How to guide

How to train the public for involvement

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Contents

Introduction

A number of training courses have been designed and delivered to help patients and the public prepare for involvement activities across the range of health and social care settings[1]. This paper has been written to share what we have learnt about this in the East Midlands. The main part of the paper sets out some general principles and values that should shape training, and

an appendix lists some local, national and international courses that might provide a stimulus or template for local initiatives.

This paper was drafted by a group[2] called together by the East Midlands Academic Health Science Network as part of its work on Public Leadership. As readers provide feedback, further insights will be used to update the paper[3]. Please contact shahnaz.aziz@nottingham.ac.uk to suggest improvements or tell us how you have made use of this paper.

A note on language and the reach of this paper

In this paper, we use the term 'public' to mean patients, service users, carers and other members of the public. While we recognise that learning happens in a wide variety of contexts, the heart of this paper focuses on training which is intentional and planned rather than spontaneous and informal, which is for a group rather than for just one person, and which is a programme delivered over a number of sessions, rather than a single event. Whilst many training events may welcome learners from different backgrounds, including people who are employed as academic researchers or clinical staff, this paper focuses on training programmes that are targeted on members of the public.

Who needs to be trained?

Some would prefer to train professionals or senior managers[4] in how to engage the public[5], rather than training the public themselves. Others choose to run every training event for a mixed group of learners comprising both professionals and the public, so that all stakeholders end up with a shared understanding. This paper explains how to train patients and the public for involvement and offers links to further advice on this topic[6]. However, we believe that an approach which trains the public but ignores the learning needs of professionals is likely to fail.

Specific audiences have been trained for involvement, including older people[7], people with learning disabilities[8], care leavers[9], people with arthritis[10] and people with mental health issues[11].

A supportive context

In order for training to deliver maximum benefit, several other things need to be in place. These include:

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- Respect for members of the public. This will be shown in the quality of the welcome, hospitality and a host of other small but significant ways.

- A focus on building a supportive working relationship with each person. Our consistent experience is that effective engagement requires a real relationship between each member of the public and a named staff member in the organisation. While people may start a training programme without such a relationship in place, if it does not form during or shortly after the training, then there will be little lasting benefit. In addition to the working relationship with a staff member, effective peer support within the group of learners adds real value.

- In addition to receiving training, members of the public who are involved in participation activities need to be able to bring emerging issues to a [learning set](#) where they can receive additional advice and information, seek solutions and receive support.

- Success is enhanced when there is real clarity about details – who is eligible to receive training, what will be covered and how, the core values and intended outcomes, future involvement opportunities and what support will be offered. In addition, flexibility and resilience is necessary to deal with the unexpected and harness previously unrecognised talents.

- Continuous structured learning experiences, with opportunities for tailoring to particular needs and interests will be more effective than a standalone intensive induction experience that is not followed up with further opportunities for ongoing development.

- The organisation needs to [monitor the impact of the training](#) it delivers and take action in response to feedback in order to continuously improve. Evaluation might build on the well-known Kirkpatrick approach to evaluating learning. For an example, see the DIAMONDs project[12].

- Adequate resources and support from all parts of the organisation will enable the elements listed above to be delivered.

What are the goals of training?

The purpose and underpinning philosophy[13] of the training needs to be clearly defined. It is important to support the learner in their role in bringing an external perspective to the NHS or academic organisation, so the training

must avoid socialising the learner into the culture of the NHS or academic environment[14]. This is particularly challenging when the public contributor has extensive prior knowledge of the health service or health research environment.

Sometimes training is used to recruit newcomers into involvement activities, while at other times it is used to train people who are already heavily involved. The Institute of Health and Wellbeing (see the Appendix) has deliberately taken their training course to marginalised groups in order to build a more diverse group of public contributors. Specific audiences may need both content and delivery to be adapted.

In our experience only a few learners want a recognised accreditation[15] that follows assessment or examination, while more people prefer a certificate of attendance and a less formal approach.

When a learner has completed the training, there should be a range of participation opportunities for them to get involved. Training that leads nowhere simply increases frustration, while harnessing the training through new levels of contribution will increase value and build self-esteem. Services that arrange training should offer opportunities for learners to get involved in their own organisation and also be able to signpost people to opportunities elsewhere[16].

