INVOLVE

NHS
National Institute for Health Research

Notes of the 75th meeting of INVOLVE held at the Kings Fund, 11-13 Cavendish Square, London, W1G 0AN

Wednesday 3rd May 2017

Attendance		
Group Members:	Eleni Chambers	Una Rennard
	David Chandler	Carol Rhodes
	Lynne Corner	Lesley Roberts
	Rosie Davies	Veronica Swallow
	Jo Ellins	Lizzie Thomas
	Joyce Fox	Amander Wellings
	Tara Mistry	Patricia Wilson
Observers	Margaret Mauchline	Public Health England
	Ian Cook	Health Research Authority
	Beth Allen	Department of Health
	Jenny Preston	Clinical Research Network
	Wendy Baird	Research Design Service
	Saumu Lwembe	Central Commissioning Facility
Presenting	Alessandra Gaeta	NIHR Office for Clinical Research Infrastructure
Staff team	Sarah Bayliss	Kate Sonpal
	Zoe Gray (Chair)	Paula Wray
	Gary Hickey	Gill Wren
	Samaira Khan	Laura Young
	Martin Lodemore	
Apologies	Deborah Bhatti	
	Tina Coldham	
	Simon Denegri	
	Pete Fleischmann	

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

Zoe welcomed the new Advisory Group members Eleni, David and Joyce. No conflicts of interest were declared.

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2. High level NIHR PPI/INVOLVE update (including Chair role & Exec Group recruitment process)

Zoe updated the group on the following:
There have been a lot of recent developments including significant changes of staff at Department of Health. Chris Whitty has now been in his job for a year and together with Louise Wood is beginning to communicate what they need to focus on.

Beth Allen outlined what herself and Mark Toal are in charge of which is: contractual arrangements; financing for NIHR; information systems and data systems and regulations. Beth also covers public involvement, engagement and research impact. There is a project starting this year looking at NIHR impact.

Zoe outlined the future direction for NIHR. Chris Whitty and Louise Wood sent out a letter earlier in the year outlining where they see the NIHR's medium term direction. Zoe was pleased to see that a commitment to public and patient involvement was outlined very early on in the letter. The key points in the letter are:

- Commitment to/support for public and patient involvement and engagement
- Research with and in the populations most affected
- Simplification: Fewer, wider schemes
- Training review – dovetail other funders
- Address the gap between scale of ambition and scale of need in public health, primary care, social care
- Life sciences, industry relationship (industrial strategy/post Brexit importance)

Beth gave a brief update on Brexit and the key areas that the Department of Health will be taking the lead on:

- Work force supply, with particular focus on social care
- Reciprocal health care
- Health protection and public health
- Medicine regulation, life sciences and research

Zoe stated that there is now a need to focus on demonstrating impact of NIHR. It has always been in a good position and protected. However, there is uncertainty about whether this will be affected by Brexit. Therefore, there is a clear need to demonstrate impact, and get the right messages to the right people. Zoe and Beth are in discussions about how INVOLVE and the

Advisory Group can engage with this impact project. There is now more joined up working amongst all the Coordinating Centres. The Centre Directors have met and are looking at new strategic plans and implementation which they will bring to the Strategy Board.

The Coordinating Centres are currently working together to develop a new communications strategy. A recent survey was undertaken on people's perceptions of NIHR. This has led to observations being made that will inform future communications strategy. A new Communications Director is to be appointed to lead this process. This appointment is likely to be made at the end of the year.

The Standard Application Form (SAF) is in the process of being changed. Chris Whitty heard feedback that the current SAF was not helpful when he first arrived at NIHR over a year ago: a lot of duplication and a need for it to be simplified.

A Core Action Group (CAG) was established prior to the new INVOLVE team establishment and is led by NETSCC, with Programme Directors of the main NIHR research programmes. Rigid Terms of Reference, principles and membership was considered to be required to lead the project forwards and change stage 1 and 2 of the form. The group has reached out to ask questions as needed. This tight group has allowed for rapid progress and focused reduction in duplication. Voices of the public and wider research communities were not integrated from the start of the process.

