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*National Institute for
Health Research*

**National Institute for Health Research (NIHR)-wide learning
and development for public involvement: working
group report and recommendations**

June 2015

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National Institute for Health Research (NIHR)-wide learning and development for public involvement: working group report and recommendations

Foreword – Simon Denegri, chair of NIHR learning and development working group

There is more public involvement happening across the National Institute for Health Research (NIHR) than ever before. It has developed rapidly in response to the NIHR's commitment to research that improves people's health and wellbeing. By expecting research applicants to demonstrate how they will involve patients and the public, the NIHR has helped to create a cultural change in attitudes to and understanding of the importance of public involvement in research. This is a significant achievement.

Learning and development opportunities can increase the potential of public involvement in NIHR commissioned and funded research. The patient or researcher who is appropriately supported is a motivated and highly-valued member of the research team. They are able to make a positive contribution to a project or study. They can demonstrate what a difference public involvement can make to research and its outcomes. The satisfaction this brings can only be positive for the research environment of the future.

Some colleagues do not experience this satisfaction. They feel unsupported and ultimately frustrated that their skills and abilities are underused. They sense that public involvement is undervalued by those they are working with. Very little seems to stand in the way of them giving up entirely. What a terrible waste.

Across the NIHR one can find evidence of both these scenarios. Our aspiration must be to reach a state where people feel they have every opportunity to maximise their contribution and where the NIHR adopts a learner-centred approach to support public involvement.

Building on the activity of a working group convened by INVOLVE in 2013, the recommendations in this report recognise and understand the many pressures on organisations and colleagues at this time. Organisations and individuals will need to determine the best way to implement the recommendations. In doing so we hope they will quickly see that supporting public involvement and those who are part of it is a sound investment for the future.

I would like to thank my colleagues on the working group for their contribution to this report.

June 2015

Summary

This report makes recommendations for improving learning and development for public involvement in research. It documents the activities of a working group established in 2013 to initiate a discussion around leadership in learning and development for public involvement in research across the National Institute for Health Research (NIHR).

The report has been written for the Department of Health to contribute to strategic thinking about the issue. The recommendations are aimed at the NIHR on a strategic and organisational level, as well as at researchers and research managers supporting public involvement. The recommendations have been embraced in the report and recommendations of the recent strategic review of public involvement across the NIHR¹. The next step will be to take forward their implementation. The report is centred on the needs of the individual learner and is intended to be responsive to all those who practise and support involvement in research, including patients, carers, members of the public, researchers, clinicians, public involvement leads and staff in research support.

The aim is for appropriate learning and development opportunities to be integrated across the NIHR, ensuring learners (members of the public, researchers and research managers) feel supported to practise public involvement in research with confidence, maximising the potential for public involvement to contribute and influence the quality of research.

There is much to build on. Learning and development initiatives are taking place across the NIHR and beyond. Organisations and individuals are adopting inspiring and innovative approaches. However, these are pockets of good practice rather than consistent practice across the NIHR, with limited sharing of approaches. Duplication of effort leads to wasted resources. There is a clear opportunity for greater coordination, consistency and effectiveness in how learning and development for public involvement is delivered across the NIHR.

The recommendations recognise that the NIHR has a complex structure and that its organisations are facing resource limitations. Central direction and the combining of resources have the potential to improve the effectiveness of learning and development.

Turning the recommendations into actions for strengthening support for learning and development across the NIHR will require support from the Department of Health Senior Management Team and from the new leadership group for public involvement in the NIHR to be set up following the publication of 'Going the Extra Mile' in March 2015².

¹ NIHR (2015) Going the Extra Mile: <http://www.nihr.ac.uk/get-involved/Extra%20Mile2.pdf>

² See footnote above.

Recommendations

Across the NIHR it is recommended that:

- All learning and development for public involvement in research:
 - provides ongoing support in three key areas - administrative, research and personal support
 - is accessible to all
 - is appropriate and relevant to the task
 - acknowledges individual readiness to learn and builds on existing knowledge and abilities. (Section 2.2).

At NIHR-wide strategic level it is recommended that:

- The NIHR supports regional and sector-wide collaborations for the delivery of learning and development opportunities. (Section 2.4).
- The NIHR funds a national lead to provide a national and strategic role for learning and development (this could be based within INVOLVE). (Section 2.4).
- The NIHR allocates funds for research to evaluate the nature and impact of learning and development to support public involvement. (Section 2.5).

