

**Notes of the 76th meeting of INVOLVE
held at the
Kings Fund, 11-13 Cavendish Square,
London, W1G 0AN**

17th October 2017

Attendance

Group Members:

David Chandler
Lynne Corner
Rosie Davies
Simon Denegri
Jo Ellins
Joyce Fox
Tara Mistry

Una Rennard
Lesley Roberts
Veronica Swallow
Lizzie Thomas
Amander Wellings
Patricia Wilson

Observers

Elizabeth Coates
Beth Allen
Iain Mallett
Gill Green
Ngawai Moss

Public Health England
Department of Health
Clinical Research Network
Research Design Service

Presenting

Mike Clark

NIHR School for Social Care
Research.

Staff team

Sarah Bayliss
Stephanie Gallimore
Sam Goold
Zoe Gray
Gary Hickey

Martin Lodemore
Kate Sonpal
Paula Wray
Gill Wren

Apologies

Tina Coldham
Eleni Chambers
Ian Cook
Pete Fleischmann
Samaira Khan
Carol Rhodes

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

Zoë opened the meeting and asked first time observers Ngawai Moss and Iain Mallett plus Sam Goold and Stephanie Gallimore recently appointed staff of the INVOLVE Coordinating Centre to introduce themselves.

Apologies were given by Tina Coldham, Eleni Chambers, Pete Fleischmann, Samaira Khan, Carol Rhodes and Ian Cook.

The Group marked Simon's last Advisory Group meeting as Chair of INVOLVE with presentation of a card and gift, recognising the huge contribution he had made to the work of INVOLVE and the Advisory Group over the past 6 years.

No conflicts of interest were declared.

2. Health Futures: Overview, Exercise, Next Steps

Simon updated the Group on the recently published 'Future of Health' report, commissioned by NIHR and published by the RAND Corporation. This had gathered opinions on what health and healthcare might look like in 20-30 years' time. The consultation process reached out to a range of stakeholders, and there were almost 300 responses from individuals and organisations.

Simon outlined the key themes arising from the report including: the need for closer integration between health and social care services; inequalities in the way people can access services will need to be addressed; the use of technology to support self-management; the growth in older people in the population and; global challenges such as anti-microbial resistance (AMR). The report also highlighted the increasing importance of public involvement in research and the need to address the 'representativeness' of current approaches to involvement.

Since publication, Simon had received feedback that highlighted some of the report's contradictions and weaknesses, including the limited number and breadth of responses, in particular from the public.

During discussion, it was felt that the report seemed to represent the 'experts' voice'. The question of 'representativeness' worried some, although others felt that it may have been the report's attempt to address diversity and inclusion. Others felt that the report held 'nothing new' and was thin on outcomes. Some considered it needed to do more to increase understanding of topics, such as multi-morbidities, and the integration of care services.

There were concerns about the degree of focus on self-management, and not enough on what might be required to support self-management beyond using 'technology', which may not be appropriate support for many.

Simon outlined the next steps for the report. This included a meeting of the NIHR Leadership Academy and a discussion at the NIHR Strategy Board. In addition, there will be a lay review, and possibly a follow-up workshop to determine where the focus of future public involvement work should be placed.

3. INVOLVE Strategic Direction 2018-2022

Zoe reported that INVOLVE had set out on a strategic review process at the beginning of 2017, having already made some significant changes in its focus and functioning during the tender and contract transition period (2015/16). The review period involved a series of steps, starting with a review of INVOLVE'S Vision and Mission alongside understanding the impact of the environment around us and looking at how future changes might impact upon our work.

Zoe explained that the review looked at which stakeholders are important to us and why, what this means for future interaction with them, as well as INVOLVE's strengths and challenges as an organisation. It examined, through an external survey (including many responses from INVOLVE Group members and Associates), what our stakeholders or potential stakeholders think about what we are doing and what we should be doing in the future. The Advisory Group and Executive Groups played a vital role in developing the strategy and will continue to do so.

Zoe advised that in the intervening period, there have been a number of other developments at the Department of Health/NIHR which are relevant to our strategy and have had to be taken account of in both the timeframe for planning as well as the content of strategy. These include the triennial review of the Office for the National Director of Patients and Public and the launch of the 'Future of Health' consultation (the outcome of which is viewed as being important to NIHR future strategy).

