



Notes of INVOLVE Executive Group Meeting

Thursday, 18th May 2017 10:30-15:30

Conference Room, Alpha House, University of Southampton Science Park, Chilworth, Southampton, SO16 7NS

1. Introductions, welcome and apologies and update of actions from meeting 22nd March

Attended: Wendy Baird (WB), Sarah Bayliss (SB) (notes), Tina Coldham (TC), Zoe Gray (ZG) (chair), Gill Green (GG), Gary Hickey (GH), Martin Lodemore (ML), Mark Mullee (MM), Una Rennard (UR), Lesley Roberts (LR), Kate Sonpal (KS) Paula Wray (PW), Gill Wren (GW), Laura Young (LY)

Zoe welcomed everyone to the meeting.

There were no changes to the notes from the previous meeting and no actions to be carried forward.

2. Latest work programme review & prioritisation (including Risk Register)

Zoe set out some context to inform the decisions to be taken by the group on prioritization of the INVOLVE work programme 2017/18. Following decisions at this meeting, the work programme would be submitted to DH for final approval (later than usual this year, due to changes within DH and delayed contract review meeting).

Zoe highlighted the additional large pieces of work within this year in the work programme including the conference, strategic development and the recruitment of the INVOLVE chair plus new members to the executive group, in addition to the work on ensuring consistency in support of PPI throughout the Standard application Form (SAF). This was adding to an already significant team workload, with core business demands growing as a result of a successful first contract year (e.g. regional networking, enquiries). Zoe anticipated later in the year that there would be business development work for future sustainability, and increasing levels of cross NIHR communication work with the centre directors. She anticipated that the Chair's role would lead to more work for the Coordinating Centre who would be providing support.

Zoe outlined that a key risk was that due to the increased workload INVOLVE couldn't deliver any emerging demands or respond quickly to changes to the system that might come about. She felt that it was important for INVOLVE to pin point in the work plan the key deliverables that will make the biggest difference, where only INVOLVE is uniquely positioned to deliver and to prioritise work on that basis. It would be important to guard the time to complete those achievable activities and recognize our limitations.

Zoe explained that we need to produce definable products, build metrics and good stories and not to get too bogged down in historic stuff, for example; the learning & development work where there was much talk but no clear outputs. She went on to say that Simon was in agreement that we need to concentrate our focus on high impact objectives, and read out parts of an email Simon had sent which echoed these recommendations.

National Leadership Areas (NLA)

The Group agreed to focus on prioritizing work under the three National Leadership Areas of the work programme initially, as these are clear areas where INVOLVE can achieve significant outputs which respond to identified needs, are visible and influential on the wider system.

Learning & Development (L&D)

Martin explained that an L&D Project Group and six subgroups had been set up to develop systems and materials, and each was led by someone in the NIHR or a charity. All were involving members of the public and each had a project plan.

The following 6 groups had been set up to complete specific objectives:

Access sub-group

Create a system to share and advertise live information of learning and development opportunities across organisations.

Websites sub-group

To coordinate sharing of information across websites, with clear links that offer resources for learning and development across NIHR and external organisations.

Learning needs sub-group

Develop tools to support individuals to identify their learning needs, for researchers, for public contributors, and public involvement staff.

Develop tools to support ongoing evaluation of individuals' development while involved, or while involving the public.

Inductions sub-groups

Create a framework and a series of templates for induction materials for staff, for public contributors new to research, and for new public involvement staff.

Top tips sub-group

Create a series of 'what to consider' top tips on learning and development for researchers, for public contributors, and for public involvement staff.

Diversity sub-group

Develop materials to help share knowledge and methods for engaging and involving diverse communities.

Martin went on to explain that the next main Project Group meeting would look at progress made and address areas of cross-over to ensure a joined-up approach. The Group will plug gaps and build consistent approaches to learning & development for researchers, PPI professionals and the public. He said that links were also being made with a 'Researcher Training' group from the Royal Society, Wellcome Trust and The Academy of Medical Sciences. An Abstract had been submitted for the INVOLVE Conference.

He explained that the purpose of this model of working was to catalyse effective collaboration between NIHR/others by reducing duplication of effort and combining expertise and resources for maximum effectiveness and efficiency and this would be done by exploring innovative solutions including the use of new tech/media.

