INVOLVE



Notes of INVOLVE Executive Group Meeting

Tuesday, 16th January 2018 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 16th November 2017

Attended: Wendy Baird (WB), Sarah Bayliss (SB) (notes), Tina Coldham (TC) (Observer), Joyce Fox (JF), Zoe Gray (ZG) (chair), Gill Green (GG), Gary Hickey (GH), Martin Lodemore (ML), Tara Mistry (TM) Lesley Roberts (LR), Kate Sonpal (KS) Paula Wray (PW), Gill Wren (GW)

Zoe welcomed Tina to the Executive Group meeting. It was Tina's first time at the meeting in her capacity as INVOLVE chair and she was there as an Observer.

The notes from the previous meeting were confirmed as accurate although there was one amendment to an action.

The action stated:

Discuss at the Exec Group the role of the Executive Group and communications with the group

This should be changed to:

Communication channels between the Executive Group, Advisory Group and RDS need to be clarified.

It was agreed that the INVOLVE 2017 final annual report was to be shared with the Executive Group. Wendy and Gill requested that time was built in to writing the 2018 annual report to allow for contributions. It was decided that the Advisory Group should be alerted when the face to Face Executive Minutes are available on the website by the INVOLVE CC and Gill and Wendy should henceforth be included in all communications to the Advisory Group for information.

Actions

Sarah: To amend the action on notes of 16th November 2017.

Zoe: Send the 2017 INVOLVE annual report to Executive Group.

Sarah: Alert the Advisory Group when the Executive notes are available on the website.

Sarah: Add Wendy and Gill to the Advisory group Mailing list.

2. RDS Partnership Development

Zoe reported that The RDS-INVOLVE partnership (in practice) celebrated its first birthday in September 2017. She went on to explain that there have been a number of mechanisms for review of the partnership and its future work in recent months, and the paper that was presented at the meeting set out what has been discussed so far, as a basis for discussion and agreement to a way forward which takes any agreed recommendations into action.

Zoe advised that in autumn 2017, herself and Lesley Roberts, as Executive member, presented to the RDS Directors about the partnership, a year on, followed by a discussion about what would be important to them moving forward. She explained that in the autumn, there had been a workshop involving the INVOLVE SPIM's and the RDS Public Involvement Community (PIC) to reflect on progress so far and to look to the future development of the partnership. This workshop surfaced some of the benefits of the partnership so far, the backdrop to our joint work in terms of system challenges, issues and ideas for future development and a deepening of the partnership.

Zoe explained that in December, herself and RDS leads discussed ways of strengthening joint working and making best use of the investment of time and expertise of the RDS leads (a role description is provided, as was previously agreed with Wendy and Gill) as funded through the INVOLVE contract. This meeting, building on the previous discussions, formed the basis of the questions posed at section 3 of the presented paper and informs the proposed next steps. Executive Group members were asked to consider the points raised in the paper and to come prepared to the meeting to discuss.

Zoe explained that the purpose of the discussion was also to think strategically about how the partnership can move forward whilst also communicating that relationship with the Executive Group, Advisory Group and Associates. Zoe advised that the INVOLVE contract was just about to start year 3 of a 4 year contract with the potential to extend for an extra year. If the option to extend for one year was granted by the DH then the full next contract would be due out in autumn 2019 (potentially when the conference is due) and we would need to demonstrate the value and benefit of the partnership when bidding for a new contract.

Zoe reported that Wendy, Gill and herself discussed that a way of acting upon agreed ways forward, would be to agree RDS-INVOLVE objectives forming part of both INVOLVE and RDS work plans in March/April 2018 (fits planning cycles for RDS – aiming to agree own focus in March) and to follow this with a communications plan. The goal was not to create new work. For example, objectives might include piloting standards, joining up on certain projects. Gary supported that a key benefit was the opportunity to get RDS views and input on INVOLVE led work, for example co-production.