She reported that the Department of Health must agree the new INVOLVE strategy, ensuring it is in line with NIHR strategy and the provisions of the INVOLVE contract (which were accepted through the procurement process). The development milestones for the strategy have therefore been affected, though the strategy is still on course to be ready in advance of the next contract year (with indications of direction agreed by the end November).

Zoe explained that from the Executive and Advisory Group input during meetings in May, she worked with the survey responses report & individual responses as well as the recommendations of the Groups to distil key themes arising. The INVOLVE team met to analyse these and consider the drivers for or against them, taking into account INVOLVE's position in relation to the environmental/stakeholder analyses previously done.

She advised that from this work, some statements were formed to frame the INVOLVE strategy over the next 5 years. These have been discussed briefly

with our Contract Manager at the Department of Health and have had positive feedback, subject to fuller discussions.

Zoe reported that the five statements which are detailed below may be tweaked in the final revision. INVOLVE Group Members and Observers were split into four groups and each group was facilitated by one of the four INVOLVE Senior Public Involvement Managers: Martin Lodemore, Paula Wray, Kate Sonpal and Gary Hickey.

Each group was asked to use their knowledge and expertise to answer the following question in relation to two of the statements listed below '*What difference would you like this strategy to make over the next 5 years?*'

The responses were collated as follows:

Statement 1

INVOLVE will drive the values and principles that underpin diverse and inclusive involvement; developing partnerships and ways of working which put the public in the driving seat.

- Standards are embedded in research practice (through levels/organisations/projects).
- All research has early involvement, including input into research prioritisations, question development and design.
- For research funders: no involvement = no funding - public priorities for research are being systematically identified and funded – in a system with funding streams that address public priorities.
- Public priorities are being facilitated and refined effectively (and developed in the “right” language).
- Effective methods in the system to bridge the ‘gap’ so that more diverse groups can access and influence the system.

Statement 2

INVOLVE will be an influencing organisation.

- We would have influenced the system / wider NIHR to effectively monitor and assess involvement.
- We have influence beyond NIHR to adopt and implement involvement standards e.g. charitable sector.
- Increased public influence in NIHR and external funding streams.
- Local and regional influence in the NIHR system.
- Developed collaborations with, and learning from, others working in public engagement (non-healthcare), and other research disciplines – links to charities may help.
- Influencing – embedding PPI across organisations. Front and centre. (Key point).

- In 5 years' time public involvement in research should be an integrated part of health and social care. Part of Future Health and the commissioning world.
- A report like the Future Health would have patient and public voice front and centre.
- Research should be part of the national strategic priority.
- INVOLVE should look to broadening its networks and extending its reach.
- INVOLVE should share methodologies for working together.
- Aim should be for equal power of the public alongside professionals and commissioner.

Statement 3

INVOLVE will develop national and international partnerships and collaborations to help the NIHR meet strategic priorities

- Share high quality collaboratively produced documents on good practice.
- Acceptance that what public involvement has to offer can make a difference.
- Mechanisms for holding NIHR and its resource to account – 'proving'.
- Standards become regulators (stick and carrot).
- National/International – There should be far more national and international 'synergy'.
- Bringing it all together with examples into a 'pot' i.e. INVOLVE to act as a catalyst and 'pot holding' bringing together and sharing learning.
- International partnerships. Examples of funding were shared, where they are mutually beneficial there is no pay and where it is one way, such as consultancy, they may have to pay. INVOLVE should do the mutual work but there is an opportunity for consultancy.
- Partnerships is the key word – where things are mutually beneficial. Don't take time out of the day job to make money.

Statement 4

INVOLVE will focus on shaping the future of involvement

- Stronger links with health and social care provider organisations i.e. NHS centred 'doers'.
- More prominent voice shaping the debate about the future of involvement.
- Demystifying research – everything is accessible, plain English etc. and relevant 'bench to bedside' – the plain research movement. People like you can get involved in research so you can get the outcomes you need. *Being able to explain what we do* Keep it simple.
- Crowd funded research tool / portal debate - James Lind Alliance (JLA) style.

- Community-based models to facilitate priority setting - help make it happen take to the next level.
- Collaboration credibility
 - Coproduction and training for professionals and researchers
 - And patients to feedback to their community / empower dissemination.
- Partnerships established NCA / CVS - both national and international.
- Recognise that diversity of involvement e.g. BME
- INVOLVE could ensure that standards are adhered too. Similar to BSI Standards / INVOLVE could audit standards via Audit template like QH9001 – respected across industry (NB a previous advisory group meeting warned against becoming a regulator). Alternatively they could seek to influence what others are collecting, auditing and monitoring.