Designing the syllabus

The following topics might form a syllabus, either for a core induction programme or tailored additional learning to support contribution in specialised roles:

- Policy and evidence context – the importance of involvement, empowerment and coproduction. Evidence of impact on services and benefits of participation for the public.

- Continuous personal development – code of conduct, reflective practice, gaining skills and confidence, mentoring, coaching, knowing yourself,

- Interpersonal skills - sharing your story, curiosity, listening skills, confidentiality and disclosure, challenging others, the power of language.

- Services and tasks – understanding the NHS and its jargon and the role of relevant organisations. Understanding the activity that is being carried out.

- Influencing organisations – scrutiny as a critical friend, accountability, teamwork and committee skills, working through partnerships and networks and understanding how [organisations learn](#).

- Training the trainer and facilitator – presentation skills, use of powerpoint and participative exercises that enable all voices to be heard, responding to different [learning styles](#) and varying levels of ability, avoiding jargon.

- Ready for the unexpected – risks and what might go wrong and what to do about it.

- Finding out more – locating further reading and other sources of expertise.

In addition, guidance on specific training is available to equip people for taking up particular roles, such as membership of a general research group[17], project advisory group[18], project steering group[19], funding application reviewer[20] public researcher[21], and NHS non-executive director[22].

An alternative approach is to review the learning needs of an early career researcher and consider which, if any, of these competencies are relevant to the Public Contributor[23].

The following topics have been suggested as a potential syllabus[24]:

- *Understanding standard operating procedures*

- *Equality and diversity*

- *Principles of Good Clinical Practice (if a clinical trial of investigational medicinal product/CTIMP)*

- *Understanding roles and responsibilities*

- *Patient confidentiality*

- *Reporting of adverse events and incidents*

- *Record keeping and data integrity*

- *Data protection and information governance*

- *Recruitment and/or consent*

A regional strategy

We considered the merits of a regional approach to training the public for involvement. Such a training programme might begin with an introductory module to cover some common ground, augmented with optional modules which would add a range of specialist topics for people interested in specific issues. For example, we might imagine modules on

- education - especially relevant to Health Education East Midlands

- research – especially relevant to the Clinical Research Network, CLAHRC, research leads in NHS trusts and user-led research organisations
- leadership – relevant to the East Midlands Leadership Academy and transformation teams
- clinical care – the Strategic Clinical Network, Clinical Senate, NHS England, all provider services, Healthwatch and advocacy organisations
- commissioning – Clinical Commissioning Groups and Commissioning Support Units

Few staff working in involvement have extensive experience as trainers, and so we thought it might be helpful to have a centralised resource – one or more people who have real expertise in the involvement agenda combined with teaching skills. Local involvement lead staff could co-lead training events with the regional expert, thereby developing their own skills, blending their effective relationships with learners with the subject knowledge of the peripatetic trainer. Centralising expertise has potential to reduce decay in the quality of training.

See Sharebank for details of local training being offered in the East Midlands.

Appendix: What training programmes are already available?

Within the East Midlands

Within the English East Midlands, the following organisations have offered short courses of training[25]:

- Jackie Parkes at the Institute of Health and Wellbeing and Paula Wray from the East Midlands CLAHRC have developed a programme called *Partners in Research*. This provides four generic modules as follows: (i) the context of PPI, (ii) knowing yourself – including the skills and insight you bring to document review and discussion, (iii) coaching, buddies and mentoring, and (iv) teamwork, including Board membership. In addition, there is one specialist module on research. Learners can choose to have their work formally accredited or not, allowing some degree of flexibility for

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a diverse group of learners. The course lasts for 16 hours, usually spread over 3 days and run for a cohort of 12 people at a total cost of £3000. Around 40 people had completed the course by July 2014. One graduate has taken their research idea forward and is now studying for a PhD. The course has been [evaluated](#).

- Patrick Callaghan, Andrew Grundy and Debbie Butler have delivered an 'introduction to research' at the [Nottingham Recovery College](#).

- [LOROS](#) in Leicester has offered a '**Beginners guide to research'** training event, covering the research process, techniques, ethics and critical appraisal.

- Adele Horobin at the [Hearing Biomedical Research Unit](#) has worked with a group of public contributors to design a training programme for lay reviewers of research funding applications.

