INVOLVE

NHS
National Institute for
Health Research

Notes of INVOLVE Executive Group Meeting

Thursday, 22nd September 2016
10:30-15:00

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

1. **Introductions, welcome and apologies and update of actions from August meeting**

   Attended: Wendy Baird (WB), Sarah Bayliss (SB) (notes), Tina Coldham (TC), Zoe Gray (ZG) (chair), Gill Green (GG), Una Rennard (UR), Lesley Roberts (LR), Paula Wray (PW), Gill Wren (GW)

   Apologies: Gary Hickey (GH), Martin Lodemore (ML), Mark Mullee (MM)

   Zoe welcomed Lesley to her first face to face executive meeting.

   Wendy asked for changes to be made to the minutes from the August Executive Group meeting as she felt the wording on page 4 under AOB was inaccurate.

   There were no other amendments required.

   Action
   ➢ **SB to make changes as suggested by Wendy and forward to Wendy for approval.**

2. **Review of 3 x Community Priority Area Project Plans & RDS partnership work**

   Standards

   Paula updated the group regarding the standards project which is co-led by INVOLVE and CCF, contributing towards the Going the Extra Mile. She explained that the Standards developed would build on the principles and values work to improve the quality of public involvement across and within the National Institute of Health Research (NIHR). They would be framed in such a way, with a clear set of self-assessment criteria, so that organisations across the NIHR see their adoption as integral to their continuous improvement in public involvement. The standards will

ensure that minimum levels of public involvement are attained and enhancements acknowledged and celebrated.

Paula outlined the objectives of the project as follows:-

- Utilise the Values and Principles identified [Public Involvement in Research Values and Principles Framework] along with existing standards and literature to develop appropriate standards.
- Draft standards and associated identifiers and guidance to be presented for consultation and prioritisation.
- Pilot agreed standards and evaluate.
- Roll out across NIHR and build standards into all activities.
- Celebrate achievements and continually improve the quality of public involvement in research.
- Capture impact

Paula explained that the next steps, following the initial workshops with public members, would be to draft a list of 6 potential standards and work up possible associated identifiers and guidance. These would then be presented to wider stakeholders for consultation and prioritisation at Shared Learning Groups, Health and Care Research Wales Conference and the NIHR Public Involvement Leads Meeting to see if there were any gaps and what support and guidance would be needed. Paula explained that some flexibility would need to be given in each organisation as standards vary so much within each organisation and will give a framework for reporting across the system.

Paula clarified that following on from this the standards would be piloted in January 2017 within the NIHR and within the shared learning group and then a public consultation would take place in February 2017. After the pilot the standards would then be evaluated and rolled out in December 2017 in phases across the NIHR with buy-in from the NIHR that the standards are upheld and will be the minimum expectation.

Discussions took place on how we can assure this is monitored and that everyone will have to report against those set standards. We need to ensure that the impact as to what has changed is recorded and a suitable reporting framework is developed to ensure that we don't add to people's workload. There should be a range of indicators with examples of good practice. Each organisation would be expected to report through their systems and will be available to public.

Further discussions took place and we should consider the following:

- Should PPI stats e.g. outcome of standards reporting be available on the NIHR PPI pages?
- Only meaningful metrics should be recorded and made public i.e. ask the public what they would like to know.
- Is money being spent on PPI as outlined in individual research applications? This should link to PPI reports within organisations as there is often

inconsistency and everyone reports in different ways. By the time it is followed up within programmes reporting it's too late to act. PPI plans should have built in protocols so they can be managed against what they are planning to do. Could this be incorporated within Research Fish, which has got public involvement questions which could possibly be strengthened?

