

**Notes of the 77th meeting of INVOLVE
held at the
Kings Fund, 11-13 Cavendish Square,
London, W1G 0AN**

10th May 2018

Attendance

Group Members:

Sophie Ainsworth	Ngawai Moss
Eleni Chambers	Una Rennard
Tina Coldham (Chair)	Carol Rhodes
David Chandler	Ruth Richardson
Rosie Davies	Lesley Roberts
Robert Droy	Veronica Swallow
Jo Ellins	Jane Taylor
Joyce Fox	Janet Tonge
Cheryl Gowar	Amander Wellings
Tara Mistry	Patricia Wilson

Observers

Amy Burgess	Public Health England
Beth Allen	Department of Health
Gill Green	Research Design Service
Ian Cook	Health Research Authority

Staff team

Sarah Bayliss	Martin Lodemore
Stephanie Gallimore	Kate Sonpal
Sam Goold	Paula Wray
Zoe Gray	Gill Wren
Gary Hickey	

Apologies

Lynne Corner
Pete Fleischmann
Iain Mallett
Lizzie Thomas (lunch only)

1. **Introductions, welcome and apologies, declarations of conflicts of interest.**

Tina welcomed the new group members, and introductions were made by existing group members, observers and coordinating centre staff. Apologies were offered, as listed above.

No conflicts of interest were declared.

2. **Getting ready for Strategy delivery**

Zoe introduced the latest version of the Strategic Review Narrative, which has been shared prior to the meeting. This outlined the process and thinking that went into developing the emergent strategy which will form the basis for the INVOLVE work programme for the period until 2023.

Zoe recapped on how this had been developed, with its basis in the existing INVOLVE contract in partnership with the Research Design Service. The new INVOLVE contract had its roots from recommendations in the *Going the Extra Mile* review's report, published in 2015. The strategy consultation process had benefitted from input from more than 150 stakeholders, and included advice and guidance from the Department of Health, Social Care and Simon Denegri.

The emergent strategy now focuses on four statements of intended direction or strategic aims. Zoe presented each in turn, focusing on how these may be approached in the early stages, and the role that Advisory Group members might have in each.

Statement 1: INVOLVE will be the platform that enables others to lead for values-led, public-shaped involvement

This will place INVOLVE as the go-to place for public involvement, providing the frameworks which enable others to take increasing leadership and push the boundaries for public involvement. The National Leadership Areas will feed this.

The initial focus will be on the standards for public involvement, embedding these in contracts for NIHR infrastructure, and into practice for regional hubs and the public involvement workforce.

Advisory Group members can help by linking with regional and local public involvement leads, and supporting links to local communities. Members can also support this by helping to shape the work in National Leadership Areas.

Statement 2: INVOLVE will shape the future of involvement

This will see INVOLVE looking further ahead as to the issues or topics over the immediate horizon, and helping the system to prepare for them (turning

the tanker). INVOLVE will be the catalyst for change and improvement, pushing the boundaries of the areas for research linked to NIHR priorities, or in topics, for example as patient-led research. This could become a future National Leadership Area, needing some cultural and system changes.

The initial focus will be on information gathering, prioritisation and exploring new National Leadership Areas.

Advisory Group members can help by offering insights into current and future trends, and with contacts to relevant organisations or communities. One example was Lynne Corner, who is now a Director of [Voice](#) and lead for the NIHR Innovation Observatory in Newcastle.

Statement 3: INVOLVE will expand international and cross-sector leadership in partnership

This will see INVOLVE driving strategic partnerships and collaborations that develop public involvement practice, while enabling exploration and piloting of innovative models. This will also see greater awareness and use of existing resources.

The initial focus will be on building sustainability into the international network, also potentially a focus on global health. It will also see the frameworks that support public involvement being taken out more widely. There will also be some focus on exploring business development opportunities.

Advisory Group members can help by sharing ideas and contacts with groups or communities, and thoughts on business development opportunities that would help INVOLVE reach its strategic goals.

Statement 4: INVOLVE will invest in people, systems and intelligence for excellence and sustainability

This will see INVOLVE build on existing knowledge, skills and systems for Advisory Group members and the coordinating centre team. System improvements would not all be digitally focused, although improved digital platforms will have an increasingly important role in how we communicate. This would also see INVOLVE building on existing information pathways, such as improved use of the enquiries database.

The initial focus would be a review of the INVOLVE website, leadership development for the coordinating centre team and development for the Advisory Group members, and improvements in the way we understand and demonstrate value.

The new strategic aims were welcomed and members commented that the strategy was clear and it was evident that a lot of effort had gone into shaping it. Discussions then raised the following points:

- Calls for Advisory Group members' input need to be clear and focused, otherwise members may not see what they can contribute.
- The next document in this process should sharpen each area, with steps, outcomes and achievements.

- There was wide support for exploring patient-led research further, and INVOLVE driving new approaches and sharing good practice. Some expressed the need for this research to remain outside the current system, to ensure acceptability for some public members. It was thought this might be especially challenging for those working in Clinical Trials Units and similar organisations. Exploring any barriers (such as ethical acceptability, robustness of evidence and publishing), and collection of examples of service-user or survivor-led research, were considered good first steps. Also strong links with current co-applicants work.
- Some NIHR emphasis should be given to supporting PPI leads – it was recommended that INVOLVE makes clear what it would like them to be doing (given variation in organisational contexts).
- The website review was welcomed. Although existing website is great, a review would allow to add functionality, such as Google Translate, to support international networking.
- Will there be a communications strategy as part of this work? It would be vital to have clear communications about the work programme, and for this to be made available in formats to suit different audiences.

During the discussions, there was also a call for examples of public co-applicants' and user-led research experiences – to be sent to Amander, who is collecting these to include in guidance for public co-applicants (in development).