At organisational level it is recommended that:

- All NIHR organisations allocate resources and provide staff with induction training on public involvement in research. (Section 2.2).
- Learning and development for public involvement is resourced, embedded and promoted as part of organisational development within all NIHR funded organisations. (Section 2.3).
- There is clear senior leadership responsibility and accountability within organisations for the implementation and review of learning and development for public involvement in research. (Section 2.3).
- NIHR research commissioners demonstrate their commitment to public involvement in research by stating what they will provide to support learning and development. (Section 2.5).

At researcher and research manager level it is recommended that:

- Researchers and research managers work with public members to develop learning and development plans for public involvement to support themselves and those they involve. (Section 2.2).
- The learning and development needs for all public involvement roles are identified and reviewed. (Section 2.3).
- Members of the public are given clear information, advice and support to enable them to carry out their roles effectively. (Section 2.3).
- Members of the public are encouraged, supported and enabled to take responsibility for their own learning and development needs. (Section 2.3).
- Researchers report on learning and development for public involvement as part of their reporting to research commissioners on public involvement. (Section 2.5).

NIHR-wide learning and development for public involvement: working group report and recommendations

1. Background

1.1 Exploring learning and development across the NIHR

The need for support and guidance in developing appropriate learning and development approaches is one of the most persistent issues raised by those involved in research. A 2011 INVOLVE survey found that over half of National Institute for Health Research (NIHR) public involvement leads identified training as a priority area for greater support. Within this, three topics were viewed as most pressing: provision of training for researchers and the public; developing collaborative approaches; and sharing good practice for training and support. In addition to the need for training, other suggestions included producing resources and materials for public involvement leads and others to enable them to provide training and support themselves.³

In January 2013, INVOLVE facilitated a NIHR-wide stakeholder workshop for NIHR directors and managers, public involvement leads and senior Department of Health personnel. The aim was to explore a collective approach to learning and development for public involvement.⁴

Following the workshop, a time-limited NIHR-wide learning and development group was established. The aim of the working group was to make a plan for learning and development for public involvement in research across the NIHR. This was underpinned by a long-term aspiration that appropriate learning and development opportunities will become part of all NIHR programmes to ensure effective public involvement in research. Membership and terms of reference of the working group are on page 13. This report and the supporting documentation contained at the end describe the working group's activities and recommendations.

1.2 Learning and development in public involvement: importance, opportunities and needs

There are currently nearly 200 people across the NIHR in paid roles providing support for public involvement in research. The total number of members of the public who are actively involved is unknown. However, in 2013-14 over 1,000 members of the public were involved as members on the NIHR's expert advisory and research prioritisation groups, or as panel members reviewing research funding applications and one-off funding competitions. In addition there are many more

³ INVOLVE (2011) INVOLVE survey of priorities for public involvement across the NIHR. INVOLVE, Eastleigh www.involve.nihr.ac.uk/posttypepublication/involve-survey-of-priorities-for-public-involvement-across-the-nihr/

⁴ INVOLVE (2013) Support for learning and development - workshop report. INVOLVE, Eastleigh. www.involve.nihr.ac.uk/posttypepublication/support-for-learning-and-development-for-public-involvement-in-research/

members of the public actively involved in advising, supporting and undertaking individual research projects.

Learning and development is an important factor for effective public involvement. It ensures that people are prepared and supported to fulfil their roles. This applies to members of the public, public involvement leads, researchers, study teams and research funders involved in NIHR commissioned and funded research. It is also of relevance to the Coordinating Centres, which manage the various areas of the NIHR's work, both in terms of their funded research programmes and the wider communities they work with. People's backgrounds, existing knowledge and tasks are varied, and their learning and development needs are therefore diverse. Approaches to addressing these needs may include structured training, peer support, mentoring or self-directed learning and reflection.

This is not a case of starting from scratch. A number of learning and development initiatives are taking place across the NIHR and beyond. Innovative and inspiring approaches are being developed and adopted. In producing its online Training and Support resources in 2012, INVOLVE highlighted 70 examples of learning and development initiatives.⁵ However, provision was often restricted, uneven and fragmented.

While learning and development opportunities continue to be developed, the lack of coordination, limited information-sharing and potential duplication of effort poses a risk to continuity, sustainability and effective use of resources.

The next section describes the activities of the working group to further examine this agenda.

2. Issues addressed by the working group

2.1 Understanding the environment

The NIHR is a distributed organisation with a wide geographical spread. There is no central direction for learning and development and no centralised budget. Individual organisations have responsibility for their own workforce. It was therefore clear from the outset that it would not be possible or necessarily desirable to create a standard curriculum for NIHR staff, public contributors and researchers who need a range of skills and knowledge for effective involvement. Instead, the working group identified the importance of leadership and partnerships, from the Department of Health and throughout NIHR, to encourage a learner-centred approach where learners feel supported to practise public involvement with confidence.

