GOING THE EXTRA MILE:

Improving the nation's health and wellbeing through public involvement in research

The final report and recommendations to the Director General Research and Development/Chief Medical Officer (CMO) Department of Health of the 'Breaking Boundaries' strategic review of public involvement in the National Institute for Health Research (NIHR)

Public involvement [should] be so embedded in the culture of NIHR that new staff or new researchers coming into the field would naturally take on the values and practices of effective public involvement.

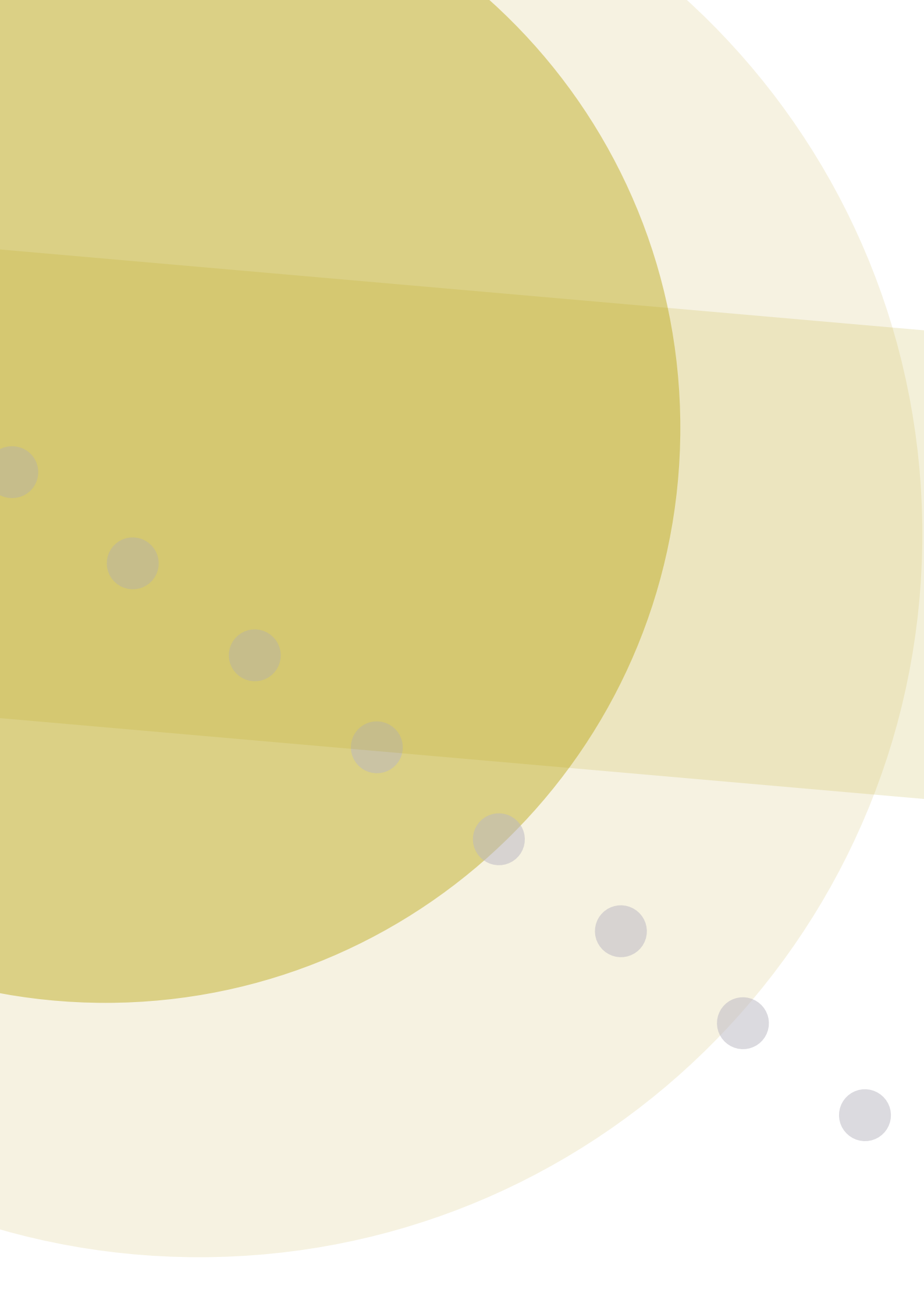
Researcher

Our vision for patient and public involvement in research in ten years' time is that of ... a vast increase in the number of people who know about PPI and have taken part in some way in local research. Researchers and clinicians will automatically include public groups when they start developing their research protocol and they will have easy access to people who want to be involved by some form of volunteers register'

Public contributor

The 'Breaking Boundaries' Strategic Review of Public Involvement in the National Institute for Health Research (NIHR) was commissioned by the Director General Research and Development/Chief Medical Officer (CMO) Department of Health. It is presented for their consideration by the Review Team. Throughout the report 'we' refers to 'the Review Team'.