He explained that INVOLVE's role should influence others to do and "add value" in delivery where our role/position as national advisory body uniquely allows us to. Martin proposed that there would be the delivery of 2 prioritised outputs by October 2017 e.g.: cross-NIHR PPI induction.

Discussion then took place with the group around the amount of work to be done and meeting the expectations and what is actually achievable. Martin explained that the project leads were taking the lead for each project and that INVOLVE was acting as a supporting role and providing useful guidance regarding systems. He explained that the leads were doing a great job and giving their own time. He was hoping that tools for offering training opportunities similar to the People in Research website could be set up and information on this (or a prototype) should available in time to be launched at the conference.

Zoe was concerned that we shouldn't be over ambitious about what can be achieved within the year and recommended managing expectations. She asked the group if we should consider prioritising delivery of the outputs under the induction and learning needs sub groups over the other groups, given that it had been clearly established that the system would benefit from these through previous work. This was agreed.

Further discussion around learning needs were discussed, with advice being given to Martin to consider as the lead for this area, as follows.

Strategic points:

 Consider learning needs work as a journey towards a long term aim of consistency over which INVOLVE has influence. Whilst at the moment it may not be possible/desirable to have common role descriptions, taking steps to influence consistency of approach now should lever this in future. Una highlighted that it was key to get RDS and Centre Directors on board now so that in 5 years when they are writing job descriptions they ask for skills sets that are defined by INVOLVE, e.g. facilitation & line management skills.

Specific points:

- Analyse PPI leads' skill and knowledge needs (from scoping work) and develop learning identification tool, with prompts for potential development areas (including soft skills).
- Develop skills sets to act as core skills and knowledge required for PPI leads

 most PPI roles should have common basic requirements, which can be included in most job descriptions.
- Similar tool needed for PPI leads and researchers to use when supporting public members to identify skills and knowledge needed for role.
- PPI skills and knowledge should have common basic requirements
- Researchers may need some personal management skills (e.g. line management).

Zoe summarized the group's input and decision on work programme 2017/18 priorities in this area (for Martin to lead forward) as:

- Production of the cross NIHR PPI induction prioritised as an output, to be delivered by the end of October 2017.
 The outcome will be to incorporate this into induction programmes for all NIHR staff involved with PPI. A first outcome would be that all RDS staff would have the new PPI induction built into their RDS induction pack for use with all new RDS employees, by end January 2018. Wendy, Gill and Mark agreed, and offered to get other RDS Directors on board to deliver this.
- Second output by end October 2017 to be the learning needs analysis core principles - (from learning needs group), focused on PPI leads/PPI lay members.

Actions

- RDS directors to promote and achieve agreement amongst other RDS Directors to the above recommendation.
- Martin to lead the Project Group and sub-group leads to achieve the output priorities.

Diversity & Inclusion (D & I)

Paula explained that the plan for the Diversity & Inclusion work programme should ensure that INVOLVE's internal processes are as inclusive as possible and offer training to group members if they hadn't already done it. She reported that all the coordinating centre staff had completed their equality and diversity training. She explained that the Diversity and Inclusion Policy had been developed. A draft policy would be discussed at the working group meeting next week and then brought back to the Executive group for further comment before final sign off by the Executive group, followed by implementation.

She highlighted the fact that the definitions needed to be updated beyond just ethnicity. She went on to say that in the long term all INVOLVE resource and guidance documents would be updated incorporating these definitions and then made available in formats that different stakeholders could access. She will also work with the Senior Leadership Team (SLT) to implement the recommendations from the work programme and she would continue to access organisational networks to ensure there was consistency of approach to Diversity & Inclusion across the research community with links already established, and sharing of resources happening with Wellcome, Association of Medical Research Charities (AMRC) and international networks.

Zoe summarized the group's input and decision on work programme 2017/18 priorities in this area (for Paula to lead forward) as:

- Prioritized outputs: D&I policy (to be adopted September 2017) and definitions
 of what we mean by Diversity and Inclusion & why produced (by end
 September 2017) and both uploaded to NIHR & INVOLVE websites (by end of
 September 2017).
- 2. Targeted outcome to be that Policy and Definitions are signed up to by the Senior Leadership Team members as a priority (by end of January 2018) and Programme Directors later (visible e.g. via websites concordat style). The group expects to see this built into the operational plan for SLT and to be a component within the L&D originating induction pack.
- 3. The above resources should be marketed as highly visual by methods, for example, like thunder clap and media splash and that agreement should be obtained by the NIHR to use these definitions moving forward.