Wendy reported that the RDS Directors were supportive of the partnership. She felt that with the new RDS contracts PPI budgets might be under pressure which would make it more essential for Directors to feel that the relationship adds value. She felt the part two report which Gary is initiating on regional networking could help address this. She explained that we need to show evidence of on-going value of the partnership and to showcase what success looks like. This could be evidenced as case studies of benefits to both partners and the NIHR.

Paula suggested INVOLVE and RDS leads need to remind RDS Directors about the partnership benefits it can bring through providing examples of how the INVOLVE/RDS partnership has made a difference. These examples should include the benefits of linking up nationally and taking national resources, like the coproduction guidance and making them useful for local areas. She suggested that we report impact case studies for networks and ask regions for specific examples of local linking up including RDS/INVOLVE to show to the directors. RDS Directors and PPI leads should play a part in preparing the report. This report can then be sent to DH, RDS directors and RDS regions to include an overarching summary. Paula suggested that by asking the RDS to pilot the Standards and the Diversity work in line with Going the Extra Mile, it will show how the local to national link up is working.

There was then a discussion about who else do we need to influence re the partnership and how this would affect the report. Zoe asked Gill and Wendy to create a stakeholder analysis table of who do we need to influence for this partnership e.g. CCF. To be sent to the Exec Group for comments and review and to decide who is most important to influence.

Gary noted his concern that we could end up writing something for several audiences e.g. RDS directors and DH and which met the needs of none. In particular, he noted that the DH did not favour a lengthy report. It was agreed that the DH required a short report but that there could be links in that report to vignettes of effective practice.

Gary noted that Andy Roberts from University of West of England wanted to undertake an evaluation of regional networks. Wendy's concern with this approach was that it could feel like a league table and affect people's goodwill. Gary explained that he felt similarly, and Andy had suggested a peer review approach. Gary would be discussing this with Wendy, Gill and Andy to ensure we get what we want out of it to achieve not only our objectives but a piece of work that will benefit and be shared across the regions.

There were discussions about how the wider contracting environment of NIHR (the outcome of the RDS bid is still awaited, then the CLAHRC contract etc will be

released) makes regional working and partnership challenging at times and means that progress in moving forward can be stalled. It was noted that the Advisory Group (AG) may be aware of this to a greater or lesser extent, and the impact upon the work of INVOLVE and the RDS partnership. It was noted that the landscape is ever changing and by the time information has been shared things have changed. It was therefore agreed a communication which gave an overview of the broader landscape and context within which INVOLVE is working, and highlighted the broad timeline and process (time involved) that might be anticipated in any future tendering process for INVOLVE. Tina agreed to prepare this and agree with Zoe, then send this in advance of the meeting, with the papers, to members of the AG.

Discussions took place regarding the best ways to link up group members and the RDS lay members through PIC and it was agreed that Tina would attend the RDS PIC 6th February 2018 to begin this exploration. Then there would be a discussion with the Advisory group about what else could be done to build closer relationships between RDS and INVOLVE lay members. We could then illustrate what we are doing in the partnership generally and connect up what relationships in regions lay members already have to try and explore how broad the relationships are. Wendy said that she could share the RDS PPI leads contacts with Advisory Group members to see if they want to contact local leads to establish links.

Wendy emphasized the importance of RDS leads having input to the INVOLVE annual report which goes to DH, to help reflect the RDS INVOLVE partnership in the best way. Wendy and Gill noted that they were discussing the RDS national PPI strategy on 6th February. Zoe noted that INVOLVE were not aware of the meeting and it was agreed that there should be an INVOLVE presence at this meeting given the partnership – it was important for both parties to be aware of and contribute to strategic developments as appropriate.

Wendy suggested that plans were made to discuss plans for the contract tender with RDS Directors once the timeline is established and this could done at the September RDS Directors Strategy meeting.

Actions:

Wendy: to send an invite to Tina and Gary for the RDS PIC on the 6th February.