Inclusion of PPI in the SAF was a hard won agreement in the past which is considered to have made a huge impact on driving public involvement across NIHR research funding. Changing/simplifying the SAF forms could have unintended consequences for how PPI is considered, represented and valued as part of research funding applications.

Zoe therefore influenced CAG agreement to take information and advice from the INVOLVE perspective, which has been considered as part of the group's decision making on stage 1 and 2 of the form. Zoe advocated with CAG for how and why it would have been more effective to have gathered wider public insights, including drawing upon the expertise of the INVOLVE Advisory Group, from the beginning. Zoe was clear that the process has not allowed for involvement in the way that INVOLVE would recommend; it has not been ideal. It is, however, reassuring that advice from INVOLVE (through both Zoe and Simon) as the national advisory body for PPI have been taken on board. For example:

- Strengthening of the wording about the NIHR expectation of public involvement
- Emphasis on following INVOLVE guidance and linking directly within forms to many of our pieces of advice
- Retaining a dedicated section for public involvement in the stage 2 form
- Getting agreement from CAG that there should be public involvement in deciding the evaluation questions to look at to determine any impact on public involvement of the change, and that the questions should be

asked of PPI members and reviewers after every round. INVOLVE to receive the data from programmes and reflect issues back to the CAG.

The CAG group took the decision that stage 1 would consist of one shorter general research plan, without separate individual sections. Aspects such as public involvement, clinical trials unit support, intellectual property etc would be expected to be threaded by the applicant throughout their description of the research plan.

At stage 2, the separate sections (including questions on public involvement) have been retained. In addition, in stage 2, researchers are expected to thread public involvement throughout the detailed research plan.

Following CAG's agreement to INVOLVE's recommendation for public involvement to determine the SAF PPI evaluation questions, Simon's office with Zoe's support has convened a meeting of public reviewer/board members on the 22nd May (note: Zoe said she thought it was the 25th May in the meeting). The PPI Senior Leadership Team (SLT) public members were expected to be invited alongside lay members of other programmes (NETS/CCF) and another INVOLVE advisory group member (in addition to Una who is also on the PPI SLT).

This group would determine what public involvement evaluation questions should be asked after each panel meeting. If feedback was revealing major issues for PPI, there would be the opportunity to influence CAG to make changes to the form earlier than the full implementation cycle of two stages across all programmes.

Two Advisory Group members showed interest in attending. Amander queried why it should only be one other public member alongside Una.

Action: Zoe to speak to Simon and see if it is possible for Una, and two other Advisory Group members to attend.

Lesley was unhappy about late involvement of the public and concerned that bad public involvement will still occur, for example, like now conditional funding granted on the condition that the public involvement is improved, but no monitoring of this. Zoe said that she had been heartened by hearing a programme manager say that research **will** be thrown out if there is bad public involvement, but we would see what happened in practice.

Eleni said that NETS PPI reference group have been involved in the changes in the SAF. Zoe said that she was informed afterwards that it was discussed at the NETSCC PPI reference group meeting, and confirmed that this was not considered by NETS to be a consultation. Zoe made colleagues at NETS aware that she felt the opportunity to discuss this should have been broader than the NETS reference group.

Amander explained that she had experience of being a public reviewer. Often only five key points are fed back to the researcher. The point on public involvement is often the sixth point and therefore not fed back to

researcher. There should be feedback on public involvement on every application.

Jo stated that annual reports on studies don't often include public involvement, therefore, why not have an annual PPI review? Gary agreed there is a clear role for monitoring of these processes and wondered whether INVOLVE might support this in some way.

Ian updated that the HRA are working on questions on their ethics application form. The old questions showed lack of understanding of public involvement from researchers. Therefore they are changing the questions. He said this should be linked in with the SAF questions so that their questions are not completely different. He feels that the applications should demonstrate how the public involvement is going to have an impact, and not just be a narrative of how they are going to do it. Zoe said she would convey these points in her discussions.

Going the Extra Mile (GtEM) update (Zoe Gray)
Implementation of GtEM is being led by Simon across involvement, participation and engagement, but INVOLVE is taking a key role in delivering this, particularly with the three national leadership areas.