We would like to thank all those who contributed to our Review and to the NIHR Collaboration for Leadership in Applied Health Research and Care North West London (NIHR CLAHRC NWL) for their expert support.



contents

introduction

The National Institute for Health Research (NIHR) is funded through the Department of Health to improve the health and wealth of the nation through research. Since its establishment in April 2006, the NIHR has transformed research in the NHS. It has increased the volume of applied health research for the benefit of patients and the public, driven faster translation of basic science discoveries into tangible benefits for patients and the economy and developed and supported the people who conduct and contribute to applied health research.

The NIHR plays a key role in the Government's strategy for economic growth, attracting investment by the life-sciences industries through its world-class infrastructure for health research. Together, the NIHR people, programmes, centres of excellence, and systems represent the most integrated health research system in the world **http://www.nihr.ac.uk**

The NIHR manages its health research activities through four main work strands:

- **Infrastructure:** providing the facilities and people for a thriving research environment
- **Faculty:** supporting the individuals carrying out and participating in research
- **Research:** commissioning and funding research
- **Systems:** creating unified, streamlined and simple systems for managing research and its outputs.

Language and terminology

We use the following terms to distinguish between activities:

Involvement – where members of the public are actively involved in research projects and research organisations

Engagement – where information and knowledge about research is provided and disseminated

Participation – Where people take part in a research study

When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services

For more information visit the INVOLVE website **www.invo.org.uk**

foreword

Simon Denegri

CHAIR OF THE BREAKING BOUNDARIES REVIEW
NATIONAL DIRECTOR FOR PATIENTS AND THE PUBLIC IN RESEARCH
CHAIR, INVOLVE

Every day, hundreds if not thousands of patients and the public go the extra mile to help make research happen in the UK. Their contribution is many and varied. One of the most important ways in which they make the difference is by improving the quality of research, how it is designed, conducted and delivered.

Within the NIHR, such is the extent to which the public have become involved that research is increasingly becoming a joint venture between patients and the public, researchers, clinicians and health professionals. If we are to meet the health and social challenges of the future then these partners must be empowered, encouraged and supported to work together.

This simple argument is the starting point for our report and recommendations: which concludes nine months of inquiry and dialogue about the state of public involvement across the NIHR as well as further afield.

Based on the views and opinions we have heard, there is no doubt in our minds that the NIHR is ahead of other Government research funders at home and abroad in the extent to which it has incorporated public involvement into what it does.

No researcher or institution who applies to the NIHR for funding can expect to be successful without a plan for public involvement that lay reviewers have scrutinised. Its James Lind Alliance Priority Setting Partnerships (JLA PSPs) lead the way in enabling patients, carers, clinicians and others to identify research priorities for future funding. Public involvement plays a vital role in strengthening the effectiveness and efficiency of the NIHR's Clinical Research Networks in recruiting people to studies. The advent of the NIHR Journals Library has enabled the results of NIHR funded research to be published and made more accessible, including accounts of how the public have been involved in studies.

INVOLVE - the national advisory group for the advancement and promotion of public involvement is an established leader in public involvement, with a solid foundation of experience and expertise in its membership. Its knowledge, guidance and support is highly respected and of immense value to the public and researchers alike. Last year almost over one million people visited its website, double the number in the previous year.

But the future is not simply about doing more of the same. The challenges facing the health of the nation means the NIHR and others must find new ways of working. As the research arm of the NHS, the NIHR must look to initiate, and be part of, work that brings together the public, researchers, health professionals, NHS staff and others as equal partners in gaining knowledge and ensure its effective adoption and diffusion across the health and social care system. With 95% of people saying it is important to them that the NHS carries out research, as reported to the NIHR Clinical Research Network (2014a) we are surely pushing at an open door.

Over the next 10 years the NIHR must therefore continue to work in partnership with the public in delivering high quality research. It must be seen to develop a relationship with the public such that it becomes second nature to what it does, as integral to the research it funds as accurate measurement. In this future scenario, research without evidence of public involvement would be considered flawed, the openness and transparency with which it is conducted, vital to maintaining public confidence in research, and their belief in its ability to improve their health and that of their neighbour. We believe this review will be important in making this happen and to the UK continuing to be the international leader in this field.

We would like to thank all those who have contributed to our inquiry. But also to thank the many people whose commitment and service to this agenda over the years has got us to this point. We would not be here without them.

About this report

Part One of this report states our recommended vision, goals and principles for the future. We also summarise our key recommendations. Part Two looks at the state of public involvement in the NIHR today and the factors that will influence its future development. Part Three sets out how we believe our recommendations should be implemented in the near-term. Part Four summarises the evidence we received, and includes a number of appendices including supporting references

part one

1 : our vision, goals and principles for public involvement

By 2025 we expect all people using health and social care, and increasing numbers of the public, to be aware of and choosing to contribute to research by:

- Identifying future research priorities and research questions
- Informing the design and development of innovations
- Participating in research studies
- Advocating for the adoption and implementation of research in the NHS

This contribution to research and a healthier nation will be openly acknowledged and recognised in the same way that other activities including volunteering are a celebrated part of civic society.