Tina: to prepare and agree with Zoe a communication which gives an overview of the broader landscape and context within which INVOLVE is working, and highlights the broad timeline and process that might be anticipated in any future tendering process for INVOLVE, then send this with the papers in advance of the Advisory Group Meeting.

Wendy: to share RDS PPI Leads contacts with Group members – communication via Tina as Chair encouraging link up

Gill and Wendy: to create a Stakeholder analysis table and send to Exec group for comments in advance of the next telecall

Zoe: To consider timescale for meeting with RDS Directors regarding the INVOLVE tender process.

3. Agenda item 3 & 4 Strategic Plan update and Work Programme 18-19/ taking National Leadership areas to the next level, including update on RDS project processes

Strategic Plan Update - Zoe Gray

Zoe reported that there was a meeting to discuss the Executive proposed INVOLVE Strategic Framework on the 13th February with Chris Whitty & Louise Wood at the DH offices in London and after this she would bring the results of those discussions back to the Executive Group.

Zoe explained that the strategy would need to be aligned to the emerging strategy from the PPI National Directors office which Zoe would need to discuss with Simon before the 13th.

Zoe reported that the 2018/19 Work Programme would be aligned to the foundations of the new Strategy but that shouldn't mean additional work as the DH were keen that we didn't take on any additional work.

International network - Gary Hickey

Gary updated the group that we had successfully hosted an event in November 2017 to launch the network and the working group are meeting on the 19th January to begin planning a follow up event. He explained that his preference was for a two day event which will a) sign off on the vision and objectives and move forward on some governance issues b) include some work on 'impacts of PPI'.

Co-production – Gary Hickey

Gary explained that the Co-production guidance had now been written and that attention now turns to implementation and dissemination. He intends to take the guidance to the Senior Leadership Team meeting on the 27th February for their support. He noted that NETSCC want to talk to him about using the guidance and he would also be seeking discussion with the wider NIHR family including CCF, RDS and TCC. He said that it would also be used as part of induction training.

Outside of the NIHR he reported that the Centre for Co-production at UCL wanted to use the guidance as part of the development of their Centre and possibly in training. And it was being used as part of a EU2020 bid (of which Wessex Institute is a partner) where they could use the methodology of co-production.

Gary then went on to ask the following questions, answers to which would inform his discussion with the project Working Group:

- 1. What is the 'route' for implementation in NIHR?
- 2. What might implementation look like for different parts of NIHR?
- 3. Time-scales?

Discussion took place amongst the group and following suggestions were made:

- Can the co-production guidance be reflected in SAF applications ultimately? We need to think about the stages pathway and look to see who we can influence before the point of no return i.e. before they get the funding.
- Aim to influence from the top down but also push from bottom up in a pincer movement.
- Speak to Programme Directors
- Public need to get to know about it how?
- Produce Briefing document for lay reviewers.
- Make people aware this is not meant to be the gold standard of PPI that they must follow religiously it is about principles they can use.
- We need more communications with NHS England regarding co-production
- Produce guidelines for different funding programmes.
- To be discussed at the NIHR strategy board.
- The evidence will be in action can we put some resource to evaluation?
- The benefits and challenges of co-production needs to be explored.
- Discuss at an RDS PIC.
- The PIC RDS working group could become coproduction ambassadors
- We need to provide funding bodies with guidance.
- RDS could use the guidance when talking to researchers but lay reviewers need to be on board.
- Somebody from RDS sit on every funding panel so they should be well informed about coproduction and able to be ambassadors for guidance
- The Advisory group and RDS PIC can help to spread the word.

Gary stressed that the guidance is not a blue print for co-producing research and that parts of it will remain contested and there are grey areas. We have moved the debate on considerably but there are still areas for clarification and future work. He said what are we trying to achieve is to create more opportunities for co-production.

Some people noted that there is still confusion for some between co-production and co-applicants.

Tina made the point that the aims/objectives in *Going the Extra Mile* were long-term and achieving a critical mass in co-production will not happen overnight.