Actions

- > Paula to circulate the draft policy, diversity and inclusion statement and definitions to the group for approval.
- Martin to ensure that diversity and inclusion form part of induction packs.
- Paula to get support for future recommendations and INVOLVE's policy, once Exec approved, from the SLT.

Community Partnership Networks

Gary explained that to the focus of this work was on identifying the key principles involved in co-producing research. The project has involved a round table discussion, a literature review and interviews with people involved in co-produced research (carried out by London and East of England RDS) and a workshop for 25 May to further develop the key principles and identify challenges and solutions.

Gary explained three aims of the project, each with measures/impacts:

Guidance

He reported that the principles guidance would be produced in time for the conference in November. The download usage of this guidance could then be monitored and a survey created to find out how useful it is.

Embedding guidance across NIHR

Staff from across the NIHR are already part of the project team. The intention is for guidance to be endorsed by the Senior Leadership Team. He also planned to discuss the recommendations with the NETSCC PPI ref group and PPI Leaders group to identify how they might best use the guidance. He would also discuss with RDS via the RDS/INVOLVE partnership. Mark Mullee also invited Gary to discuss at an RDS event.

Wendy suggested that INVOLVE could produce information that could be embedded within the guidance provided for NIHR funding programmes longer term.

Gary suggested that it could also be included in the induction packs being developed as part of Martin's Learning and Development project.

Zoe asked the question where can we most effectively influence behaviors towards co-production and it was suggested that we could influence the induction of fellows provided by NIHR TCC to make sure people were aware and understand the need to consider coproduction.

Increasing the volume of co-produced research

Gary noted that he was not sure that this should be something that INVOLVE has as an aim a) because it fell out of scope of INVOLVE's remit and influence and b) because it may be decided that a shift towards co-produced research is problematic in some way for NIHR, so the challenges/recommendations to address for NIHR needed to be addressed as part of the work.

It was agreed that it was not INVOLVE's role or remit to increase the volume of coproduced research, as it has no direct influence. Taking action to grow the understanding of coproduced research and its principles can reasonably be expected to lead to more coproduction in research over time, assuming that any challenges for NIHR are able to be addressed.

Zoe summarized the group's input and decision on work programme 2017/18 priorities in this area (for Gary to lead forward) as:

- 1. Outputs for 2017/18: co-production workshop May 2017, co-production review completed (draft) June 2017, present at international coproduction conference September 2017, draft principles guidance on websites November 2017.
- 2. Outcomes for 2017/18: NETSCC agree how they will adopt/align to the principles guidance (by end December 2017). RDS agree how they will adopt/align to the principles guidance (by end December 2017). Key elements of principles guidance included in L&D induction pack (by end October 2017). SLT agree how will work to principles through operational plan/support challenges to be addressed by end January 2017.

Work programme general

Discussion took place regarding the National Enquiries Service and due to increased workloads it was suggested that policy and timescales for responding to enquiries is changed to ensure the management of expectations. It was recommended that we should have a Key Performance Indicators for enquiries and frequent reporting on the changing nature of the calls to pick up trends and build new Frequently Asked Question and follow up surveys to see what impact we have had.

Members expressed concern about the range of expectations emerging about INVOLVE's role in "monitoring", reinforced by the Advisory Group's feedback about confusion in the system about what monitoring actually means, its value and how it is used. The group were clear that INVOLVE's role was about using data it was collecting/appropriate with capacity to collect (for example on trends in enquiries) to hold a mirror up to the system and to act as its conscience – prompting, what needs to happen next?

With regard to Shared Learning Groups, the Executive agreed that INVOLVE should move the responsibility along to other partners to substantially reduce time and resource impact on the team, whilst acknowledging value of the relationships and information gained, and how that influences INVOLVE NLA's etc. SPIMs already had plans to delegate minutes/chairing. It was suggested that perhaps timescales could be slipped so that perhaps groups didn't meet quite as frequently, which would reduce work too.