The working group established a series of project groups to develop ways to explore and challenge how people learn about and develop their skills in public involvement.

⁵ INVOLVE (2012) Developing training and support for public involvement in research. INVOLVE, Eastleigh. www.involve.nihr.ac.uk/posttypepublication/developing-training-and-support-for-public-involvement-in-research/

Each project set out to be learner-centred, embracing the principles that, with support, people:

- can identify their own learning needs
- recognise their existing knowledge and experience
- are aware of how best they learn
- can make informed decisions about available learning resources that meet their learning needs and style.

The activities undertaken and subsequent recommendations are described below.

2.2 Principles and indicators for learning and development

The working group produced a draft set of principles and indicators for learning and development for public involvement in research (see page 15 for full details). These aim to guide practice and promote a learner-centred approach for members of the public and researchers and research support staff. The principles are:

Learning and development for public involvement in research:

- provides ongoing **support** in three key areas – administrative, research and personal support
- is **accessible** to all
- is **appropriate and relevant** to the task
- acknowledges individual **readiness to learn** and builds on existing knowledge and abilities.

These principles draw on relevant literature, good practice and consultation with people experienced in learning and development. They are underpinned by adult learning theory and build on the principles for training and support in the INVOLVE Values, principles and standards draft framework, which includes indicators for each of the principles as guidance for how they can be applied locally.⁶

In addition, the working group surveyed the views of 13 Biomedical Research Centres and Units, to explore the value of a formal accreditation system or kitemark for learning and development. After much debate, it was agreed that this would be impractical within such diverse NIHR settings. It is suggested that the principles could be developed further to create a tool for individuals or organisations to self-declare and assess their activities. This could be part of a training needs assessment, as well as provide standards to aspire to. Feedback on their use would help to further refine them. This could be facilitated by a national lead for public involvement learning and development (see section 2.4).

⁶ INVOLVE (2013) Values, principles and standards for public involvement in research. INVOLVE, Eastleigh. www.involve.nihr.ac.uk/about-involve/current-work/standards-for-public-involvement-in-research/

It is recommended that:

- All learning and development for public involvement in research:
 - provides ongoing support in three key areas - administrative, research and personal support
 - is accessible to all
 - is appropriate and relevant to the task
 - acknowledges individual readiness to learn and builds on existing knowledge and abilities.
- All NIHR organisations allocate resources and provide staff with induction training on public involvement in research. **(Organisations)**
- Researchers and research managers work with public members to develop learning and development plans for public involvement to support themselves and those they involve. **(Researchers)**

2.3 A learner-centred framework for involvement in research

The working group explored various approaches to promoting a learner-centred framework for involvement. This included a rapid scoping exercise examining the range of public involvement learning needs identified by people linked to two Research Design Services. A second piece of work explored the support people might need to become involved in research. This was undertaken by a Collaboration for Leadership in Applied Health Research and Care (CLAHRC).

From this, two example learning assessment resources were developed. One provides a tool to assist organisations in assessing the public involvement learning and development needs of researchers and patient and public contributors. This is on page 21. The second resource is designed for individuals to assess their own learning and development needs. It can be found on page 23.

In addition, a workshop was held to discuss how the notion of competencies and capabilities might contribute to and support a learner-centred framework. The language of competency caused concern due to its association with workplaces and appraisal systems. Public involvement is more about supplementing existing strengths and skills, and valuing people's knowledge and experience. It was also felt that competency-based approaches could be difficult to operationalise. However, it was also suggested that a modified competency-based approach could clarify role expectations for researchers, research managers and public members themselves. This could:

- help systematically identify what a person with specific role responsibilities should know, understand and be able to do;
- assist them in being effective performing a role; and
- provide them with the right ethos and values.

It was agreed that organisations and study teams should define what roles are needed locally for involvement and identify the associated skills and knowledge. As well as using modified competency frameworks and needs assessments, job descriptions could be developed and shared to promote wider learning and information sharing. There is also a need for individuals and groups to be supported to be self-reflective and proactive in identifying and addressing their own learning needs.

More widely, it was strongly felt that embedding opportunities for public involvement learning and development – as integrated, standard aspects of the research process - requires clear and accountable leadership. NIHR organisations should develop strategies to meaningfully support those in public involvement roles, recognising how this contributes to workforce and therefore organisational development.