The NIHR must continue to lead by example; enabling and empowering patients and the public to 'get involved,' supporting those it funds to ensure they involve the public, influencing public, charitable and private funders as well as its partners across health and social to do the same. It is imperative that what have traditionally been seen as distinct activities – involvement, engagement and participation – as important bedfellows in opening up research to the public. The guiding rule should be that work or activity in any one of these areas should do no harm to the others. On the contrary, it should complement and strengthen them.

Over the course of our inquiry we have seen and heard how public expectations about how research should be conducted have changed. The suggestion that members of the public are 'subjects' or 'silent partners' in research is no longer a tenable position to maintain for any research organisation wishing to fund high quality research. Partnership, reciprocity and

openness are now fundamental to how research is done and to the successful translation of research results into practice.

The practice of co-production which is more often applied to service design and improvement merits further exploration in relation to research as a way to foster partnership, reciprocity and openness. This is a contested area and there is no agreed definition (Boyle and Harris, 2009; Boyle, Slay and Stephens 2010; Boyle et al 2010). Linked to this is evidence submitted to the review that explored the participatory research paradigm which offers a different approach to working with patients and carers in research. Cook (2012) explains:

"In recent years an approach to research that embeds active participation by those with experience of the focus of that research has been championed both from the human rights perspective, that people should not be excluded from research that describes and affects their lives, and from a methodological perspective in terms of rigorous research: ... knowledge constructed without the active participation of practitioners can only be partial knowledge" Somekh, 2002, p.90

This paradigm seems to chime with the views expressed by patients and carers who want to support and take an active role in improving healthcare through involvement in research. Hubbard et al (2014) published a study where women with breast cancer worked alongside academic researchers as co-researchers investigating the supportive care needs of women with this cancer in rural Scotland. The Rome Declaration on Responsible Research and Innovation in Europe in November 2014 emphasises the need to evolve a more inclusive approach to research:

"Hence, excellence today is about more than ground-breaking discoveries – it includes openness, responsibility and the co-production of knowledge." p.1

Consequently, the review team feels that the six characteristics of co-production described by Boyle, Slay and Stephens (2010) and documented in the principles section of this chapter offer a starting point from which to evolve and improve public involvement in research.

The characteristics of co-production encourage collaboration and underline the value of people's expertise through experience. We think these are critical to the design and delivery of relevant research and to improved health and wealth of the nation. Moreover they convey the importance of public involvement activities as a means to an end rather than ends in themselves.

In order to achieve a consistent focus, we think public involvement in the NIHR should be aligned to common goals which take account of localised experience and expertise Below we set out our recommended vision, mission, strategic goals and principles. They are intended to provide a clear sense of direction for the next decade and to make transparent the purpose and intent of public involvement to all of the NIHR's partners, but most especially to the public and researchers.

Vision

A population actively involved in research to improve health and wellbeing for themselves, their family and their communities.

Mission

The public as partners in everything we do to deliver high quality research that improves the health, wellbeing and wealth of the nation.

Strategic goals for 2025

1. Opportunities to engage and become involved in research are visible and seized by the public
2. The experience of patients, service users and carers is a fundamental and valued source of knowledge
3. Public involvement is a required part of high quality research conducted by researchers and their institutions
4. Public involvement is locally driven and relevant whilst strategically consistent with the NIHR's goals
5. Evidence of what works is accessible so that others can put it into practice
6. The NIHR has maintained its global presence and influence for working in partnership with the public

Principles

1. Building on people's existing capabilities
2. Promoting mutuality and reciprocity
3. Developing peer support networks
4. Breaking down boundaries
5. Facilitating as well as delivering
6. Recognising people and their experiences as assets

Adapted from Boyle, D, Slay , J and Stephens L. (2010) Public Services Inside Out. Putting Co-production into Practice. NESTA, London

2 : the purpose of this report

The Breaking Boundaries strategic review of public involvement was commissioned by the Department of Health and announced on March 31st 2014.

This review is the first, full-scale inquiry into how far the NIHR has been successful in achieving its original strategic goals in public involvement. More importantly, it has been an opportunity to conduct an open and collaborative exercise involving patients, the public, other funders and partners with the aim of guiding the NIHR as to how it can improve and strengthen its approach to public involvement. Our formal terms of reference were to recommend:

- A compelling vision and clear objectives for NIHR's leadership in public involvement.
- Areas where NIHR should be looking to maximise the public's contribution to health, social care and public health research in the future.
- Ways in which NIHR organisations should be thinking about, linking, planning and executing public involvement, participation and engagement activities.
- Options for the future support and organisation of public involvement across NIHR so that it is embedded in policy and practice.
- How the NIHR can grow a diverse and inclusive public involvement community
- Innovations and new thinking in public involvement in health, social care and public health research.