Gary reported that 28 examples of co-production have been collected, including some within clinical trials. These will be assessed and 10 included as case studies to accompany the co-production guidance document.

Ian mentioned that the Health Research Authority (HRA) receives around 6,000 applications through its Local Research Ethics Committees, and the PPI team at HRA are to look at how they might improve their use of the data collected, and the questions asked on the application form.

Paula led an exercise for members to identify and share their local, regional, national and international links, so that everyone can see the broad reach that the Advisory Group has. Patricia and Tara offered their own links to a broad range of healthcare, health and social care research and related communities. The members then completed tables or maps, which will be collated and shared with members in due course.

Action: Sam to share collated information with the Advisory Group.

3. Building on the INVOLVE RDS partnership and the role of the Advisory Group

Gill updated the group on the INVOLVE RDS partnership, including the role of the RDS and how the Advisory Group can support the partnership.

Questions asked were:

1. How can we build on relationships between RDS and the Advisory Group to strengthen the INVOLVE RDS partnership?
2. What is the potential for the RDS and the Advisory Group to work together to reach out and build relationships with a wider community.

Zoe introduced a pilot project the partnership are aiming to fund to enable PPI leads to work together regionally to reach out into communities. The anticipation is to run as a 12 month, two phased programme starting in the summer. There will be a key opportunity for Advisory Group members to link in and support.

After breaking out into smaller area groups the Advisory Group came back together to feedback:-

North West

- Lessons learnt from People In Research North West Forum, the timing provides an opportunity, although sometimes a challenge is the devolved Greater Manchester.
- Members of the Advisory Group from the North West were keen to have a meeting with the RDS leads in their area. This meeting could then be developed into a celebration event to see if a new network could be formed.
- News article mentioned Menopause Cafes, maybe think about Patient Involvement Cafes.

Action: Paula to arrange a meeting between North West RDS leads and AG members from that region

South West and Yorkshire and Humber

- We need to know who the Public Involvement leads in the region are and how to get in touch with them, INVOLVE could have a role to link people up.
- We talk about groups and charities but what about individuals – how do we link up with them? Also discussed support available and the question about follow through if you have ideas will they be taken forward?
- Discussions about Action Research and perhaps the need to focus on methodology rather than health theme. Concerned about 12 month time scale as need time to build relationships and for communities to work in their own way.

West Midlands

- Plan the relationship but it needs to have a clear purpose. It will be difficult to get people to attend more meetings without there being a purpose.
- An example shared was sandpit events (public, clinicians, and academics) that develop and prioritise research questions and then take them forward as a collective to apply for funding.
- Sustainability is key, need long term money rather than short term and consider succession planning.
- Currently in the region activities are very Birmingham focused.

- There also need to be benefits to patients and the public for being a part of the network.

South East

- Community engagement skills training would be a good first step.
- RDS Public Involvement Community group suggested joint meeting for the Advisory Group members and the RDS public involvement teams and this meeting could include this type of training.

East of England

- The option of mapping condition groups and looking at multi/co-morbidities and public health was discussed to try to have a focus and reflect local population demographics, and avoid usual suspects.
- People need to consider language and approaches for communication as these need to be appropriate, also need to consider training for communities to demystify research.

London

- Charities and organisations are already doing work and connecting in to public health and NHS England so RDS could support as this is often not happening in clinical research.
- How do you expand/validate what is already there?
- It was noted that most marginalised groups self-commission provisions.

South Central

- Learning from social care and others.
- Build on relationships – Wessex PIN – opportunity north of the region (Oxfordshire), how can we improve? Una can make a link.
- It is positive we can develop existing relationships and locations. Currently running a project monitoring diversity, where they are reaching and how representative they are, using demographic data and having regular meetings.
- Co-production – exposure to new public involvement representatives and invite them to be involved in other areas.
- Use the model of working with people in social care and move it into the medical field. This will help access and understand the communities and feed this into research opportunities.
- Consider how we use language that inadvertently turns people off as the first impression is critical?

The Advisory group gave permission for their contact details to be shared with the RDS Public Involvement Leads and there will hopefully be a joint meeting of the Advisory Group and RDS in the future to incorporate some community engagement skills development.

Action: Share slides, share contact details with RDS and look to potentially have a joint meeting to develop community engagement skills.

4 Preparing for the next Advisory Group meeting

Tina thanked everybody for their contributions and took the opportunity to introduce Beth Allen to the new group members. Beth thanked the group for all their work and said that she really appreciates the opportunity to attend the meetings and hear about opportunities, problems and challenges that members are facing.

Eleni requested that future meetings are made more interactive and less presentation based.

Gill Wren explained to new members that there are 5 NIHR newsletters available to sign up for. She said that the next public involvement newsletter was due on 28th May and if people wanted to receive any of the newsletters they can sign up via NIHR website <https://www.nihr.ac.uk/news-and-events/mailling-list-sign-up/>. Gill explained that Tina would also forward Simon Denegri's newsletter to the group unless they inform her that they do not want to receive it.

Actions:

Kate to send out photographic consent forms to new members.

Kate to email Advisory members who are leaving to invite them to join the Associate group.

Tina to forward Simon Denegri's newsletter to group, unless they decline this offer.

Zoë to send out the final formatted strategy with a document outlining ways it will work before the next meeting.

Team to discuss what projects need new Advisory Group members on, and what opportunities may be coming up in the future.

Gill Wren to send out email to all members about how to use forum.

Members to send an update to INVOLVE CC with an account of their public involvement activities before every meeting.

Tina, Kate and Una to develop questions to frame members activities so people have guidance on what to write.

Date of next meeting

13th November 2018 – Kings Fund, London