It is recommended that:

- Learning and development for public involvement are resourced, embedded and promoted as part of organisational development within all NIHR funded organisations. **(Organisations)**
- There is clear senior leadership responsibility and accountability within organisations for the implementation and review of learning and development for public involvement in research. **(Organisations)**
- The learning and development needs for all public involvement roles are identified and reviewed. **(Researchers)**
- Members of the public are given clear information, advice and support to enable them to carry out their roles effectively. **(Researchers)**
- Members of the public are encouraged, supported and enabled to take responsibility for their own learning and development needs. **(Researchers)**

2.4 Promoting regional and sector-wide collaborations

The working group recognised the diversity and complexity of the NIHR environment, and the need for collaborative approaches to learning and development for public involvement. This can happen between NIHR organisations but also with external partners and agencies, where there are many opportunities for collaboration and co-production. A number of examples were investigated.

The Central Commissioning Facility (CCF) public involvement team is leading on the development of an online forum. The purpose is to support the learning and development of members of the public involved in reviewing commissioning briefs, research funding applications and other documents for the NIHR. Following a survey of NIHR public contributors, CCF has set up a test site for the forum. User feedback will be obtained to test how easy it is to access and to use.

The working group also identified that there is work needed to influence formal undergraduate and postgraduate learning to include public involvement in research. One example initiative, developed as a result of the working group's discussions, is the creation of an introductory online public involvement distance learning module for

NIHR trainees. The NIHR Infrastructure Training Forum is working with the CCF to develop this resource.⁷

The working group concluded that funding should be provided for a post, which could be located within the INVOLVE Coordinating Centre, to provide a national and strategic role overseeing learning and development. This role would enable the mapping of learning and development activity across the NIHR, as well as coordinate regional and sector-wide activities. In addition, the post would collate and widely disseminate examples of good practice and information using social media and online platforms. Importantly, it could actively encourage the adoption of shared principles across the NIHR. While a national lead would not have a governance role, NIHR organisations should be expected to state how they would work with the lead.

It is recommended that:

- The NIHR supports regional and sector-wide collaborations for the delivery of learning and development opportunities. **(NIHR-wide strategic)**
- The NIHR funds a national lead to provide a national and strategic role for learning and development (this could be based within INVOLVE). **(NIHR-wide strategic)**

2.5 NIHR research commissioning

Research commissioning is an area where there are particular opportunities to support and encourage learning and development for public involvement. NIHR research commissioners such as the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), the Central Commissioning Facility (CCF) and the Trainees Coordinating Centre (TCC) should make a stated commitment to how they will provide learning and development for those they involve in their work. For example, to support people who are members of boards and panels as well as those who assist with peer reviewing. This might include providing individuals with a linked person who will manage their relationship with the organisation and who is responsible for addressing the public contributors' learning needs.

As part of their budgeting for public involvement, researchers submitting applications for funding should include, within the costing section of the Standard Application Form, a budget for the learning and development they and their public contributors will require for meaningful and impactful public involvement.

For research studies, NIHR research commissioners and funders should emphasise the importance of learning and development by including a link to INVOLVE's learning and development resources on the NIHR Standard Application Form guidance.

The evaluation of learning and development for public involvement is linked to reporting. Individual NIHR organisations should undertake evaluations of activities and their impact on both the research and the individuals – public contributors and the research team – and contribute that learning to a continuous cycle of improvement.

⁷ Central Commissioning Facility (2014), Progress Report: Central Commissioning Facility PPI Plan 2013-15 www.nihr.ac.uk/CCF/PPI/CCF_PPI_Progress_2014.pdf

It is recommended that:

- NIHR research commissioners demonstrate their commitment to public involvement in research by stating what they will provide to support learning and development. **(Organisations)**
 - Researchers report on learning and development for public involvement as part of their reporting to research commissioners on public involvement. **(Researchers)**
 - The NIHR allocates funds for research to evaluate the nature and impact of learning and development to support public involvement. **(NIHR-wide strategic)**
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3. Next steps

In this report the learning and development working group has recommended strategies for advancing learning and development in public involvement across the NIHR. It has also made specific proposals and identified a number of tools to help colleagues make this happen within their respective organisations.

Following discussions with the Department of Health, the working group plans to hold a meeting with the original stakeholders, who contributed to its early discussions and direction. The workshop will aim to generate wider collective responsibility for implementing the recommendations and discuss practical proposals to achieve implementation.

The NIHR is a complex set of organisations and it will take time to ensure this learning and development agenda becomes more widespread, integrated and sustained within this system. However, there is much that the working group has observed that gives rise to optimism for the future. Good practice already exists across the country. Many colleagues are demonstrating energetic support for learning and development. There is ongoing commitment from INVOLVE and from public involvement leads across the NIHR.

The working group believes that the recommendations contained in this report are essential to maximising the contribution that public involvement can make to the NIHR in the future. With committed leadership from the NIHR, and support from managers, researchers, and public members, they are achievable.

