

Going the Extra Mile

The National Institute of Health Research is 10 this year and prior to this the *Breaking Boundaries Review* was commissioned to inform the public involvement strategy for the next 10 years. The results from this review formed the *Going the Extra Mile Recommendations*. This document is designed to provide you with an update on these recommendations including the key strategic leads.



FIGURE 1 NIHR'S GOING THE EXTRA MILE ROSETTE. ILLUSTRATING THE SYSTEM WIDE ROLES AND RESPONSIBILITIES FOR EACH OF THE COMMUNITY RAISED PRIORITY AREAS. WHERE POSSIBLE STRATEGIC LEADERSHIP IS ALIGNED TO THE KEY ORGANISATION THE OVERARCHING VISION IS FOR THE NIHR TO ACT AS ONE SYSTEM TO DELIVER THE [vision and mission](#) OF NIHR.

Many of the recommendations in Going the Extra Mile reflected the key issues raised as priority areas at the previous public involvement leads meeting in July 2014. Areas that have already progressed include:

- *The publication of the public involvement sections on the NIHR [website](#).*
- *Establishment of regional and national networks for public involvement.*

Recommendation 1: Information and Communication. *To improve the ways in which the public can learn about and become involved in research the NIHR will work with partners.*

Strategic Leads: National Director with NIHR Co-ordinating Centres

- *Currently reviewing ongoing portfolio of work aimed at improving patient access to NHS research and, in particular, the information provided to patients and the public as part of their care pathway. This aligns with the NIHR Strategy Board's focus on health and social care engagement. The key question is how we can build upon existing initiatives such as 'OK to Ask' and 'Patient Research Ambassadors' so that this engagement activity has greater impact.*
- *[UK Clinical Trials Gateway](#) (UKCTG) is being redeveloped as a service that will deliver on the NHS Constitution pledge to inform patients about research that they are eligible to take part in and encourage their participation.*
- *Public involvement has been crucial to this as it has been to the success of [Join Dementia Research](#)*
- *New NIHR Website with Patient and Public Involvement pages. <http://www.nihr.ac.uk/>*

Recommendation 2: Culture: *The NIHR will commission the development of a set of values, principles and standards for public involvement, to be co-produced with the public and other partners.*

Strategic Leads: INVOLVE and NIHR CCF Coordinating Centre

- *NIHR and Health and Care Research Wales (HCRW) have agreed to jointly develop a set of PPI standards. This work will be delivered by a PPI Standards Development Partnership, with representatives from INVOLVE, NIHR Central Commissioning Facility, HCRW and members of the public.*
- *The partnership will create a shared online space for updates on progress of developing PPI standards. The partnership has agreed a draft set of 6 core PPI standards that they will now test/consult on.*
- *Partnership is also closely working with the other devolved nations.*

Recommendation 3: Culture: *The strategic goals identified in the report will be included in the NIHR overall strategic plan and become the objectives against which public involvement, engagement and participation are planned and reported across the NIHR.*

Strategic Leads: National Director and NIHR Co-ordinating Centres

- *Public involvement, engagement and participation have been identified as a ‘business as usual’ priority by the NIHR Strategy Board.*
- *The National Director and wider senior leadership team are linked into this process to ensure appropriate focus on public involvement etc. The standards will underpin this to ensure consistency and quality.*
- *Look for stronger governance, accountability and audit processes for PPIE.*

Recommendation 4: Continuous Improvement: *INVOLVE will provide leadership and co-ordination across the NIHR, ensuring that the public and researchers are better supported to do public involvement. NIHR leaders, researchers and staff will receive an induction in public involvement and leads across the NIHR will have their own leadership and development programme as well as opportunities to share good practice.*

Strategic Leads: INVOLVE Co-ordinating Centre

- *Formal part of INVOLVE’s work programme. Looking at the learning and development needs of staff, researchers, patients and the public.*
- *Across NIHR several courses available from formal training courses to more informal mentoring and support.*
- *Hosting Public Involvement Leads Meeting*

Recommendation 5: Continuous improvement: *The NIHR will measure success along these indices:*

1. ***Reach:** the extent to which people and communities are engaged, participating and involved in NIHR research including the diversity of this population.*
2. ***Relevance:** the extent to which public priorities for research are reflected in NIHR funding and activities.*
3. ***Refinement:** and improvement: how public involvement is adding value to research excellence as funded by the NIHR.*
4. ***Relationships:** collaborative working for the advancement of public involvement across NIHR.*

Strategic Leads: National Director

- The NIHR PPI Senior Leadership Team working with National Director to define and support the delivery of these measures.
- There may be the opportunity for more public involvement ‘research on research’ and building stronger evidence for our work.

