

**INVOLVE Advisory Group Members' submission to NIHR Breaking
Boundaries review of public involvement 2014
June 2014**

Review of Progress to date

- NIHR has made good progress establishing structures and processes (for example, questions about public involvement as part of standard application forms, and INVOLVE work on plain English summaries) that promote and facilitate public involvement in health research.
 - Progress has been hindered by the distributed nature of NIHR organisation resulting in uneven and inconsistent support for public involvement and delivery of public involvement in practice.
-

Future of public involvement in NIHR

- The NIHR needs to strengthen the methods and criteria for auditing, monitoring, assessing, evaluating and reporting public involvement throughout the research cycle. This should include the quality, conduct and cost-effectiveness as well as the impact of involvement throughout research delivery. Research teams and research coordinating initiatives need to provide transparent evidence that they have delivered the public involvement strategies they describe in their funding applications.
- Continuing effort needs to be made to gather evidence on the impact of public involvement in improving focus, process, methods, outcomes and engagement and to demonstrate the difference involvement can make.
- Continuing efforts need to be made to gather evidence on the impact of public involvement to demonstrate how routinely using public involvement to inform research priorities, improve research methods, manage and disseminate research adds value to research outcomes and enhances patient benefit. This evidence should be used more proactively to tackle the evident scepticism and resistance to public involvement that is still influential in the health research community. Across the NIHR, there needs to a strategic approach to evidence, with

greater understanding of audiences, key concerns and how evidence addresses these concerns.

- Good progress has been made in establishing processes and structures to develop and support public involvement but these are being implemented in a variety of different ways across the NIHR. Challenges include funding for public involvement in the early stages of research design and reimbursement. For example, there were comments regarding standardising RDS pre-protocol award schemes to avoid postcode lottery. INVOLVE is well placed to provide strategic leadership and practical guidance on this.
- The NIHR needs to place stronger emphasis on the ability and capacity of research teams and research initiatives to facilitate the translation of research outcomes into innovative and improved routine clinical practice for patient benefit.

Dissemination of research outcomes needs to be rigorous and improved - directed more broadly at public and patient stakeholder groups. Dissemination strategies are too focused on academic publication and academic audiences. Research findings should be easily accessible to all members of the public.

- There is a need to create a comprehensive and consistent strategy for learning and development relating to the concepts, rationale and delivery of public involvement in research.

Learning and development: Properly funded and integrated training and support is critical. There should be greater understanding of public involvement in research for NIHR early career researchers and also undergraduates, nursing, allied professionals and a wider range of public and Community and Voluntary Sector contributors. High quality training and support should be provided for everyone involved in public involvement and all NIHR funded researchers required to undertake training. This would build on existing work such as INVOLVE's contribution to NIHR trainees programme to avoid duplication or reinvention.

- NIHR should work to ensure a greater understanding of public involvement and research in education systems and curriculum, embedding grounded principles and values around citizenship, equality and diversity and public accountability.
- There is a need for further development in actively and visibly supporting and promoting equality and diversity in NIHR public involvement.

- Promotion of public involvement and continued advocacy of public involvement requires more clarification of the conceptual underpinning of public involvement and more sensitivity on the part of advocates that structures and criteria have to have regard for variations in scale and purpose of health research. e.g. public involvement input into a Ph.D should be evaluated and scrutinised differently from a full and complex research application for a programme grant or Academic Health Science Network (AHSN). There is a need for proportionality and more guidance on how to adapt involvement for these different circumstances.
- Responsibility for public involvement at both local and regional levels needs to be clarified and more clearly located and coordinated as appropriate. NIHR structures should provide organisational capacity to achieve this and it would be pragmatic to build on existing and well-developed links. This might include funding for structured public involvement and public involvement support roles within Clinical Trials Units and large research Centres.
- NIHR should become more outward facing and play a part in joining up public involvement in health research and service delivery as well as encouraging further growth of public involvement by other research commissioners such as Research Councils, Voluntary organisations and industry, including commercial pharmaceutical companies. International links, with Cochrane Consumers, should also be explored.
- We need clarity on engagement, involvement and participation. They are part of the same spectrum of inter-related activities, but involvement must not be seen as of lesser importance than participation. User led research remains important to support.
- Greater guidance should be developed on exactly how patient or public co-applicants should be involved to avoid tokenistic approaches.

The role of INVOLVE

The INVOLVE Coordinating Centre supported and advised by Group Members has been very effective in influencing and embedding the purpose, value, evidence of impact and creation of organisational capacity to deliver effective public involvement.

INVOLVE is a nationally and internationally respected and trusted source of intelligence and expertise. This experience and expertise should be safeguarded and harnessed to provide national leadership for Public involvement, to establish and enhance NIHR capacity and capability to deliver

public involvement strategically and coordinate public involvement systematically across NIHR activity streams.

INVOLVE has played a crucial role championing and influencing the growth of public involvement, generating information sharing, providing coordination, and developing standards across the NIHR.

The experience and expertise of the INVOLVE Coordinating Centre and its members should be safeguarded and harnessed. Members not only have a breadth of experience of NIHR activity but also have external experience regarding patient experience, and embedding research outputs in service design/ delivery. As such, INVOLVE is well placed to expand its role to link public involvement in research and service delivery.

The central, strategic, leadership and co-ordinating role of INVOLVE should be maintained and strengthened to reduce duplication and to support and connect best practice at a local and regional level.

INVOLVE is a constant at a time of ever changing structures within the NIHR. This is of particular importance at the current time.