Supporting documentation

A. Terms of reference and membership of learning and development working group

Aim of the working group

The aim of the working group is to develop and initiate a plan for a National Institute for Health Research (NIHR)-wide approach to learning and development for public involvement in research. The plan will be the first stage in working towards the longer term vision for learning and development for public involvement in research.

Our vision

Across the NIHR appropriate learning and development opportunities are integrated into all programmes to ensure effective public involvement in research.

Participants

The working group will be chaired by Simon Denegri, Chair of INVOLVE. A vice-chair will be drawn from the membership of the group. Secretariat for the group will be provided by the INVOLVE Coordinating Centre.

Participants will initially be drawn from across the parts of the NIHR that took part in the workshop convened by INVOLVE in January 2013, including two INVOLVE advisory group members.

Participants will:

- be invited by INVOLVE and join with agreement from their centre, which will cover the resources needed to participate
- have a good knowledge of issues related to learning and development for public involvement in research
- be able to bring wider intelligence to the working group than just their individual centre (for example from across the Research Programmes or across the national Research Design Service)
- be able to report back to a relevant oversight or strategy body for their part of the NIHR
- support the work of this group by contributing to taking forward the aims and objectives in between as well as at working group meetings.

Working methods

- The working group will be time limited to 12 months and will have a clear focus with specific objectives.
- INVOLVE will cover the costs of the working group (for example venues and catering for meetings, facilitators for specific activities and report writing).
- Whole group meetings will be one way to work towards meeting the objectives. Other methods and activities are likely to be required.
- A maximum of six whole group meetings are anticipated throughout the life time of the group. These will usually be held in central London.
- The meetings will adopt different styles to best meet the objectives. For example they may include small group working, facilitated sessions and

invited speakers and experts on specific topics. Meeting topics/agenda will be planned at least one meeting in advance.

- Any papers for the working group will be circulated, by email, at least one week in advance. Printed copies of all documents can be posted to participants and alternative formats can be provided, if requested.

Accountability

- INVOLVE will report on progress to its Advisory Group through quarterly Director's Reports.
- The working group will report back to the Department of Health at the end of the 12-month period.
- Participants will be responsible for reporting on progress and outcomes of the working group to their centre and relevant oversight or strategy body for their part of NIHR.

Progress review

The working group will be reviewed after six months to check progress towards the objectives.

Membership

- Simon Denegri (chair), Chair INVOLVE, Director for public engagement and participation
- Claire Ballinger, Wessex Collaboration for Leadership in Applied Health Research and Care (CLAHRC), previously Research Design Service (RDS) South Central
- Peter Bower, NIHR School for Primary Care Research
- Michael Clark, NIHR School for Social Care Research
- Alison Ford, NIHR Evaluation, Trials and Studies Coordinating Centre
- Deborah Hall, NIHR Nottingham Hearing Biomedical Research Unit
- Karen Inns, NIHR Clinical Research Network
- Rachel Matthews, North West London Collaboration for Leadership in Applied Health Research (CLAHRC)
- Tony Sargeant, INVOLVE member
- Derek Stewart, Associate Director, NIHR Clinical Research Network (March 2013-18 November 2014)
- Peter Thompson, NIHR Trainees Coordinating Centre
- Amander Wellings, INVOLVE member
- Philippa Yeeles, NIHR Central Commissioning Facility
- Sarah Buckland, INVOLVE Coordinating Centre
- Martin Lodemore, INVOLVE Coordinating Centre (February 2014-)
- Lucy Simons, INVOLVE Coordinating Centre (March-December 2013)

Supporting documentation

B. Draft principles and indicators for learning and development for public involvement in research

Deborah Hall, Director
NIHR, Nottingham Hearing Biomedical Research Unit

Purpose

This document is intended to support good practices in learning and development for public involvement in research. It is relevant to NHS, public health and social care research, and for both members of the public and researchers alike.

A set of general principles can guide practice and promote a learner-centred approach. The principles in this document apply to learning for members of the public getting involved and researchers and research support staff supporting involvement.

While indicators of good practice are difficult to define in ways that are relevant to all research activities and organisational settings, this document provides some real-world examples of what best practice might look like, to encourage individuals to reflect on how they might implement learning and development activities in their own setting.

Overview

The principles and indicators for learning and development for public involvement in research were developed by a sub group of the learning and development working group following consultation of individuals associated with INVOLVE and NIHR, which was facilitated via working group members.

Section 1: Principles for learning and development. The principles describe four codes of conduct that are specifically relevant to learning and development for public involvement in research.