- Raksha Pandya-Wood at the [Research Design Service](#) has trained lay reviewers of research funding applications.

- Kirsty Neal at [Health Education East Midlands](#) has trained lay partners to work with the quality team in scrutinising service delivery by the Higher Education Institutions that train health professionals.

- Andy Wragg at the [Digestive Diseases BRU](#) is developing a project called 'Study Advocacy Volunteers' through which experienced patients support people who are newcomers to research participation.

- The University of Nottingham offers a number of [short courses](#) on Public Engagement to its staff and students.

- Nottingham CVS runs occasional courses on how to chair meetings and how to take minutes. Contact training@nottinghamcvs.org.uk.

Elsewhere and online

- NIHR Involve are collating training materials at https://www.invo.org.uk/current-work/learning/, including a course to equip people to review research funding applications http://www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/.

- Some Massive Open Online Courses (MOOC) are available, including:

- o [Introduction to cyber security](#)
- o [Health Technology Assessment: Choosing Which Treatments Get Funded](#),
- o [Making Sense of Health Evidence: The Informed Consumer](#),
- o [Improving Healthcare through Clinical Research](#)
- o [Building Research Partnerships](#)
- o [Attribution costs for Research and Development](#)
- o [Patient and Public Involvement: Inspiring New Researchers](#)
- o [The Ethics of Research](#)
- o [Medical Humanity: Engaging Patients and Communities in Healthcare](#)

- A peer-to-peer online support forum is available [here](#).

- The Personalised Care Group at NHS England and Improvement is running a [Peer Leadership Development Programme](#) as part of their commitment to develop 500 Peer Leaders by 2024. Jo Fitzgerald leads the Lived Experience Team in the Personalised Care Group which runs a personal development programme for people with lived experience who want to become Peer Leaders and a network for graduates of the programme. Read more about it [here](#).

- A [programme](#) developed by MacMillan and supported by the Clinical Research Network.

- A [web course](#) which has been created by the United States Cochrane Center as part of a project undertaken by Consumers United for Evidence-based Healthcare (CUE), and is designed to help consumer advocates understand the fundamentals of evidence-based healthcare concepts and skills. Registration is open and free of charge.

- The University of Leeds have created an [online course](#) that demands 4 hours a week for four weeks.

- Online training is available from the [European Patient Ambassador Programme](#).

- A 30 minute [PPI e-learning module](#) has been developed by Health & Care Research Wales and is aimed at people who are new to involvement.

- The *Engage to Change* online programme has been funded in 2015 by the Department of Health in partnership with UCLAN and [PEA](). Modules include (1) Understanding the Health and Social Care Environment (2) Facilitation and Engagement in the Health and Social Care Environment and (3) Using Data in the Health and Social Care Environment. Further details from [Alice.williams2@nhs.net]().

- A [Citizen Leadership]() programme (with [videos]()) has been developed by the Scottish Centre for Learning Disabilities.

- CLAHRC North West London has developed a [Fellowship programme]() that is open to both staff and the public.

- This [Healthtalk Online]() discusses Patient and Public Involvement in health research.

- Bec Hanley and Derek Stewart sell the following range of courses [here]():
  - Research Matters: Communicating your research
  - Groups or Individuals: is a patient reference group the answer
  - Beyond the Bench: Laboratory based Research and Involvement
  - Developing Partners: The Involvement of Patients and the Public as Partners and Co-applicants in Research
  - Completing Funding Applications: Making involvement meaningful in research proposals and in filling in the form
  - The Point of Care Foundation is offering the course on [Patient Leadership]() devised by David Gilbert.
  - The ESRC Centre for Society and Mental Healthat King's College London offers a '[Practical Guide to Peer and Community Research]()'.

University qualifications

Courses are offered by many academic institutions and other bodies[26] under a range of titles[27].

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[1] For an example of an evaluated training programme that equipped people with lived experience to coproduce mental health research, see Bellingham B, Kemp H, Boydell K, Isobel S, Gill K & River J (2021) Towards epistemic justice doing: Examining the experiences and shifts in knowledge of lived experience researchers over the course of a mental health research training programme *International Journal of Mental Health Nursing* DOI: 10.1111/inm.12910

[2] Zenn Athar, Peter Bates, Mick Crossley, Anne Marlow, Jill Guild, Evelyn Koon, Kirsty Neal, Jacqueline Parkes, Kate Sartain, Dave Waldram, and Kirsty Widdowson met on 5 August 2014. The text of the resulting paper was compiled by Peter Bates, who has continued to make minor amendments.