We would like to note from the outset that there is much to celebrate across the NIHR in terms of how it currently works with the public. NIHR's annual reports document examples of involvement and more information can be found by visiting any of the websites hosted by different programmes and departments funded by the NIHR. None of this would have happened without the commitment of the NIHR and the thousands of patients, the public and researchers. **A real sense of the amount of progress being made in public involvement is evident from the opinions, ideas and views gathered during the course of our work. We will ensure that this evidence is made available to the wider community by INVOLVE in due course.**

The primary purpose of our review is to set a clear course for the future. In setting about this task, it soon became clear that there was a palpable tension between those colleagues who advocated radical departures from the status quo and those whose preference is for continuity and steady improvement. Both are natural and symptomatic features of a social movement that is still relatively immature and underdeveloped in the NIHR. On the one hand, there is the impatience to achieve more; on the other, the desire not to undo what has gone before.

Against this background, **our task has been to recommend a set of actions that will create the right environment in which innovation can thrive – particularly at a local level – and strong and sustainable improvement in public involvement be achieved across the wider landscape.**

3 : recommendations

Recommendation 1 – Communication and Information: To improve the ways in which the public can learn about and become involved in research:

a. A consortium including the NIHR, NHS England, Public Health England and public representation should be established on a time-limited basis to consider the needs of patients and the public for information about research. It should have the ability to develop and test different approaches to providing people with information as part of the care pathway and in different health and social care contexts.

b. A single access point or 'portal' for enabling patients and the public to access information simply and easily about research how they contribute locally and nationally should be co-produced by the NIHR, NHS England, patients and the public and third sector organisations. NHS badging and placement will be an important to public trust.

c. The NIHR should run an annual competition to identify best practice and new ideas in using social media and new technology in public involvement, engagement and participation.

Recommendation 2 – Culture: The NIHR should commission the development of a set of values, principles and standards for public involvement. These must be co-produced with the public and other partners. They should be framed in such a way, and 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 achievements of the public, staff and researchers in promoting and advancing public involvement should be celebrated and acknowledged by the NIHR.

Recommendation 3 – Culture: The strategic goals identified in this report should be included in the NIHR overall strategic plan – otherwise known as Vision, Strategy, Actions, Measures (VSAM). These should be the objectives against which public involvement, engagement and participation are planned and reported across the NIHR health research system.

Recommendation 4 – Continuous improvement: We recommend that INVOLVE builds on its forthcoming report on organisational approaches to learning and development by providing leadership and co-ordination including working with workforce development initiatives across the NIHR. It is clear from our inquiry that the public and researchers need to be better supported to do public involvement. All NIHR leaders, funded researchers and staff should receive an induction in public involvement as part of the overall change programme

set out in this document. Public involvement leads across the NIHR should also have their own leadership and development programme and opportunities to network and share good practice.

Recommendation 5 – Continuous improvement: We recommend that the NIHR measures success along three indices for the foreseeable future:

- Reach: the extent to which people and communities are engaged, participating and involved in NIHR research including the diversity of this population
- Relevance: the extent to which public priorities for research are reflected in NIHR funding and activities
- Refinement and improvement: how public involvement is adding value to research excellence as funded by the NIHR.

The results of the 2014 Research Excellence Framework (REF) should be analysed by INVOLVE for key learnings and ways to develop this evidence base for REF2020. Above all, public involvement, particularly in relation to the gaining of knowledge, should have an equal importance to wider forms of engagement and science communication, within the REF 2020 definition of societal benefit for panels that have a health and social care remit.

Recommendation 6 – Co-production: The public, researchers and health professionals should be empowered and supported better to work together in the future. In respect of the co-production principles that we have been minded to embrace we recommend that the NIHR consider establishing a co-production taskforce to examine how these can be applied in practice. The taskforce should have the ability to undertake rapid-testing of these to establish their importance in delivering research excellence.

Recommendation 7 – Connectivity: What's happening at grassroots level must continue to be the driving force in public involvement. Here we wish to see further support given to work that is ***locally inspired and driven whilst strategically consistent*** with the NIHR overall goals:

a. Regional public involvement, engagement and participation 'citizen' forums and strategies should be developed in each of the Academic Health Science Networks (AHSN) geographies. We would expect the NIHR's Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), Research Design Services (RDSs), Local Clinical Research Networks (LCRNs), Biomedical Research Centres and Units (BRC/Us) to play a key leadership role in the development of these.

b. Regionally, locally and institutionally, NIHR infrastructure (CLAHRCs, BRU/, BRCs, LCRNs etc.) Directors and Boards should support and encourage public involvement leads to identify cross-cutting activity in public involvement and develop joint plans and stable resourcing where relevant.

c. Regional and local partnerships should 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.

d. Building partnerships beyond NIHR boundaries – with health and social care partners, third sector and civic organisations - should be seen as a marker of success in this area and measured appropriately.
e. Strengthening and improving the support available to researchers locally and regionally through current delivery mechanisms such as the NIHR Research Design Service.