Gary explained what the ideas were for dissemination were so far:

- INVOLVE website
- Twitter
- Newsletter
- Webinar
- Synergising patient engagement (SYNaPsE)
- Article on the journal Evidence and Policy
- Discuss with wider NIHR Comms

Gary asked for any further ideas for dissemination to be sent to him.

Action

Gary: Bullet points to be produced for the executive Group showing the difference between co-production and co-applicants

All: Send Coproduction dissemination ideas to Gary

<u>Standards – Paula Wray</u>

Paula updated the group that she had focused her attention on the development of the National Standards for Public Involvement in Research as these would provide a driver for the Diversity and Inclusion work programme. She explained that the first of the standards is Inclusive Opportunities this would encourage more inclusive practice. The standards are being piloted from April 2018 so now the focus is on the resources and guidance to support the standards.

Diversity and inclusion

Paula reminded the group that there is now a policy, statement and definitions for INVOLVE around diversity and inclusion and that the next step was to produce an operational plan to ensure that we are meeting the expectations set in the statement and policy. She reported that the working group had been instrumental in developing these and plans are to refresh this group with additional members from the NIHR Centres, Wellcome, Health Research Authority and other medical research charities. Paula asked the group for any other suggestions to join the group.

Paula updated the group by advising them that the Diversity statement, policy and definitions were presented at the PPI Senior Leadership Team meeting and were met with support. These were then taken to the Centre Directors Executive Board where again there was support for this work but clarity was needed about INVOLVE's role and the remit of the work. Paula is clarifying that INVOLVE's remit is purely around increasing inclusive involvement practices but that this may raise awareness across the system of opportunities to improve practice to improve health outcomes for the wider population. The statement and definitions will be presented at the NIHR Senior Leadership Team and Strategy Board in March.

Paula explained that a Top Tips guide for Diversity and Inclusion is being produced as part of the Learning and Development project. A template to capture and share examples/case studies has been developed and is being piloted by one of the projects presented at the conference.

Paula asked for others suggestions as to how to take this work forward, suggestions are detailed below:

- Piggyback events that are already happening eg panel's development days.
- Join the Equality, Diversity and Inclusion in Health Science Network launched by GlaxoSmithKline, Frances Crick Institute and Wellcome where we will contribute a nominal amount and we will bring our expertise.

- Diversity and inclusion is an area we are all seeking to address so messages and principles should be across the NIHR not just INVOLVE.
- Use examples of good practice, where adopted elsewhere.
- Young person voice needed to be included in the group
- We need to lead by example, using different methods to get voices heard.
- Tap in to the ageing network.

Action

Paula: Draw up a Diversity Logic model to show where we will get to and where we can positively influence that we haven't thought about. Paula to send model to exec for comment

4. Continuation of agenda item 3 after lunch.

Learning and Development (L&D) – Martin Lodemore

Martin outlined the learning and development plan for 2018-19. He reported on the progress of the Project Group and six sub-groups, and what they delivered during 2017, including:

- New INVOLVE webpage going live this week.
- Top Tips the first 7 launched at the Conference (including 3 on L&D), with more in development. These have been well received and already being used in and beyond NIHR.
- A learning needs tool to help identify what is needed for each role, in line with the 'learner-centred' approach recommended by the previous L&D Working Group.
- Induction materials frameworks for researchers and research staff, and the 'Starting Out' guidance for new public contributors.
- A new 'Find and Share' website a project brief is about to go out for tender, developed by the subgroup in conjunction with the learning needs subgroup.
- Diversity and inclusion (D&I) strong links with this workstream, to enable learning and guidance to inform training materials (a set of Top Tips for D&I in development).
- A session and exhibition stand at the Conference.

The Executive noted the contribution made to this work by Amander Wellings and congratulated her for her continued commitment to the learning and development programme.

Martin explained that for 2018, further testing and promotion of the above resources would be ongoing. The Project Group will meet for the final time in February 2018, wrapping up much of the above activity and looking at future activity.