With the Executive Group's support it was agreed that the centre team would take away the work programme and consider where other priorities could be delegated elsewhere in the system appropriately or timeframes shifted forward, as even changes above did not create flexibility for the unexpected and would be demanding to deliver. Members emphasized that INVOLVE's absolute focus should be on the NLA delivery. The amended final draft would be sent to Exec and Simon for final agreement before going to the Department.

Actions

- Zoe/Gary to feedback on the progress of the Coproduction guidance to the RDS Directors meeting planned for September and to the Advisory Group in October.
- Gary to update Coproduction project plan to include all of the suggestions for embedding the guidance into the work of the NIHR.
- > Zoe to send the final draft to Exec and Simon for final agreement, then submit to the Department.

3. INVOLVE Chairs role

Zoe reported that she had received the following comments back from the Advisory Group in relation to the chair role that she had circulated to them after the Advisory Group meeting:

- Call the role a Chair of the Advisory Group not ambassador.
- Simplify the role description.
- Retain focus on influence but make clear how this will be different to the role of Director and Simon, including a relationship diagram.
- Emphasise the role of helping Executive Group/Advisory Group/Coordinating Centre link cohesively and communications amongst the different parts.
- Emphasise knowledge of system/INVOLVE needed and gravitas for influence.
- Change "reporting to" to "accountable to".
- Make the expectations (what role will do in the days) explicitly clear
- Make the fees etc explicitly clear for the advert).
- Increase the days but retain the flexibility.
- Consider if a Vice Chair is required?

On a cost benefit analysis (looking at resources available, considering the reduced size of the Advisory Group and the likely impact), it was decided not to create a Vice Chair post. The reasons for the suggestion were acknowledged and the group agreed a mitigation to address one of the concerns raised by Advisory Group members; in the event of the Chair's absence, the INVOLVE Director could chair Advisory Group meetings. The justification for a Vice Chair would be re-considered once more by the Executive once the Chair was in place and had been operating for several months.

It was acknowledged that there is no current budget for the INVOLVE Chair role (the change of Chair was not budgeted for in the tender), and the cost of this role (involvement fees and expenses) could absorb up to 15% of the programme budget in any year, reducing ability to fund projects and deliver the work programme. The Executive emphasized that it was essential to have administration support for the Chair to deliver value without over imposition on the compact centre team, and agreed that this could not be delivered as part of existing stretched administration. Additional funding has been requested from the Department of Health to cover these administration costs. The Department will not fund the Chair role as it is no longer a direct appointment of the Department.

Members recommended that the person specification should be made less demanding and were satisfied that Zoe had reduced the spec from 17 to13 points, and it would be challenging to remove further points without diluting important requirements. It was recommended that the specification be grouped under sub headings to break up the text and make it easier to follow for potential applicants.

It was recommended to check whether the costs of the chairs broadband and telephone calls etc would be included in expenses. Zoe said she would check this with Beth/finance and update the job description as necessary.

Zoe asked Gill, Mark and Wendy (RDS (Research Design Service) Directors) if they would be able to be able to answer questions from applicants who weren't sure if they had the right skills to apply. They all agreed that they would be able to do that and it was agreed one or two of the Directors telephone number to be included on the advert

The following points were agreed as not being eligible to apply for the role of INVOLVE Chair:

- You can't be an executive member and the chair of INVOLVE which needs to be clear on the application information to avoid conflict of interest.
- Bullet point 2 should be removed.
- Clarify that those who lead with a public voice could be a chair
- Change to "current" employees of the NIHR

Tina suggested that the Nolan principles should be considered when writing the role description

Other points suggested by the Advisory Group members were agreed, as indicated in the tracking table.

There was agreement that everyone agreed the content and approach subject to the changes discussed.

Actions

- Zoe to check with Beth Allen (DH) if the funding of the post included the Chairs broadband and telephone expenses etc and to update the job description as necessary.
- > Zoe to make the changes agreed above to the job description.

4. Strategy Development – moving towards strategic choices

Zoe introduced the context for the discussion, including recapping on the input and feedback from the Advisory Group at the May meeting.

Zoe reminded everyone that the Advisory Group (AG) had not had the opportunity to consider all 6 of the themed areas emerging which would inform strategic priority forming, so relevant information had been posted on the AG forum, with the invitation for the AG to feed in their input to Zoe by 31st May. This exercise was therefore running parallel with the AG input, so there would need to be some subsequent marrying together of the feedback, with consideration to any common views or divergences.