Recommendation 8 – Coordination: Leadership and appropriate governance structures will be vital to ensuring 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 should establish a leadership group consisting of public contributors, senior researchers, public involvement and engagement leads, and a supporting NIHR-wide public involvement forum of public involvement and engagement leads, to provide consistent and coordinated strategic leadership for public involvement, engagement and participation activities across NIHR and identify clear priorities for resourcing.

Recommendation 9 – Co-ordination: All NIHR Coordinating Centres and infrastructure organisations should 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 must be clear and transparent. Progress should be reported annually, made publicly available and an overview included in the NIHRs annual report.

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. We have been struck by the degree to which researchers and public contributors have encountered barriers when trying to work with different communities and populations. This suggests a system-wide issue that needs considered and careful attention. We would recommend that a specific NIHR workstream be developed in this area in the same way that it has developed other work programmes such as 'Adding Value' or 'Pushing the Pace.' At a bare minimum, a meeting of NIHR senior leaders and colleagues should be convened in the next 12 months to surface the key issues for wider debate.

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

part two

4 : public involvement in the NIHR today

In 2006 the Government set out the following goal in its strategy for health research: ***Best Research for Best Health***:

> 'Patients and the public must be involved in all stages of the research process: priority setting; defining research outcomes; selecting research methodology; patient recruitment; interpretation of findings and dissemination of results.' Department of Health (2006) p.34

Since then public involvement has become an important strategic priority for the NIHR and a growing focus of activity.

Public involvement is a requirement of NIHR funding across its centres, units, schools, facilities, programmes and networks. Plans developed by researchers together with the public to meet this requirement, set out a range of public involvement activities aimed at improving the relevance and quality of research – from members of the public being co-applicants for research grants, to the setting up of advisory groups composed of patients, service users and carers or similar. There is also evidence of service users acting as researchers and working alongside academic and professional colleagues during the course of research projects. The review was unable to determine the exact numbers of people involved in research across NIHR but we do know that:

- Nearly 700 public contributors were involved in reviewing over 1000 applications received by the NIHR in 2013/2014.
- The NIHR is currently involved in twenty active James Lind Alliance Priority Setting Partnerships (JLA PSPs) which bring together patients, carers and clinicians to identify research priorities in a range of disease areas and are becoming increasingly influential with research funders

- 1 million people visited the INVOLVE website last year, double the previous year and 106,000 people visited the website in September 2014 alone.

Welcome though these developments are, we were struck by the observation of one contributor that **there is now a 'frenzy' of public involvement activity happening across the system.** An informal and unpublished census by INVOLVE suggest, for instance, indicated that there are now upwards of 200 'public involvement leads' across NIHR itself. At the other end of the spectrum, it is evident that many colleagues – particularly at a local and regional level - are inhabiting an uncertain planning and funding environment in which an emerging activity such as public involvement is highly vulnerable. Overall, this suggests a lack of overall strategic prioritisation and planning for public involvement across NIHR.

Recurrent issues for these colleagues and most importantly, for the public, are summed up in figure 1.

Given this, the emerging issue for NIHR is how to support and encourage public involvement so that it increasingly adds value to research, leading to better health outcomes for patients and the public, rather than being a tokenistic exercise or an end in itself. How does it reach the same status as other elements of the research cycle without which that work would not be seen as tenable?

Fig 1. The Review asked people about the current state of public involvement in health research in 2014. In summary they highlighted:

- The value of working with the public and the difference it makes
- Inconsistencies in practice and implementation across the NIHR
- Barriers to the public contributing to research including negative attitudes and lack of support
- The importance of partnership and collaboration to future success
- How we might do things differently

INVOLVE

One of the most important actions that the NIHR took when it was established was to bring INVOLVE – the national advisory group for the advancement and promotion of public involvement in research – under its wing and provide it with long-term support and funding. This has been crucial to the development of public involvement within the NIHR, across the UK, and internationally.

We welcome the fact that the NIHR will be continuing its support for INVOLVE for a further five years. This review has provided input into the specification for the new INVOLVE Co-coordinating Centre Contract informed by views from the public, researchers and organisations. The tender for this contract will begin shortly, with new arrangements taking effect early in 2016.

We were unanimous in our conclusions that it is unrealistic for the NIHR and the wider community to expect INVOLVE to continue to serve all needs across the system We believe INVOLVE will continue to have a critical strategic role to play, with a particular focus on supporting continuous improvement in public involvement across the NIHR: facilitating networks, defining quality and providing appropriate guidance, and monitoring and evaluating activity. **It will be important for INVOLVE to work closely with other influencers across the NIHR - its clinical research networks, coordinating centres and Research Design Services to name but a few – and towards common goals to ensure that the role of public involvement activities in different parts of the overall system is clear, well-understood and properly coordinated.**

Charities and industry

Other funders have an important part to play in nurturing public involvement across the wider health research system. **Overall, neither the medical research charity sector nor industry have made as much progress in nurturing public involvement in their funding processes as the NIHR** (Tarpey and Bite, 2014).