Two subgroups will continue into 2018 to:

- Oversee the development, testing and promotion of the 'Find and Share'
 website. This will allow individuals to find suitable training, or promote local
 activities. An online version of the learning needs tool will be included, to
 suggest training for particular roles.
- Develop further Top Tips with D&I, coproduction, and children and young people already on the agenda.

New for 2018 will be:

- To develop an L&D supplement to the Briefing Notes for Researchers.
- To design and deliver an L&D webinar planned for the autumn.
- To produce materials to support self-evaluation of development and learning achieved during involvement.
- To further development of induction materials to include coproduction, D&I, and the involvement of children and young people.
- To develop training materials for audiences with specific needs to address access issues for those with disabilities, cognitive impairment or learning needs.
- To explore development of a PPI e-learning package for delivery in 2018 possibly a MOOC, if a modular version can be developed within budget.

Discussions took place amongst the group for ideas for 2018 as follows:

- Rolling banner on the INVOLVE website to include a new top tip
- Posting opportunities on website should be made easy
- Should INVOLVE help others to evaluate their own learning eg create a CPD learning tool?
- Could there be a repository to store a list of all your learning?
- Discuss at SLT who is responsible for more researcher trainer courses and understand what is out there.

There was further discussion regarding updating the RDS PIC handbook in conjunction with updating the Briefing Notes for Researchers, Martin explained that we were not currently looking to update the Briefing notes as the information is current. It was suggested that a coproduction supplement could be produced as well as updating existing Briefing Note supplements which RDS PIC could use alongside their updated handbook. The question was asked as to whether sections of the RDS handbook could be included as supplements to the Briefing Notes, which may be possible – although there also may be need for the handbook as a single resource as regularly used across the RDSs.

Action

Martin: Look at creating a rolling banner on the INVOLVE website for a new top tip

Martin also outlined a recent development in seeking a national roll-out of the East Midlands Training Sharebank. He explained that The East Midlands Training Sharebank was developed by the public involvement leads and public members from the Research Design Service (RDS), Biomedical Research Units, and Collaboration

for Leadership in Applied Health Research and Care (CLAHRC) and local Trust, to share the training they were each delivering independently.

This was piloted and proved to work well in sharing resources and also reaching out to new public members, people who attended the course went on to become public reviewers for RDS for example. Other regions have expressed an interest in developing a similar initiative. There was overwhelming support for this when it was presented at the conference and INVOLVE is seeking further funding to support a one-year project to roll-out the Sharebank model to regional networks.

Children and Young People – Kate Sonpal

Kate explained that the Vision of the Children and Young People (CYP) work was to advance the involvement of CYP through education of researchers and PPI Leads and promotion of the impact that CYP have on research.

She reported that the objectives of the work-plan were as follows:

- 1. To form a working group of public and non-public members.
- 2. To map the CYP groups that exists nationally.
- 3. To send out a survey to researchers and PI Leads by utilising contacts in the regional networks, to understand their learning needs and the barriers that they face when involving CYP in research, in addition to finding out where they think INVOLVE can support this.
- 4. To develop a learning package in response to the survey.
- 5. To update the CYP section on the INVOLVE website in response to the survey in partnership with the working group.
- 6. To recruit CYP into the INVOLVE wider network.

Kate outlined the draft Time-plan for this work:

February 2018: Formation of working group

February/March 2018: Workgroup meeting

March 2018: CYP group mapping exercise

March 2018: Send out CYP survey

May 2018: Working group meeting to discuss survey response and

plan for website

September 2018: CYP pages on INVOLVE website updated Ongoing: Recruit CYP to INVOLVE wider network

Potential workgroup members:

Louca-Mai Brady Jenny Preston Sophie Ainsworth Simon Stones

Kate asked the group for any comments or advice to take this forward. There was support for the proposals.

The Executive Group approved the 2018/19 work programme draft, pending team finalization and review for achievability.