The key priorities for a three year period, and which Centre should lead on which priority will be decided on the Senior Leadership Team summer away day, and will result in an 'operational plan'. CCF are already designing a project to monitor impact (reach, relevance and refinement etc).

Wendy highlighted that we need to look across NIHR and stop the duplication of effort. Zoe offered reassurance and stated that the SLT has a focus on ensuring that the right people are leading on the right things.

Rosie Davies expressed her concern that she is unsure about what the CLAHRCs' response is in relation to GtEM, and also that there is not a joined up process across them. Zoe said that Simon Denegri is receiving information from the CLAHRC's.

GtEM (draft) rosette was discussed. Feedback included:

- Difficult to understand.
- Not useful to explain GtEM to new people or as a communication tool
- Needs to be stripped back to illustrate why people get involved in the first place and include collaboration and implementation of research. A linear graph may represent this better, and could be used as a complimentary diagram.
- Uncertainty as to why the Centres are in diagram and size of the blocks.
- Impact is missing from work programmes.
- Need to incorporate the patient voice as well as the Corporate.
- Additional work needed on what impacts are going to be looked at and how they fit in with the recommendations.

Regional networks update (Gary Hickey)
Gary explained that INVOLVE have undertaken a review of its regional networking with the RDS. Benefits included:

- Support for new and existing networks
- Support for local events
- Support national projects
- Greater promotion of local initiatives
- Potential to be a vehicle for wider NIHR projects e.g.) People are Messy.

However, what has become clear is that you can't run partnership like it is a project. It is more of a development of an ongoing relationship, and therefore it is part of our core work, like enquiries. A quarterly update has been developed in response to lack of knowledge and communication on events. There may be a RDS partnership workshop for future development organised in the future.

Amander expressed concern that there was a lack of clarity on general invitations from organisations regionally about payment and reimbursement. Gary explained that INVOLVE don't have control over external events, but that the team do try and get these issues clarified when sending out invitations on behalf of other organisations. NIHR is so big that it would be difficult to keep everything coordinated. It is good that there is not a one size fits all approach also as this allows for innovation. Gary also explained that there is an NIHR calendar of events. Public Involvement Leads need to keep it updated. Gary agreed that he would champion the use of it via the Communications Programme Board, and INVOLVE will also signpost people to it.

Learning and Development Update (Martin Lodemore)
A learning and development project group has been established which shows that more cohesion and less duplication is needed. The group will provide support for the public, researchers and public involvement leads. Six subgroups have been set up which will provide support for public, researcher and public involvement leads. The six subgroups are:

- Access
- Diversity
- Top tips,
- Inductions
- Learning needs
- Websites.

Conference Update (Kate Sonpal)
Advisory Group members were encouraged to register for the conference if not done so already. Anne McKenzie has agreed to speak at the opening plenary session. She will cover how INVOLVE has helped shape public involvement in Australia, and the particular difficulties that they face, for example, engaging with particularly remote communities.136 abstracts have been received. SPIMS, Advisory Group members and Associate members are reviewing them with the final decision being made at a meeting on 22nd May.

The standards will not be ready to be launched at the conference, rather it will be an opportunity for them to be actively developed. Kate thanked the conference planning group for all their help so far.

INVOLVE Ambassador Role
Zoe explained the new INVOLVE Ambassador Role to the group and the role description was circulated for comment. This is a new role and in line with the Department of Health requirements and the new contract. The feedback was that:

- Extremely important for the individual to have influence and gravitas
- Need clear explanation of payment
- Keep the title as Chair rather than Ambassador
- Change “reporting to” to “accountable to” the Advisory Group
- Simplify the role description
- Emphasise knowledge of the system and NIHR
- Retain focus on influence but make clear how this will be different to the role of Director and Simon
- Emphasise the role of helping Executive Group/Advisory Group/Coordinating Centre link cohesively and communicate amongst the different parts

Executive Group Recruitment
There are two places that will become available on the Executive Group in the summer. The Executive Group recruitment process was outlined by Lesley, and it was emphasized that the new Advisory Group members could apply.

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3. Introduction to the INVOLVE group members forum

Laura and Gill explained that at the last group meeting a request was made to create an area where group members could have closed discussions as well as somewhere they could post events in their local area, news items and ideas that might be of interest to others in the group. It was explained that Advisory Group members who weren’t already registered would need to register if they wanted to join the forum.