Section 2: Indicators. The indicators demonstrate how these guiding principles can be applied to different aspects of learning and development. The indicators give ideas of the agreed way to involve the public and allow development of instruments to assess the quality and impact of learning and development for public involvement.

The indicators can be used to guide you in thinking about how to make these principles real within your local setting. It is not an exhaustive list, but should be useful and might inform future steps to develop standards of practice.

1: Principles for learning and development

Principles describe codes of conduct that guide good practice and provide a supportive environment for effective public involvement in research.

Principles for learning and development for involvement

Learning and development for public involvement in research:

- provides ongoing **support** in three key areas – administrative, research and personal support
- is **accessible** to all
- is **appropriate and relevant** to the task
- acknowledges individual **readiness to learn** and builds on existing knowledge and abilities.

This is the first project to identify principles and standards specifically around learning and development for public involvement in research. Other projects have considered learning and development within a wider remit. For example, an early study by Telford et al. (2004) reported eight principles of successful public involvement in NHS research, one of which was to offer people 'training and personal support, to enable them to be involved in research'.

The principles are intended to apply to learning for members of the public getting involved and researchers and research support staff supporting involvement. A separate NIHR INVOLVE review carried out in 2013 (INVOLVE, October 2013) identified the following six values that underpin good practice in public involvement activity:

- respect
- support
- transparency
- responsiveness
- diversity
- accountability.

These values and principles are being developed by INVOLVE into a framework which will include generic standards for public involvement in research⁸. The proposed principles and indicators for learning and development build on the generic value and principle of **Support** – 'Researchers and the public have access to the practical and organisational support necessary to enable them to involve and be involved'.

Section 2: Indicators

These questions are a pilot set of indicators and can be used to guide you in thinking about how to make these principles real within your local setting. They provide examples of the types of questions to consider but are not an exhaustive list. They may be useful to inform future steps to develop standards of practice.

⁸www.involve.nihr.ac.uk/about-involve/current-work/standards-for-public-involvement-in-research/

Ongoing support:

- Is your learning and development adequately resourced?
 - Have you sufficient funds to support the learning and development needs of those involved?
- Who is responsible for learning and development?
 - Is it one individual, the research team or the broader organisation?
 - Who will verify that the training is of a high standard?
- Does each member of the public have a named contact?
 - Who is this person?
 - Is their role clearly defined?
- What long-term support can you provide to promote continuous development?
 - Do you have a network of researchers, facilitators and the public to promote ongoing support?
 - Are one-to-one support programmes possible?
 - Do you have a mentorship scheme? (For example - engaging more experienced public involvement members to support and mentor newcomers and those with less experience.)
 - Can people access any online discussion forums or face-to-face discussions? Are these local or regional?
- Are people signposted to other sources of support?
 - How are standards maintained?
 - Who is responsible for keeping this information up-to-date?
- Are people signposted to opportunities to apply their learning?
 - How do you avoid people being ‘trained up with nowhere to go’?
 - Who is responsible for collecting information on opportunities?
 - How are these links maintained?
- How do you use feedback as a means for support?
- How do you ensure that you are sensitive to the emotional aspects of involvement?
- How do you maintain standards of good practice?
 - Does your organisation have a governance structure for public involvement with leadership support from senior managers?
 - Do you have a nominated person in your organisation who takes an active role in sharing best practice and supporting it where possible?
 - Have you considered whether accreditation is appropriate?

Accessibility:

- How will you promote and deliver your learning and development opportunities?
 - Are your materials presented in jargon-free, plain English?
 - Do you provide only written background information? Are there other presentation media you could use to help consolidate individual learning?
 - How much do you rely on internet-based sources? (Not everyone has access to the Internet, but for those who do it can widen accessibility as people can participate when it is convenient to them.)

- How accessible is the physical setting?
 - Where is the venue? (For example - travel distance, public transport links, parking.)
 - What is accessibility like? (For example - provision for people with mobility or visual /hearing impairments.)
 - Is the environment comfortable and welcoming? (For example - temperature, acoustics, refreshments.)
 - What time is it happening? (For example - daytime or evening as well as potential restrictions for bus pass users, people who rely on carers.)
 - How much time do people need to set aside?

- How accessible is the format of the activity?
 - Have you provided appropriate English language support?
 - Do people need large print, audio, Braille, visually supported speech?
 - Have you considered any relevant cultural, religious or ethical issues that might be a barrier to involvement?

- How flexible is the research team?
 - Will people be able to move in and out as they need or wish to? (For example - through illness, carer responsibilities.)