5. Advisory Group Development

Kate reported that Tina Coldham was successfully appointed as Chair last year and this Chair role is different from the one occupied by Simon Denegri, which was more like a Chair of a Charity role. Kate explained that Tina's role would encompass promoting INVOLVE, chairing Advisory Group meetings and supporting and endorsing INVOLVE's values. Tina will also have an important role in developing the Advisory Group; ensuring that they have regular contact outside meetings (forum); increasing the productivity of the Advisory Group and capturing this information.

Kate explained that the tenure of 5 public members of the Advisory Group is due to expire in 2018. She said that in order to provide stability and support and ensure that INVOLVE's strategic vision is realised, Zoë and the recruitment subgroup decided that two members would extraordinarily have their tenure extended. Each member was offered this opportunity. Lizzie Thomas and Veronica Swallow were both happy to become Associate members at the end of their tenure. Jo Ellins informed us that she had been on maternity leave for a period of her membership so her tenure has been extended until September 2019 to take this into account. This left one extension available.

Kate reported that the four who were interested were asked to explain how their skills, knowledge, working relationships and influence would support the Advisory Groups contribution to progressing INVOLVE's future strategic intentions. This formed a basis for one to one conversations with Zoë. Zoë and Tina will make a joint decision regarding which of the members concerned will be offered an extension to their tenure.

Kate advised that the current recruitment subgroup have been thanked and disbanded as they had achieved their initial objectives and Kate has now drafted an expression of interest document for those interested in joining the new recruitment subgroup. This opportunity will be sent out to Advisory and Associate Group members. She explained that once formed the group will review the timescale of recruitment; help design the application form and decide how we are going to reach a diverse range of people.

The Draft timeline for this work:

January 2018 Recruit to subgroup

February 2018 Meet with recruitment subgroup (either face to face or

teleconference)

February 2018 Finalise members of interview panel
Late February 2018 Design application forms with subgroup
February/Mar 2018 Open recruitment to Advisory Group.

Disseminate opportunities to apply via website, Twitter

and regional networks.

March 2018 Write interview questions

End of March Interview panel to shortlist applicants

Mid-April 2018 Interviews

9th and 10th May 2018 New member have induction and attend Advisory Group

meeting

Discussions took place amongst the group:

- Think about the diversity of the INVOLVE Advisory group and consider access issues. Seek to do differently to attract interest from a diverse audience/range of voices.
- As well as using word of mouth as a tool to find lay people we could ask PI leads to go out to their networks to find them.
- Could we consider welcoming applicants that have not worked within NIHR.
- Look at the skills mapping exercise done at the last group meeting and see where there are gaps in Group skills.
- Consider providing the Advisory Group with training on Unconscious Bias and any Learning Opportunities.
- At the induction meeting explain who was Public and who PI Lead perhaps a Speed dating –getting to know you session.
- At the induction provide information to the new members around what can I
 do as a new person and how do I find out what I can do? New members need
 to know how they fit in and need to establish a feeling of achievement.
- As well as providing one buddy to the new members, consider providing two buddies consisting of one public and one professional so that both perspectives are provided.
- Consider members with a social care background as research in this area is lacking.
- Consider follow up meetings after the induction with new members, SPIMs and chair.

Kate reported that she was currently updating the declaration of interest information and this would be sent to Group members in due course.

6. Review Exit Strategy

Zoe asked the Executive Group to review the INVOLVE exit Strategy which is a standard document required by the Department of all contracted NIHR services, to set out how risks of impact to service would be mitigated in the event of service transfer.

This was approved by the Executive Group and to be reviewed annually.

7. A.O.B

The Executive noted that they would like to formally thank Samaira for the important work during her time with INVOLVE. She has made a valuable contribution to a range of projects including the INVOLVE conference, the diversity and inclusion project, work with shared learning groups and of course the INVOLVE/RDS partnership.

Action

Zoe: Send a letter of thanks to Samaira