However, there are some wonderful examples of public involvement by individual charities such as the Alzheimer's Society and Parkinson's UK, as well as a number of companies, with some evidence that for many others it is becoming more of a priority. The Association of Medical Research Charities (AMRC) has also underlined (2014a) the importance of public involvement to realizing its vision for research in the NHS.

We note the view expressed by some medical research charities that the NIHR is regarded as rigid and inflexible in its interpretation of what public involvement is. Whatever opinion we might have of this, the more important point for the future is that **there could be a much more vibrant discourse between the NIHR, charities and industry as to understand how to collaboratively act to develop the relationship between health research and its many publics.**

The recently announced Innovative Medicines and MedTech Review as reported by GOV.UK (2014) which will look at, among other things, 'how charities and patient groups can play a greater role so that NHS patients can get access to cutting-edge treatments' may offer an opportunity to scope out this area in greater detail.

International

It says something about the high regard in which the NIHR is held that colleagues from Canada, USA, Australia, Denmark and the European Patients Academy on Therapeutic Innovation (EUPATI) were generous with their time so that we could better understand the international context in which the NIHR is now operating.

The UK is seen as a leader in public involvement across the world. One of our international contributors commented that 'if the UK is the adolescent in this area, we are the toddlers.' INVOLVE was cited frequently as an important factor in the NIHR's successful approach to public involvement and one that they wish they could replicate on their own national stage.

At the same time, it is evident that **there is much the UK can learn from what is being done in other countries.** Public involvement in the UK over the last twenty years has been very focused on improving research processes and on the contribution of the individual patient, service user and carer. In comparison, **the strengths of the models of public involvement being developed in Canada and the USA include their focus on communities and their assiduous attention to maintaining a clear line of sight from research design and delivery to patient outcomes and experience.**

Recent international workshops at the INVOLVE Conference in 2014 highlighted the benefits that **would be gained from the NIHR initiating and promoting international networking and dialogue with public involvement colleagues in other countries. We welcome the fact that, closer to home, the National Director has indicated his intent to hold regular meetings on public involvement between the four UK nations, beginning in 2015.**

5 : the changing context for public involvement in research

The context for public involvement in the NIHR is changing rapidly - from health and social care reform, to changes in the way research is conducted. We note below just some of the trends and shifting boundaries that we perceive in the external environment. They represent both opportunities and challenges for public involvement.

- Patients involved in research can benefit in a number of ways which can also improve their experience of care (Coulter, 2011; Robert, 2013; Foot et al, 2014)
- Healthcare organisations that are research active are more likely to show better performance (Hanney et al, 2013)
- People's knowledge gained through their experience of health and social care and research is vital to developing the treatments, interventions and services required to tackle the health needs and priorities of the population (All Party Parliamentary Group 2014).
- Public expectations about health and social care are changing (KPMG Global Healthcare, 2014) including the importance of research to the quality of their care
- Public involvement has a significant role to play in improving the effectiveness and efficiency of research (Ennis and Wykes, 2013)
- 'Community and patient empowerment' are seen as critical elements to helping the NHS meet future challenges. (NHS England, 2014)
- Policy and legislative developments including the Health and Social Care Act 2012 have opened the door to the NIHR, working with NHS England and others, to increase opportunities for the public to contribute to research (NIHR 2014b)
- Public involvement, engagement and participation will have an important bearing on the impact of NIHR research as measured in the Research Excellence Framework (REF) in 2020.

- The medical research charity sector makes a significant contribution to UK research in terms of funding and public engagement and has articulated a clear vision of the increasing role that patients and the public have to play in NHS Research (Association of Medical Research Charities, 2013)
- The Life Sciences Industry is seeking to build new partnerships to maintain its capacity and capability for innovation. (Association of Medical Research Charities, 2014b)

Public involvement in governance will be an important determinant of the success of research and related initiatives and public trust in them (Nuffield Council on Bioethics, 2015)

6 : pushing at the boundaries of public involvement, breaking new ground

There was considerable consistency in how people expressed their vision of public involvement for 2025. Many people talked in terms of wanting public involvement to be 'embedded,' 'normal,' 'usual,' 'standard practice.'