- Can you reimburse personal costs?
 - Does each project clearly specify the time commitments and reimbursement policy for that particular public involvement activity and associated training?
 - Are all payments open and transparent?
 - Can you pay in cash?
 - Can you reimburse costs in advance or on the day?
 - What about invisible costs such as office costs? (For example - paper, printing, telephone, postage.)
 - Can you organise and pay for travel for people in advance of the meeting?

- Are a diversity of experiences and viewpoints represented?
 - How can researchers engage with seldom heard groups? (For example - black and ethnic minorities, older people, children and young people, other marginalised groups.)

- Do you have a public ambassador to promote involvement within particular seldom heard groups?

Appropriateness and relevance:

- Do you have an explicit recruitment process for different types of public involvement in research?
 - Do you state the purpose for involving the public?
 - Do you clearly specify skills and personal attributes needed for each particular public involvement activity?
- Have you carried out a needs assessment?
 - How can you tailor learning and development opportunities to the needs of each individual?
 - How can you effectively manage people's expectations?
- Are you building on someone's existing skills, experience or prior knowledge?
 - How are these valued?
 - How do you make best use of an individual's unique perspective?
- To what extent will people 'learn by doing' the task?
 - Are there examples which focus on real problems and real contexts? (For example - vignettes, grant applications, study protocols, patient information sheets.)
 - Will participants be able to explore and evaluate their learning by using practical examples where the learning objectives can be explicitly demonstrated?
- What about feedback?
 - Do you evaluate each learning and development activity?
 - Do you use this feedback to continuously improve our programmes?
 - Do you share feedback with all those who have been involved?
 - Do you give feedback in a timely way?

Acknowledges readiness to learn:

- Have you set the ground rules or ways of working?
 - Will members of the public be involved in delivering training or supporting others?
 - Will researchers, facilitators and the public be learning together and supporting one another to share in their personal development?
 - How will you promote an environment of mutual respect?
 - What is your etiquette for workshops and interactive activities?
 - How do you ensure that all contributions are valued?

- Have your learning objectives been negotiated, agreed, made explicit, and understood by all?
 - Have you considered specifying learning objectives using active verbs such as 'at the end of this session, you will be able to do X, Y, Z'?
 - Can you provide a variety of different approaches and modes of delivery?
 - Are there both formal and informal opportunities for learning? (For example - lecturing, tutorial, experiential and paper-based, DVD, web-based, one-to-one, small group work, mentoring.)
 - Do you promote tools for independent learning?
 - Do you encourage debate and questioning?
 - How do you manage mixed-ability groups?
-

References

INVOLVE (2013) Values, principles and standards for public involvement in research, INVOLVE.

Telford R, Boote JD, Cooper CL (2004) What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations*, 7: 209-20.

Supporting documentation

C. Learning assessment tool for organisations to assist in assessing the patient and public involvement (PPI) learning and development needs of researchers and patient and public contributors

**Dr Claire Ballinger, Principal Research Fellow and PPI lead
National Institute for Health Research Collaboration for Leadership and Applied Health Research and Care Wessex**

This tool can be used by organisations working with both public contributors and researchers to identify for each stakeholder group:

- the desired focus or content of learning and development opportunities
- the preferred method(s) by which this content might be delivered.

The survey tool asks the respondent to reflect on the needs of researchers, public contributors and their own needs (with an opportunity to identify which group they align themselves with). In addition to providing information about PPI learning and development needs and modes of delivery, the survey tool can generate discussion about the perceived similarities and differences between the groups, how much insight each group has into the needs of the other, and whether stakeholder groups should explore learning and development opportunities together or separately.

This tool was used by the Research Design Service (RDS) South Central and others to carry out a brief scoping study of PPI learning and development needs ahead of the national NIHR PPI learning and development working group work.

Public involvement learning and development needs survey

<p>What, based on your experience, should be the focus of learning and development opportunities for researchers? (ie content).</p>	<p>What, in your experience, would be the most effective ways of meeting these PPI learning and development needs for researchers? (ie method of delivery, or process).</p>
<p>What, based on your experience, should be the focus of learning and development opportunities for patient and public contributors? (ie content).</p>	<p>What, in your experience, would be the most effective ways of meeting these PPI learning and development needs for patient and public contributors? (ie method of delivery, or process).</p>
<p>And finally, in terms of your own PPI learning and development needs, what would you identify as your highest priority in terms of content?</p>	<p>And what are your own preferences in terms of how these needs might be met? (ie method of delivery/process).</p>

If you are happy to do so, please share which category you fall into by putting a tick into the relevant box:

<input type="checkbox"/>	Patient or member of the public
<input type="checkbox"/>	Researcher
<input type="checkbox"/>	Other

If 'other', please write here how you describe your role:

Supporting documentation

D. Tool for researchers and the public to assist in assessing their learning and development needs

Rachel Matthews

**Theme Lead Patient and Public Engagement and Involvement,
National Institute for Health Research, Collaboration for Leadership and
Applied Health Research and Care, Northwest London**

Summary

This tool can be used by researchers and service users and is intended to start a conversation about the support a person may need to be involved and to generate reflections on the time and resources that may be required.