It was agreed that alerts for information going on the forum would be sent out via email so members knew that information was going on the forum. Responses back to the Coordinating Centre about content on the forum would need to come back to the centre via email, as Gill and Laura would only be monitoring lightly for appropriate content etc.

ACTION: Advisory members to email the CC if they would like to be registered for the forum.

4 Future Health Consultation

Zoe shared the invitation from Chris Whitty and Louise Wood for input into a consultation on ‘health futures’, looking forward 20 years. This would take the pulse on which areas science may be exceeding needs, and which are considered areas where science is falling short of needs. This could influence future NIHR strategy.

The Group fed back that the letter was written in an inaccessible way for those outside of scientific circles, and that this exercise was important and would greatly benefit from the input of the public.

It was agreed that a joint INVOLVE response should be sent, with addition of input from the Senior Leadership Team. Individuals were also encouraged to respond. It was also agreed that the Forum should be used to collect feedback, and, if time, a sub-group be formed to collate a joint response. Zoe said that hopefully this wouldn’t be the only opportunity to input as Simon was working with RAND to see if there could be public input after synthesis of the responses.

Small table discussions looked at the challenges we may face in 20 years’ time. Zoe asked the tables to focus on what areas are under-represented and what populations might be affected by them?

Feedback included:

- A change of emphasis needed to push prevention, especially with a shift in responsibility towards self-management.
- Along with self-management, the need for more health education, especially teaching in schools.
- The ‘quality of life’ agenda, versus longevity (where to focus resources?)
- Difficulties with increased privatisation or outsourcing of services – possible 2-tier system.
- Pre-symptomatic screening.
- Challenge of multi-morbidities – training of healthcare professionals to look at multi-morbidities, rather than becoming specialist.
- Diversification of workforce – new roles, different types of teams.
- Need more focus on public health?
- Being smarter about translational medicine (bedside to bench) – PPI will be critical to this.
- Need to examine the whole business model from patient / carer viewpoint – a service designed around health needs or market forces?
- We need a transformation in the relationship between people providing services and people using services – not just redesigning systems and processes.
- Financial drivers – doing more for less - managing expectations and meeting demand will require money!
- Patients may be very different in 20 years – more tech savvy, more demanding, less deferential.
- Will increased use of technology be appropriate, appealing, wanted by public?

- Research should be done by default – it's everyone's business.
- PPI in research prioritisation will be critical.
- What are benefits to purse-holders of more PPI? So often involvement seen as a cost, not a cost-benefit.
- Use of personal data – overcome any ethical issues and move towards better use of technology (may be equality issues with under-represented groups).

ACTION: Advisory Group to debate the issue using the Forum and give feedback to the Coordinating Centre via email
ACTION: Individuals to respond to the survey.

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5. Public Involvement and NIHR collaboration with industry (Alessandra Gaeta from NOCRI presentation/discussion)

Paula introduced NOCRI and explained that as industry is such a significant part of the research system it was important for the INVOLVE Advisory Group to be aware of developments and how public involvement was taken forward within industry, with a view to future consideration of how INVOLVE engages with industry.

Alessandra Gaeta, Operations Manager at NOCRI, presented an overview of NIHR Office for Clinical Research Infrastructure (NOCRI) to the group. (Slides attached for information). NOCRI are a small team of 13 who work to promote NIHR's offer to industry, to act as a single point of access. They provide a signposting service, matching industry partners to researchers. The Translational Research Collaborations (TRC) bring together expertise around a key topic for example; dementia, rare diseases. A key element of the TCRs is to accelerate the process of getting research into practice. NOCRI promotes the sharing of best practice and are currently looking at the impact of these connections.

NOCRI presented ideas to discuss going forward that would ensure strategic alignment with INVOLVE, these included:

- Industry guidance to ensure access is streamlined.
- TRCs have strategic plans but public involvement is currently not embedded throughout, opportunity to support this and help include public involvement in prioritisation.
- Communicate the impact of involvement, the value added.