Achieving this vision of public involvement by 2025 will require a strategy and comprehensive set of actions which push at current boundaries Informed by the evidence, views and opinions that people shared with us, we have identified a number of significant areas of change, including the need for:

- Communication: a clear and simple message
- Collaboration: the development of a mutual partnership
- Co-ordination: processes to ensure strategic development
- Connection: regional and local activity as the engine room for national progress
- Continual improvement: best uses of information and good practice
- Community: the need to involve a diverse and inclusive public
- Culture: of empowerment and support

We enlarge on the individual elements of these below:

When asked, the public, researchers and other colleagues identified some common priorities for the future including the need for:

- Greater public awareness of research and NIHR's role in making it happen
- Public involvement to be seen as normal and accepted practice
- An enhanced evidence base on the value of public involvement
- An improved understanding and agreement about quality in public involvement.
- Agreed measures for how public involvement is making a difference
- Global leadership in public involvement in research

- **A simpler and more straightforward message needs to be presented to the public in the manner of the 'Get Involved' or Involved banner used by Charities and others.** The growing lexicon for public involvement including acronyms, coupled with inconsistencies in how language and terminology are applied, is becoming a barrier to the active collaboration of people and researchers.
- The NIHR has shown a willingness to initiate and support important and innovative campaigns to raise public awareness and understanding of research - from 'OK to ask' and 'Research changed my life' to social media competitions. **However, we believe a more coordinated approach involving a wider alliance of partners in support of a simple proposition about research would make a significant difference to the numbers of people getting involved.**
- **We have concluded that principles of co-production such as 'reciprocity' are ones upon which the NIHR should base research culture involving the public in the future.** Meeting the challenges of the nation's health and wellbeing will need research collaborations that go beyond traditional boundaries. In our view, the most successful collaborations will be those where knowledge is shared in a mutual partnership between researchers, the public and health professionals.
- The boundaries between traditional notions and definitions of public involvement, engagement and participation are blurring as are the boundaries between research and the provision of health and social care services. **Understanding these changes but also sharing models and examples of flexible practice that ensure a strong patient voice at all stages of research will be essential.**
- **There is a pressing need to facilitate appropriate strategy development, co-ordination and reporting of public involvement across the NIHR.** The growth and expansion of public involvement has inevitably outgrown current approaches and is causing issues of accountability, consistency and continuity.
- **Regional and local activity in public involvement is the engine room for progress nationally.** It will be important to ensure that the future delivery of public involvement facilitates work that is locally driven and relevant whilst consistent with the NIHR's strategic objectives and business plan. The public's engagement in identifying how to make better use of existing local resources at this level will be vital to improving the efficiency and effectiveness of research in a financially difficult climate.

- **The NIHR make more constructive use of its current systems for gathering information and reporting on public involvement.** This should enable good practice to come to light and be shared much more quickly but also ensure issues are managed more effectively. Existing qualitative and quantitative data about public involvement in the NIHR is under-utilised. In some areas the data quality is poor.
- **A diverse and inclusive public involvement community is essential to the NIHR in developing excellent research that is relevant to the population's needs.**
- **More can be done by the NIHR to generate a culture which will support and empower the public, researchers and health professionals to work together.** From ensuring that staff receive basic induction in public involvement, ensuring consistency in the application of expenses and reimbursement policies, to recognising and rewarding their achievements in this area.

part three

7 : what will happen next?

This report recommends a comprehensive set of actions for strengthening the NIHR's relationship with the public. Implementation will require:

- Support from the NIHR Strategy Board for the direction of travel set out in the report
- Organisations signing up to these new priorities
- Collaboration and partnership working across the NIHR to deliver them
- Careful planning and refocusing of existing resources
- Management through new lines of accountability

1. In the immediate period following publication of the report we ask those who submitted their views to us but also those who didn't to reflect on our vision, recommendations and let us know what you think about the priorities we have identified and future work. You can email your thoughts to the National Director for Patients and the Public Research at: Simon.Denegri@nihr.ac.uk
2. The National Director for Patients and the Public in Research will begin to establish the systems and structures needed, working in partnership with others, from 1 April 2015 **(Recommendation 8)**. The recommended Leadership Group will provide oversight of the implementation agenda for the remaining recommendations in the report
3. In the 12 months after publication of this report the National Director and Leadership Group will lead a 'line of sight' exercise, supported by a small delivery group of champions from each region. The aim of this will be to assist the NIHR's co-ordinating centres and infrastructure organisations to begin to align their plans with the strategic goals we have identified for public involvement.

4. Local NIHR organisations will be expected to take the lead on facilitating regional conversations about the report with patients and the public and how they can support its implementation in their area, including identifying those priorities where they believe they have the expertise to lead future work **(Recommendation 7)**.
5. This year the National Director will lead a piece of work to engage and encourage colleagues and public contributors across the NIHR to share their stories of how their work has added to the reach, relevance and refinement of NHS research to improve health and wellbeing.

8 : conclusions

We conducted our review under the title of 'Breaking Boundaries' to encourage people to look beyond their present-day experiences of public involvement. Our final report title: 'Going the extra mile: improving the nation's health through public involvement in research is deliberately intended to set the bar higher for public involvement; to set a tone and style for the future in which research and the public are seen as indivisible.