The tool has been tested and feedback received with particular thanks to Claire Ballinger at RDS South Central who coordinated a number of responses and Dr Allison Worth, Patient and Public Involvement Advisor, Wellcome Trust Clinical Research Facility Western General Hospital, Edinburgh. We think it would benefit from testing to develop it further and feedback can be emailed to r.matthews@imperial.ac.uk.

The comments show how some people have used the tool:

‘The tool was a springboard for a very useful discussion, even though we struggled with some of the wording, so we felt we would use it in an adapted form. For myself, it reminded me that I need to discuss this with each person I involve in a project right at the start and regularly throughout the involvement process. We used it electronically, but one of the patients said she wouldn't have done it electronically on her own.’

‘I like the idea of asking people to think about their hopes, fears and expectations of projects / activities they are about to start.’

‘The examples were helpful. I like the fact that they are not all examples of traditional training.’

Learning and development needs assessment tool for researchers and the public

Who is it for?

This tool is aimed at researchers and the public.

What is it for?

It can help to explore what support is required in order to form an effective partnership for meaningful involvement in research. The tool was created in response to the experiences of researchers and service users who find themselves involved with something they are unsure about and in recognition that more preparation is needed to enable people to understand what involvement could offer and enable them to make an informed choice about how it could work.

How is it used?

- Individuals can use the tool independently but, in practice, those who have found it beneficial used it as a tool to guide a face-to-face or telephone conversation and to create a dialogue between the researcher and service user. This builds a relationship from a shared perspective.
- It enables people to ask questions, identify relevant experience, challenge assumptions and set out shared aspirations for the task, project or study they will be involved with.
- The tool can be revisited over time to track progress with learning and experience by reflecting on changing needs and documenting examples of learning and development.
- Some people have used the tool to think about developing their CV and it could also support preparation for appraisal. It is **not** a performance management tool.

Before you start

Begin by reading through the whole document before starting.

For researchers it is helpful to assemble information about the task, project or study that people will be working on so that those with no prior knowledge can understand why it is being conducted and what it hopes to achieve. The use of language that is easily understood and the avoidance of acronyms can go a long way to generate interest and reduce the risk of people being discouraged at an early stage. You can look at the 'make it clear' campaign on the INVOLVE website for further guidance⁹

For service users it is helpful to take some time to think about things you enjoy doing and are interested in. It is also worth considering what new areas you would like to understand and are curious about or what makes you anxious. You could think about questions you want to ask. This can help you work through ideas with researchers and move towards specific personal goals.

The following questions may also help to consider before moving onto more specific questions about learning and development.

1. Why are you interested in working with others?
2. What do you want to happen?
3. What would you hope to achieve and how would you feel?
4. What's the worst that could happen and how would it make you feel?

Getting started

Over the next pages you will see a number of boxes with the following headings:

⁹ www.involve.nihr.ac.uk/makeitclear/

- What do you need?
- How can you get support?

The questions are deliberately broad to capture ideas in the widest sense and to recognise that people come from different backgrounds and have varying experiences. In the boxes are examples or prompts of what knowledge and skills people may need to acquire and how they might attain them. These can be changed and customised according to the nature of the task, project or study and this should be encouraged to more accurately reflect localised and personalised need.

Thinking about knowledge, skills, practice and experience – What do you need?

What can you bring from life, voluntary and work experience?

What do you need to know?	Record your ideas
For example What is research? What are clinical trials? What are statistics? Where does funding come from?	
What do you need to do?	Record your ideas
For example Read scientific papers Read reports Give feedback	
What personal qualities do you need to have?	Record your ideas
For example Influential Assertive A good listener Critical Able to speak to large groups	
What do you need to be able to work with others?	Record your ideas
For example Understand roles and responsibilities	

**Thinking about how your needs can be met – How can you get support?
How do you learn?**

How do you prefer to receive new information?	Record your ideas
For example Attend formal teaching sessions Hold a face-to-face session with another person Use online tools	

How do you like to learn new skills?	Record your ideas
For example Practise writing a report Observe an effective meeting Join an action learning set Get a mentor / coach	

How can others help you?	Record your ideas
For example Introduce me to the people I'll be working with Tell people how they can support me	

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INVOLVE

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