The group asked Alessandra the following questions:

1) What is NOCRI's alignment to the Academic Health Science Networks (AHSN)?
   Answer: They do align but the key difference discussed was NOCRI's national remit versus the different regional priorities of the AHSNs.

2) Due to the different subjects covered in the current TRCs what were the different methods of involvement utilised?
   Answer: NOCRI work with the local infrastructure (Biomedical Research Centre) and use their expertise and knowledge of public involvement to access and work with the appropriate population.
3) How much public involvement is in NOCRI?
   Answer: This varies and this is what they are looking to standardise and improve with INVOLVE.
4) NOCRI work with cancers and rare diseases but do they link in with National Cancer Research Institute (NCRI)?
   Answer: Not currently but they will link in if the local infrastructure organisations around this TRC are not already working with NCRI.

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

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6. INVOLVE Strategy Planning Exercise

Zoe reminded the group of the strategy process and timeline and of the importance of the Group's advice in guiding the development of strategic options. The exercise today built upon the SWOT (which the Group were invited to contribute to further) and the feedback from the external survey about what INVOLVE should/should not be doing, what is valued about what INVOLVE does and why, and how people engage with INVOLVE/what they expect of INVOLVE.

Wendy set the context for discussion by introducing the feedback from the external survey. She commented that it was clear there needed to be strong prioritisation about what INVOLVE focuses on in future, as the survey highlighted that there were extensive views about what INVOLVE should do, but no one had any suggestions for what INVOLVE should stop doing, but clearly not everything would be able to be delivered.

The Advisory Group were asked to consider INVOLVE's future role in 1. Monitoring and 2. Advice and Guidance.

1. Monitoring
What should/could be monitored?

- Reach, relevance, refinement, relationships
- PPI in any research project, post funding
- Quality standards
- The extent to which PPI standards are being adhered to
- INVOLVE could collect stories on the impact of PPI
- PPI on funding panels
- Transparency of the process used for the recruitment of public members
- The 'copy and paste' culture in funding applications
- PPI in training programmes.

What should/could a monitoring system look like?

- Annual reporting
- Provide opportunity for lay feedback
- Other parts of NIHR already monitor their own PPI work. Perhaps INVOLVE establishes/oversees a monitoring framework/system but the monitoring is done by other parts of NIHR.
- Overseeing a monitoring framework would mean INVOLVE setting the agenda, determining/shaping what was monitored
- It could involve a 'whistleblowing' system whereby lay people can contact INVOLVE if they deem something to be inappropriate/have some concerns
- INVOLVE could also provide guidance on the various parts of the monitoring framework
- INVOLVE could 'shine a light' on issues emerging from monitoring.

Other monitoring issues

- INVOLVE needs to consider the type of monitoring role it could undertake. For example, does it want to evolve into an accreditation body or not? It may be that INVOLVE starts with self-assessment, seeking to influence other parts of NIHR to monitor, and then moves towards a more regulatory role.
- INVOLVE has to get the balance right between oversight/regulation on the one hand and the provision of support/guidance on the other.
- What sanctions would INVOLVE have/want if poor practice is found?
- What would INVOLVE stop doing if it took on a monitoring function?

2. Advice and guidance

What should guidance achieve?

INVOLVE guidance is/and should be regarded as authoritative and there is a strong public perception that INVOLVE should take a lead on guidance.

Future advice and guidance scenarios for INVOLVE

- INVOLVE could provide a sign posting service, pointing organisations and individuals in the direction of various guidance.
- INVOLVE could focus on generic guidance which is used as a starting point for local and organisational approaches.
- INVOLVE could endorse/kite mark guidance produced by others such as Health Research Authority, Research Design Service, Clinical Research Network and funders.
  NB the above point comes with a warning about the difficulty in a) agreeing 'quality standards' for any given piece of guidance and b) the significant time involved in managing/reviewing guidance from across the system
- INVOLVE could become a repository for various guidance documents.
- INVOLVE could focus on providing support/backing and guidance to lay members who are experiencing problems/want advice.
- INVOLVE could develop guidance on 'how to assess impact'.

Action: The questions on strategy to be placed on the forum for the Group to discuss any further input and send this to the coordinating centre

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Date of next meeting

19th October 2017 - Kings Fund, London