Statement 5

INVOLVE will invest in its own systems, intelligence and capabilities for patient and public centeredness & voice, efficient delivery and long term future

- Collaboration aids sustainability – demonstrate value for money. INVOLVE end result:
- Leadership – regulate and auditors. Standard achievement would guarantee funding for research
- Share knowledge
- Income generation / self-funding provide training, consultancy expertise – culture building.
- Measure impact, provide leadership, and develop frameworks.

Zoe explained that this discussion would help her, with members of the Executive Group, to further consider implications of the strategy and refine it, as well as to inform the first-year annual business planning

In the afternoon session the same groups came together to discuss '*What would you see your role - and that of Associates - as being in making this strategy happen (think about the skills, knowledge and networks that you have)*'? The skills, knowledge and networks information was captured and will inform how everyone can best work together to help implement the strategy.

Zoe reported that a strategy document would be produced in two parts, before the end of the contract year (February 2018). The first part - an internal document - would contextualise the strategy by describing the process of review, who has been involved, summary of inputs which informed it etc. The second part would be diagrammatic/picture based - a maximum of a few pages - to illustrate the strategic framework, which is designed to be accessible to all.

She explained that once the strategic framework had been signed off, it would provide the basis for annual business planning via the contractual process with the Department, of which the Executive Group has oversight. Annual Plans

would show the specific objectives and actions that contribute to strategy in that year.

4 Public Involvement in Social Care Research; Presentation and discussion

Mike Clark from the National Institute of Health Research School for Social Care Research gave a presentation about the role of social care in response to requests from the Advisory group members to understand more how INVOLVE can support this area of work. The presentation covered the range of social care activities, the published and ongoing research in this area and the identified gaps, the slides are attached for information.

Mike mentioned the forthcoming School of Social Care Research conference in March 2018 and suggested that group members sign up to the newsletter (<http://www.sscr.nihr.ac.uk/sscr-newsletter/>) to receive more information on this free conference as it is made available.

A James Lind Alliance Priority Setting Partnership has just been launched on Adult Social Work and Mike requested that the group raise awareness of this and if relevant can contribute to this. They are particularly keen to get this out to communities and community groups. More information can be found [here](#).

The Journal of Long-Term Care was due to be launched at the end of the month. It is peer reviewed and will be open access. (Journal.of.Long-Term.Care@lse.ac.uk)

The group asked Mike the following questions:

- 1) How do representatives of Social Care link in with the School to help inform their role on funding panels like Policy Research?

Answer: Mike was happy for anyone wishing to link in to the school or to know more to contact him.

- 2) How does the school interact with Social Care Institute for Excellence (SCIE)?

Answer: SCIE are members of the advisory board and many of the school's funded projects engage with SCIE.

- 3) Are all funds allocated to member organisations?

Answer: No two thirds of the budget is allocated to the members but the remaining third is allocated through open calls as this was seen as a great opportunity to get external ideas and build capacity in social care research.

- 4) What do you fund in terms of evaluation?

Answer: Capacity is the main issue here, local authorities do not have much flexibility to commission this themselves and funders like NIHR are unlikely to fund local evaluation projects. The school has encouraged people to bid for external evaluation of innovations through the open calls but there was no interest. There is an issue of resources,

connections between academics and local social services, what needs evaluation and who can do it. Social care does not always value evaluation as do not fully understand the scope. There is a need to encourage a culture where evaluation is valued and there are more robust ideas for studies. NIHR are encouraging more applications around social care research but need more panel members and peer reviewers with an understanding of the complexity of social care.

- 5) Why did the college of social workers cease to exist after three years?

Answer: Essentially there was not a way to make a sustainable business case for the college.

- 6) How many social workers are there?

Answer: Skills for Care survey the social care workforce, which may be able to assess the size of the work force.

Finally, Mike stated that the Department of Health appointed Lyn Romeo as the Chief Social Worker for Adults, which is a real step forward as on an equal footing to health.

Action: Sarah to send out a copy of the presentation with the minutes

Action: All to share information on the Priority Setting Partnership for Adult Social Work