[3] An update is a single addition rather than a thorough review of the whole content of the paper.

[4] In 2022, NHS E/I launched an Engagement and Equality Champions project through which senior leaders act as champions for public involvement in their region or area of work. Part of this is a network and learning programme. Contact r.beatty@nhs.net.

[5] For an example, see http://www.invo.org.uk/working-together-to-develop-public-involvement-training/ or http://onlinelibrary.wiley.com/doi/10.1111/hex.12671/full

[6] See, for example, http://www.invo.org.uk/wp-content/uploads/2015/09/FINAL-NIHR-LD-report-July-2015.pdf. Also http://www.invo.org.uk/wp-content/uploads/2012/11/INVOLVETrainingSupport2012.pdf. Also http://www.invo.org.uk/wp-content/uploads/2011/11/TrainingSupportWEB140610.pdf

[7] http://www.invo.org.uk/resource-centre/library-resource/?id=553&section=invonet

[8] See Tuffrey-Wijne I, and others (2020). Developing a training course to teach research skills to people with learning disabilities: "It gives us a voice. We CAN be researchers!" *British Journal of Learning Disabilities*.;00:1-14. DOI:10.3310/alert_41365. Also http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132979.pdf

[9] http://www.invo.org.uk/resource-centre/library-resource/?id=318&section=invonet

[10] http://www.invo.org.uk/resource-centre/library-resource/?id=556&section=invonet

[11] http://www.invo.org.uk/wp-content/uploads/documents/MHRN_CaseStudiesAugust_2013.pdf

[12] See https://www.clahrcprojects.co.uk/news/clahrc-yh-evaluation-public-involvement-training-service-users-and-carers

[13] This is discussed at http://www.bris.ac.uk/social-community-medicine/people/sabi-m-redwood/pub/30888605

[14] A discussion of the different ways in which subcultures meet and influence one another can be found at http://thenadd.org/modal/bulletins/v11n6a3~.htm. As the socialisation process can both silence radical challenge and add value to it by enhancing its accessibility, relevance and applicability, it should not be viewed as an overly simple mechanism.

[15] Accreditation can be achieved via universities, further education establishments and other agencies, such as the NOCN.

[16] A key resource for finding out about opportunities for involvement across the East Midlands is *Public Face*. Please register for the *Public Face* bulletin here.

[17] http://www.invo.org.uk/posttyperesource/training-and-support-for-research-panel-member/

[18] http://www.invo.org.uk/posttyperesource/training-and-support-for-project-advisory-group-member/

[19] http://www.invo.org.uk/posttyperesource/training-and-support-for-project-steering-group-member-2/

[20] http://www.invo.org.uk/posttyperesource/training-and-support-for-public-reviewer/

[21] http://www.invo.org.uk/posttyperesource/training-and-support-for-peer-interviewers/

[22] https://www.gov.uk/government/publications/nhs-trust-and-foundation-trust-non-executive-directors-programme

[23] A competency framework for researchers has been set out by Vitae - https://www.vitae.ac.uk/researchers-professional-development/about-the-vitae-researcher-development-framework/researcher-development-framework_modified-v1.pdf/@@download/file/Researcher%20Development%20Framework_MODIFIED%20v1.pdf

[24] NHS Research and Development Forum (January 2019) *Involving service users and carers as co-applicants, project team members and co-researchers in research. Guidelines for sponsors, research managers and governance leads.* Page 4. Interesting to note the absence of any training on safeguarding here.

[25] The list here may be out of date and incomplete. We have not examined the detail or quality of any of these programmes so cannot offer any recommendations.

[26] See, for example, the *International Association of Public Participation* or the *International Association for Community Development*.

[27] Possible search terms include community learning, education or organising; community participation and leadership; community work; applied anthropology; civic, public or community engagement; citizen involvement and inclusion; community advocacy; dialogue; social, community or rural development; community enterprise, social entrepreneurship, deliberative techniques; community building; social change; public affairs; community sustainability.