Actions
> **PW to consider who might pilot the standards, consider the 10 RDS, which could help improve consistency across the RDS's.**

> **PW to attend PIC meeting to explain the how the pilot might work and the potential system for reporting standards.**

> **PW to consider the word count for the standards reporting system to ensure consistency.**

> **PW to take forward discussions around PPI involvement in projects with NETSCC to include evidence of the impact of patient & public involvement in research projects. Provide a link to this information and provide annual checks to ensure PPI plans incorporate protocols & keep the exec group informed.**

Diversity & Inclusion

Paula reported that The Diversity and Inclusion Work stream had arisen from Recommendation 10 in the Going the Extra Mile report (http://tinyurl.com/llekart) as well as previous work championed by INVOLVE through its Advisory Group. Paula explained that INVOLVE will have at its core an approach that integrates consideration of diversity and inclusion and it is envisaged that the role of INVOLVE will be to ensure that researchers are challenged and supported to improve their practice, working with other key bodies. She clarified that the values and standards work programme would also feed into this work stream and through benchmarking instill a greater and unified understanding of what constitutes inclusive and ethically sound practice in research and wider health and social care contexts. This work would be underpinned by a range of activities and resources that would serve to increase researchers' and clinicians' confidence and competence in this area and support active involvement of communities to help shape and deliver these activities.

Paula explained that although public involvement is accepted and done some researchers exclude those individuals who would potentially benefit the most through their exclusion criteria (non-English speakers). She wanted to produce practical guidance for researchers working with marginalised groups, giving practical examples for example actually going to these marginalised communities to talk to them instead of expecting them to come to you.

Discussions took place as follows:-

- We need to showcase good examples.
- People are afraid of offending as they don't understand culture.

- We need to think in different ways for example – use community venues rather than hospitals for meetings.
- Researchers need to go to where people are e.g. to care homes etc.
- Researchers say they don't have the time or money – they either need resource timescales or to be shown how it can be done.
- Is there a way of doing research differently Manchester are engaging the community in doing arts activities before even bringing up the possibility of research?

Paula outlined the work plan and a reported that a working group had been set up to steer this project, which would include members of the INVOLVE Advisory Group and other partners while exploring the challenges of this project. The Group would be working on methods of sharing information wider so that others could contribute. Paula went on to explain that the work plan for Diversity & Inclusion would be updated by the INVOLVE Diversity & Inclusion working group when they met in October, then discussed at the NIHR Voices event in Yorkshire & Humber on 10th November. Paula confirmed that the use of shared-learning groups to help broaden the reach of this work will be vital.

Actions
➢ **PW think about how you monitor diversity as it is much broader and can't be tokenistic, we need to move on and forward.**

➢ **PW to discuss with GG regarding a Diversity event to be held in spring that we could link into.**

Co-Production

Zoe asked the group to discuss the Co-production work plan, the long term objective of this plan is to ensure that NIHR staff, members of the public, and researchers who bid for NIHR funding are aware of and understand the NIHR approach to co-production and to ensure that NIHR is perceived as a leading voice in the wider debate about co-production and PPI in research.

Discussions took place as follows:-
- Key principles need to be looked at in more depth and attitudes need to change.
- How committed are the NIHR to co-production?
- We need to try to get a common view of what co-production is?
- Consider SCIE principles, who needs to be in room, how do we do that, how do we make it welcoming, how are boundaries broken by working together for a common aim?
- Understanding the possibilities of co-production and how it will improve research.
- Provide examples of where co-production can be applied and at what points in the research cycle.
- More inclusion and diversity is needed throughout the process with user researchers at the top of a hierarchical pyramid.

Actions
- ➢ **GH to please update the 'Building on people's existing capabilities' section of the project plan (page 2) as the group did not consider this was in a plain English format.**

- ➢ **GH to make amendments to the project timeline table on page 15 as it is unreadable as it stands.**

- ➢ **GH to ensure the timescales and outcomes of this project are realistic.**

- ➢ **GH to send the Co-production specification that has been sent to the RDS's to the Executive group.**

Regional Networks

The aims of the Regional Network Project is to ensure that the INVOLVE-RDS Partnership explores and supports existing networks and forums in each of the 10 RDS regions, and creates new networks where none exist. Links will be created to and from the regional networks to the national agenda, through the INVOLVE-RDS Partnership. Sustainable funding models for local networks will be explored, as no central funding will be provided by the INVOLVE-RDS Partnership.