Recommendation 6: Co-production: *The public, researchers and health professionals will be empowered and supported better to work together in the future using the principles of co-production.*

Strategic Leads: INVOLVE

- INVOLVE have established a co-production taskforce to develop these principles and consider how they could be applied in practice
- Round table event where key principles were discussed and identify what aspects of co-production require further investigation
- Information gathered around identified gaps or issues



The project group will meet again in January 2017 to identify some options/further work.

Recommendation 7: Connectivity: *NIHR will support work that is locally inspired and driven whilst strategically consistent with the NIHR overall goals:*

Regional public involvement, engagement and participation ‘citizen’ forums and strategies will be developed.

Regional and local partnerships will be identified by the National Director for Patients and the Public in Research to lead on tackling key challenges in the development of public involvement, beginning with diversity and inclusion.

Building partnerships beyond NIHR boundaries – with health and social care partners, third sector and civic organisations - will be seen as a marker of success in this area and measured appropriately.

Strengthening and improving the support available to researchers locally and regionally through current delivery mechanisms such as the NIHR Research Design Service.

Regionally, locally and institutionally, NIHR infrastructure Directors and Boards should support and encourage public involvement leads to identify cross-cutting activity in public involvement and develop joint plans and resourcing where relevant.



Strategic Leads: National Director with INVOLVE and RDS

Regional networks are developing and evolving with different models in terms of membership, geographical boundaries, direction etc. These networks are supported by INVOLVE and the RDS, building on the published [review and analysis of regional working](#).

This work has included an initial mapping exercise and the allocation of a Senior Public Involvement Manager to work with partners in each of the RDS areas. However, public involvement colleagues are expected to address other aspects of this recommendation in the course of their normal business planning and strategic thinking. We will be evaluating the extent to which this work is happening as and when people submit their annual reports.

Recommendation 8: Co-ordination across NIHR: *Leadership and appropriate governance structures will ensure that the future development of public involvement in the NIHR has a clear sense of direction and is accountable. The NIHR National Director for Patients and the Public in Research will establish a leadership group to provide strategic leadership for public involvement, engagement and participation activities across NIHR and identify clear priorities for resourcing.*

Strategic Lead: National Director

- *Senior Leadership Team for Public Involvement with key leads from the NIHR Programmes and Infrastructure and public members.*
- *The INVOLVE Advisory Group is a smaller diversified body and with a membership which is more reflective of the NIHR family. Its work will also be focused primarily on the strategy and activities of INVOLVE.*
- *Public Involvement Leads Meeting*

Recommendation 9: Co-ordination: *All NIHR Coordinating Centres and infrastructure organisations will have a strategy, framework or plan that covers the promotion and advancement of public involvement, participation and engagement in research. Leadership accountability and funding for this agenda within organisations will be clear and transparent. Progress should be reported annually, made publicly available and an overview included in the NIHRs annual report.*

Strategic Lead: NIHR CCF

- *Delivery of Recommendation 9 links to the development of standards and self-assessment criteria for NIHR initiatives as cited under Recommendation 2.*
- *NIHR now makes public all the involvement and engagement sections of annual progress reports from 100+ NIHR initiatives [Public Involvement Sections of Annual Reports](#)*

Recommendation 10: Community: *A diverse and inclusive public involvement community is essential if research is relevant to population needs and provides better health*

outcomes for all. There are barriers when trying to work with different communities and populations, suggesting a system-wide issue that needs considered and careful attention. We will develop a specific NIHR work-stream in this area to look at these issues.

Strategic Lead: INVOLVE

- Provide support and resources for researchers
- Explore the needs of community groups and individuals
- Support equality, diversity and inclusion in our events, resources and communications.
- Deliver the new NIHR work stream on equality, diversity and inclusion

Recommendation 11: Review: An independent review will be commissioned by the NIHR in three years' time to assess the progress made in taking forward the recommendations in this report.

Strategic Lead: Department of Health

This has been built into the Department of Health audit process.

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