideas for the structure and content of each session

Following the development day small teams co-produced a template, guidance notes, slides and resources for the half day training.

This is made up of six sessions:

1. An introduction
2. What is PPI in research?
3. How and when to involve people
4. Communicating well with people you involve
5. Planning involvement in your own research
6. Sources of further information and review

Each session is designed to be interactive and enjoyable as well as educational.

Piloting and refining

Arthritis Research UK piloted the training in May 2016, and we made small changes as a result of the feedback from the facilitators and the participants. A second pilot was undertaken by Parkinson's UK in June. Both pilots were very well received with participants rating the content as very useful and highly informative, and reporting an increase in their confidence for involving people in their future research.

A final version of all of the materials that are needed to run this training has now been developed and is being made freely available to Shared Learning Group members to use either alone or in partnership with other organisations. We are continuing to evaluate the effectiveness of the training as it is delivered by member organisations.

We believe that this project demonstrates the value of charities, patients, carers and researchers working together, and hope that it will encourage other organisations to collaborate to develop and offer training in the future. We are sharing our experience through INVOLVE's project on learning and development.

More information

If you would like to find out more about the PPI training or how to access training from specific funders, please contact Bec Hanley, Shared Learning Group Facilitator, bec.hanley@gmail.com

Isabelle Abbey-Vital, Becky Driscoll, Anna Grinbergs-Saull, Maureen Grossman, Bec Hanley, Chris Macdonald, Matt Murray, Matthew Sullivan, Eleanor Wheeler – for the Shared Learning Group on Involvement in Research Training Group

noticeboard

As this is our last Newsletter we would like to take this opportunity to thank all of our contributors and readers over the past 16 years. You can download and read all of our newsletters from our website <http://www.involve.nihr.ac.uk/news/involve-newsletters/>

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We are busy planning the next INVOLVE Conference, which will be held on 28 November 2017, at Church House, Westminster, London.

The 2017 Conference will be a one day event. It is our 10th Conference and is being held in our 21st year.

We will keep you informed through our dedicated conference page on our website <http://www.invo.org.uk/news-events/involve-conference/> and will be using the hashtag #INVOLVEat21 on Twitter for any tweets about the conference.



#twosides campaign

THE NIHR is launching a striking new campaign urging patients and the public to get actively involved in health and social care research which affects the lives of millions of people.

Featuring an iconic split face image, the #twosides campaign highlights ways for people who aren't medical or academic professionals to play an important part in shaping research and helping researchers and healthcare staff make life-changing differences.

We have commissioned three posters combining the faces of a diverse range of people in public and professional research roles.

Our campaign calls for people to make their voices heard by sharing their patient and carer experiences and their ideas for making a difference to the health and wellbeing of their families, friends, colleagues and communities.

The campaign webpage, www.nihr.ac.uk/twosides, will signpost people to opportunities to get involved with suggesting research topics, participating in studies, serving on study groups and ethics committees and providing comments on research applications.

Visitors can also download and print A4 and A3 or order free A2 versions of the posters to display in their community centres, schools, workplaces, GP surgeries, and other public places to spread the word.



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