Discussions took place as to when and how funding should be used to support regional networks. It was agreed that any discretionary INVOLVE financial contribution from its limited budget to events or activities in regional networks would be exceptional, as much of the work expected falls within remit of the organisations involved and shows their commitment to the network. INVOLVE are already offering resource (time) and boundaries should be established along these lines. However, INVOLVE budget holders reserve the right to contribute small amounts towards mutually beneficial activity in a regional network, where that activity aligns to INVOLVE strategic priorities and work programme goals and INVOLVE is acknowledged/co-branded, and where the organisation/s involved couldn't reasonably be expected to deliver (or deliver as well) without. Executive Group members advised that it should be on the basis of business case, in agreement with Director, and that it should be recognised that in some areas this will be needed, in others not, so INVOLVE should not be expected to contribute evenly. Executive Group members advised that rules are set on eligible and ineligible activities for any INVOLVE contribution.

Actions
- ➢ **ML, GH, PW to share the regional network current activity status paper with shared learning groups.**

- ➢ **GH, PW to find out if Lesley can be invited to the West Midlands network meeting on the 14th November 2016.**

Learning and Development

Zoe asked the group to discuss the Learning and Development project plan. The aim of the project will be to provide improved awareness and access to Learning and Development opportunities, using systems and tools that share information and improve understanding of learning and development for public involvement in research. This improved understanding will ease the identification of learning or skills that would benefit individuals and improve their experience of involvement.

Discussions took place about the CRN PPIE zone and it was mutually agreed that clarification was needed as to who it was actually meant for as public members are unable to access the NIHR hub. It was felt that INVOLVE needs to be more directive regarding Learning and Development especially at the Senior Leadership Team Meetings.

Gill Wren expressed her concern that the NIHR website doesn't have the facility for searchable databases and therefore having a route map to look at the different stages of research would be beneficial to public members. She mentioned that the new NIHR website will include a Learning and Development tab on the public page, within 'what's useful for the public'. Links will point to the CRN 'learning zone', which is very CRN-specific, but wider contributions from regional Learning and Development activities are welcome for the new Learning and Development tab.

Action
➢ **GW to make contact with Mick Mullane who is looking to produce a route map.**

Comments were made from the Executive group that the first page of Project Plans were not consistent across the board, some detailed sign offs, deputies and team and some didn't.

After discussions the Executive Group supported each of the Work Plans, subject to their reformatting

Action
➢ **PW, ML, GH to discuss format of front page of project plans so that they have an identical template.**

➢ **PW, ML, GH to ensure that if these project plans are to be sent to Advisory Group members that they are summarized and font 12 Ariel is used as Executive Group members struggled with the small print.**

3. Hub & Spoke – Sharing Information (invoDIRECT)

The group discussed the invoDIRECT paper. Gill Wren considered that the invoDIRECT system would be the best way of sharing information to enhance the RDS hub and spoke model, including how the work with regional networks would be displayed. She felt this could help those searching regionally, nationally or locally. She explained that this system could be used to hold local RDS information that is currently not on invoDIRECT. She felt the system is already working well and by adding new information would make it a more useful tool. Gill would be working with RDS's to develop a mechanism to populate invoDIRECT to make it even better.

Action
  ➤ **GW to attend next PIC hangout to be held on the 27th October and face to face meeting in December – contact GG for more details.**

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4. Conference – progress and approach

Zoe confirmed that INVOLVE approach on conference was coming together now and would be discussed further at the Conference Working Group Meeting being held on the 26th September. She outlined the likely regional flavour to the conference, with events feeding into the Conference in late 2017, which was subject to discussion of the working paper with the Conference working group, including Advisory Group and Associate members.

Wendy updated the group on RDS methods for organising regional events. She explained that administration of these events is provided nationally which included regional coordination of venues and local delegates and that good processes were in place. She clarified that it would be useful to get dates in diaries sooner rather than later, to ensure other regional events do not clash.

Looking forward Zoe mentioned that it might be possible to collaborate on ongoing regional events after the conference year, potentially in the same format i.e. 4 x events.

Action
  ➤**ZG to update the Executive Group as plans develop.**

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5. Work programme & Risk Register

Zoe updated the group regarding the work programme and Risk Register. The group discussed showcasing what INVOLVE had done so far and communicating the new ways of working and how INVOLVE had changed. It was felt important to do this by a drip feed method so by time the conference arrives people were already aware of that change and movement. It was felt that this should be communicated in many different ways. It was suggested that for INVOLVE Advisory Group members to get a feel of the new culture any good news and thoughts about conference should be communicated on a weekly basis ideally, starting before the next group meeting.