The following 4 strategy areas were discussed

Influencing cross system policy strategy and process

Prompts for discussion:

Should INVOLVE be looking to influence system policy strategy and process. If so, where? What types of influence are needed in the future system? What tools or evidence would be needed to achieve this?

The following points were raised:

- Our influence needs to be wider than the NHIR and extend to international, business, trusts, universities, public and pharma. Priority by exclusion.
- We need to be sharing and identifying opportunities with pharma. Can we create opportunities to collaborate with them, so that we can influence them to do good PPI? In 3-5 years pharma may be more patient-led.
- We already have influence with those who have NIHR funding but may need to spend more time influencing others, with the expectations of NIHR in mind.
- We need to raise awareness of/change practice in involvement through NIHR rather than participation – others exist to do that.
- We need to influence the quality in PPI and we should be promoting INVOLVE guidelines to drive up standards.
- We should be using INVOLVE standards as a framework to improve the quality of PPI. The standards is the key mechanism by which to influence organizational practice.
- We should be educating the public on what is involvement via better communications. The role of influencing is perhaps more advocacy?
- Diversity recommendations will influence policy but what will change? Putting it into practice is more important than policy. Policy sometimes follows practice but there are many (outside) examples of policy never influencing practice. It is recommended to focus on influencing practice NOT policy.
- Encourage PPI in various sectors provide guidance on doing it well.
- We need levers for influence.
- The biggest impact ultimately will be if funders refuse to fund research projects unless PPI is done well.
- We need big ticket changers What can we do to influence big strategic level change? For example – from the past; the impact of NIHR putting PPI on the application form.
- "Changing hearts and minds is the better strategy longer term" (e.g.: influencing reporting in contracts people can end up getting round requirements by answering well but not doing what they're supposed to be) but can funders stick with this longer term gain without empiric evidence of change? Use the "stick" sparingly.

Learning and development (training)

Prompts for discussion:

What role could INVOLVE play in the future PPI learning and development environment (e.g. delivery, quality control, resource library)? How would this add value to what others are/should be doing?

The following points were raised:

- INVOLVE should not be delivering Learning & Development but influencing those setting the curriculum e.g. Deans of Universities.
- There should be career progression for PI leads, with perhaps a qualification in PPI? Query if this is INVOLVE though?
- Use standards as a quality control but not a 'kitemark for courses' or accreditation - but use standards to drive up quality.
- INVOLVE could consider setting up a training arm which would be a separate business but whose role would it be to fund this. Discussions raised a number of concerns with this, including viability/investment levels/timeframes from those with previous involvement in establishing training ventures.
- Influence CRN and networks to add PPI training for nursing staff.
- The INVOLVE L&D lead should be more visible and recognized externally as the NIHR INVOLVE expert on this topic.
- If we use a similar system as People In Research (PIR) for advertising opportunities for L&D then we should be there for just signposting/facilitating and not endorsing/producing courses but can link back to our standards.
- We need to drawer on the NIHR community and pool resources / knowledge and work more collaboratively. "INVOLVE encapsulates the collective knowledge of the community and knows the local and regional leads to connect you with".
- Potential to charge for attending conferences/speeches?
- To enable us to be more efficient we need to prioritise the work loads of staff.
- We need to put down the foundation stones by making cross links now
 which will then bear fruit in the future but make DH aware that results are
 not necessarily related to activities in this period as there may be time-lag.

Participation and engagement

Prompts for discussion:

How will participation and engagement fit into INVOLVE's business in future?

The following points were raised:

- INVOLVE's main focus should still be on driving involvement. Driving involvement as recognize increasing evidence of benefit for increased participation – uniquely a role that INVOLVE plays.
- We recognise that the boundaries between involvement, participation and engagement are blurred but the latter two are not our core work.
 Look for opportunities where we can fulfil common objectives by working across and in alignment with other leads in these areas.
- PPI SLT to take responsibility for determining responsibilities re involvement, participation and engagement.
- INVOLVE's role should be to sign post people to other parts of the NIHR for participation and engagement.
- The INVOLVE strategy will be a framework which staff can use to determine what work we take on.

- We want to be proactive not reactive.
- More respect for partnership working is needed e.g. respect for the workload of others, that partnerships involve 'give and take'.
- INVOLVE/RDS partnership could be a conduit for signposting for participation.