Discussions took place regarding the possibility of INVOLVE Advisory members/Associates to attend external meetings as INVOLVE ambassadors, to free up time for INVOLVE staff. Consideration would need to be given as to what events would be the most productive for them to attend. Training would need to be given to Advisory Group members with clear strategic objections and the corporate identity would need to be clear. This role should be offered to the best person for the job and be transparent.

Zoe clarified that the INVOLVE/RDS consortium agreement was very close to being signed off.

Actions
  - ➢ **ZG to chase Ellie for contract.**

  - ➢ **ZG/GW to discuss communications to go out to the advisory group and wider.**

  - ➢ **GH, PW, ML to discuss the INVOLVE ambassador programme further.**

  - ➢ **ZG to Add additional Risk to register regarding the RDS re-commissioning process as any changes to the current 10 RDS regions could affect the partnership with INVOLVE.**

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6. **International work**

Zoe updated the group to say that she would be attending the NHS research Scotland Annual conference held in Glasgow in October and the PCORI Annual Meeting in America in November where she was hoping to build some international partnerships.

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7. **Update from wider meetings e.g.: NIHR Strategy Board, PPI.**

Zoe updated the group regarding the Senior Leadership Team meeting, she felt there was a genuine commitment to work collectively and to refine the key objectives for next 3 years. She felt there was a willingness for Centre's to work together and for the group to give more direction e.g. in reporting to all parts of the system. Wendy commented that she thought a lot of the objectives were coming to INVOLVE that shouldn't necessarily be for INVOLVE.

Action
  - ➢ **ZG to consider the SLT recommendations and work out who should be doing what.**

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8. Future meetings – timings/approach

Wendy explained that there was a themed call launched event in January and she wasn't sure if this clashed with the Face to Face Executive meeting.

There were discussions around the Executive Group team building day that was planned for January. It was decided that this should be put on hold until the spring when the new public members would be in place.

Una wondered whether the public membership of the Executive Group should be a mix of INVOLVE Advisory Group members and wider PPI as it could make it too insular. Zoe explained that it was discussed with the recruitment sub group that for someone to feel able to fully contribute to the Executive Group, prior membership of INVOLVE was considered necessary, also this meant a clear flow through from the Advisory Groups strategic advice into strategy setting and work programme oversight.

Actions
> ➤ **SB to find out when the themed call launched event is in January in case it clashes with the January Executive Meeting (check with Sarah Puddicombe).**

> ➤ **ZG to consider new plans for the Executive Team Building Day with the team and make Ruth Nash aware of the change.**

9. AOB

Public involvement leads' meeting
Paula confirmed that a second Public Involvement Leads' meeting is scheduled for Friday 25th November in London, with Chris Whitty, Louise Wood and Simon Denegri confirmed. She explained that planning would be for 100 to 120 people, in line with the 2014 meeting. She explained that Sally Crowe would facilitate, but may need RDS PIC members to help with small-table work. Allocation of places will be managed, similar to 2014 i.e. expressions of interest to be sent from representatives from each region. The programme would include standards work, *Going the Extra Mile*, Learning and Development for Public Involvement Leads. It was agreed this would be a good opportunity to showcase how the INVOLVE-RDS partnership is working. Tina suggested that highlighting the dynamism of NIHR activity in public involvement might sway high-level attitudes towards the topic.

Wendy suggested that we raise the event at next RDS PIC meeting, to get members' input into how this meeting might best work. Also Executive Group members might be able to help where facilitation would benefit.

Part of the meeting will be to assess what would be useful for Public Involvement Leads and one suggestion was that perhaps INVOLVE could host an on-line

community for Public Involvement Leads for them to ask questions that others in the community might have answers to.

Actions

➢ **PW to raise event at next RDS PIC.**

➢ **PW to ask for help from Executive Group members to help with facilitation if required.**

➢ **PW to discuss with Public Involvement Leads if an on-line community would be useful.**

Who uses your Data Workshop?

Lesley updated the group regarding the 'Who Uses Your Data Workshop', she recently attended.

Action

➢ **LR to keep the group updated at future meetings.**