Public Involvement Research

Prompts for discussion:

What's the future priority? Science or service – what's the balance? How important is a robust evidence base to advancing PPI? What would INVOLVE's relationship with the evident base look like in future? The following points were raised:

Service

- The enquiries handling should be looked at as part of our core service and should be valued more - perhaps with Key Performance Indicators.
- A key role should be giving guidance to NIHR colleagues via the website and Tweeting and supporting other groups.
- A scoping exercise should take place to identify the gaps/problem areas in PPI.
- The INVOLVE conference is a major piece of work and will remain a priority for the future.

Science

- There should be more rigor behind projects, and we should do fewer but do them better, all of which would lead to more credibility. In short do less but do it better.
- The guidance should be credible as researchers use it as well as members of the public but not research in itself.
- The key PPI issues should be identified and prioritised. INVOLVE should then focus on the core issues and lead on providing the necessary guidance.
- Could we partner/be a co-applicant with other organisations re funding bids to explore impact of PPI where it clearly adds value?
- If we can't be a co-applicant can we have a bank of people e.g. advisory group members and offer training on being a co-applicant?
- INVOLVE should be about producing clear, credible, authoritative guidance, not research.
- We should be encouraging more research by others (those well positioned) on PPI but not do it ourselves, to add to the evidence base. We can support researchers by giving advice to co-applicants and general PPI advice. How much time can we give to this and should we be charging?
- We should be making research accessible to lay people including the interpretation of evidence.
- Case studies are useful.
- We could promote existing guidance/PPI work developed by others, and where necessary turn it into plain English, to save reinventing the wheel.

- Is INVOLVE the middle man between research and practice influence?
 Interpreting research for guidance.
- INVOLVE's focus is on influencing practice and whilst PPI research is important it is acknowledged that it doesn't always influence change (time lag – methods change in interim, not always reflective of involvement as it is today).
- Perception is that INVOLVE doesn't lose anything from work not being peer reviewed - as guidance is accepted as authoritative.

Monitoring of PPI system

Prompts for discussion:

Which areas/parts of the system are the most important to monitor, about what and why? Who is and who should be monitoring? How can we tell what difference monitoring makes in improving/advancing PPI? What might the reasons for against

The following points were raised;

- Should INVOLVE be monitoring?
- What should and could be monitored?
- What makes the biggest difference in monitoring?
- What are we thinking is it monitoring or quality assurance?
- Should we be collating data to be the conscience to influence people?
- Going the Extra Mile recommendations are Simon's focus, delivered with support from the Centre's through SLT. Our role is to encourage best practice is driven through the SLT.
- The SLT should take the Standards as a benchmark and then the Centre's should roll it out. Once people are doing it there should be a mechanism for reporting back.
- INVOLVE's role is driving and reflecting good practice.
- We should broaden our reach by getting trust in the community to do PPI and do it well.

Advice & guidance

Prompts for discussion:

What guidance role might INVOLVE play in an evolving system? What should guidance or advice achieve? Who else provides it? Who else should provide it? What does advice and guidance which meets needs even look like in the future?

- INVOLVE should lead on involvement guidance.
- All guidance should be of good quality.
- We can't do kite marking or accreditation for reasons discussed at Advisory Group etc.
- We should be signposting but not endorsing disclaimer.
- Do we sell our quality expertise strongly enough? This is a necessity for our existence.

Next steps for strategy were that Zoe would identify themes and gaps from the input received from the Executive and Advisory Groups, and reflect this back with a plan for further finessing.

Department of Health wanted to understand the emerging themes as at end July and consider how this fits with current contract/Department future vision.

5. A.O.B – pre notified

Lesley spoke about a research project that she has become involved with, and wanted to highlight how effective and successful the PPI element of the research is. It is being run by the School of Life Sciences and Education at Staffordshire University who had sought advice and guidance from their local RDS and from the INVOLVE website prior to starting. They had recruited PPI representation through the patient groups at local GP surgeries (which is how Lesley got involved) at the outset of the project thereby ensuring PPI input from the start. The researchers have also been very positive and complimentary about the value and impact of having patient and public representation on the Programme Advisory Board for the research project, and recognise that it will enhance the research.

Action

➤ Gill Wren thought that this might make a good newsletter article and will follow up.