Helen Keller said: "Alone we can do so little; together we can do so much." We believe our review reflects the fact that the NIHR has made important strides in building a strong partnership with the public as part of the high quality research it funds. But it is just a beginning. The NIHR must now bring the many strands of this partnership together into a joint venture with the public, and support it appropriately. This venture should be focused, cohesive and have mutuality at its core. Research will be the better for it, as will the health and wellbeing of the nation.

part four

9 : our findings

How we collected views, opinions and evidence

Submissions were invited from a wide range of sources and the following opportunities were created to gather information:

- Questionnaire available in word format to download from the NIHR website to send electronically or by post
- Online survey monkey questionnaire
- Audio and video evidence
- Documents
- Invitation to international, third sector and industry representatives to meet and share views with the panel
- Workshops, meetings, social media

The review questions were designed to allow people to share as much or as little information as they wished. We invited those submitting views to respond to five questions. Open questions were used with a series of prompts to help people explore elements of why, what and how.

Over 80 responses were received from an institutional, organisational or collective perspective and these were submitted to thematic content analysis too. The volume of data is large and could support further detailed analysis and will be transferred to INVOLVE and made available to others in line with relevant information governance policies and procedure.

The findings are presented by review question. The emerging themes were tested with individuals and groups outside of the panel to check for any areas of contention and dispute. Some respondents expressed a preference that their views were not included directly in the report.

Question 1 : overall evaluation of progress

Many views noted that there is progress across the NIHR to raise the profile of public involvement, foster good practice and make a difference for patients and their families.

Making a difference

Not surprisingly, individuals recounted a diverse range of experiences, many positive, of being personally involved in research. Patients and carers described learning more about conditions and treatments that affect them or others and gaining insight into the research process. They reported positive relationships with researchers and finding opportunities to gain new experiences, knowledge, skills and contacts. For example:

'It has given me a platform to represent the views of carers and service users in the design and implementation of research. It has given me a role in life as a lifelong carer I have often felt apart from the world of work and have before my PPI work floated without a purpose.' ID 156 Public

Researchers expressed the positive impact they gained from public involvement. This included changing the research focus to make it more relevant to patients, altering study designs to take account of experience and to improve recruitment. Researchers reported feeling more purposeful and connected to the potential beneficiary of research.

'It has helped to keep my research close to the concerns of service users. Working with service user researchers in designing studies has been important in keeping the research questions and methodology focused on the concerns of those who will ultimately benefit.' ID 332 Researcher/ Academic

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'A huge difference. I have worked with people with learning disabilities to make research information and materials easier to understand. It has made me see how complex most information sheets and consent forms are and how they assume a level of literacy which is not common. We have seen how to many people, the explanations we give out about research use terminology people do not understand. We now begin by explaining what research is - a researcher is not a job anyone has ever heard of and they are amazed it's what I do for a living!' ID 285 Researcher/Academic

There is evidence that the commitment from the NIHR to include the public in research activity has strengthened over the last ten years and the presence and positive influence of INVOLVE was noted as important in achieving this.

Poor experiences

However, this is not a universal picture. Some respondents reported negative experiences. These ranged from very personal disappointments of being involved in research to a general sense of frustration in being unable to understand what research is, what the NIHR does and how it links to NHS services. There was also confusion around how to access information and opportunities to be involved. This suggests a varied picture of personal practice, organisational commitment and institutional culture for example;

'I wholeheartedly agree with the intentions and principles of PPI… Unfortunately, I think that lip service is given to PPI by some academics. There is a lack of transparency about how service users who are involved in research studies are selected, approached, recruited and what biases might be operating.' ID 15 Researcher/Academic

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'… Some organisations are in a frenzy of PPI because they know they have to do it not because they want to.' ID 260 Public

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'When I began I sat on a clinical studies group and was largely ignored, unless I made a big effort to get noticed, which I did'. ID 29 Public

Scepticism and professionalisation

Researchers and other respondents reported similar frustrations in managing public involvement ranging from scepticism about the value, underpinning theoretical concepts and practice standards of this endeavour, through to confusion, apprehension and anxiety about how to conduct it in a way that demonstrates a positive impact and shows a return on the investment of time and money. There is also concern about 'professionalisation' where experienced patient advisers feel they are penalised for gaining expertise and are labelled as 'professional' patients. Researchers are wary of using experienced advisers because they perceive that the very experience those individuals started from may evolve and be diluted over time. Professionalisation may manifest in others ways. Some believe it is a voluntary duty to support research and the NHS as a way of giving something back, others are unable or unwilling to be involved without financial support. Attention is drawn to narrow opportunities for involvement that place a disproportionate burden on some patient groups;

'PPI architecture tends to call for a small number of individuals to make a massive commitment. This means it is hard to find people who can do it and those who do come forward are probably not representative of the wider population. We should try to design more distributed systems which are less clunky and more dynamic (more "Web 2.0"). Instead of periodic half-day meetings, break things up into smaller modules/components that can be distributed among more people so it is less of a burden for each person. This could allow more people to get involved and it would democratise PPI.' ID 216 Public Involvement Lead/Specialist

Relevance and usefulness of research with public involvement

A number of respondents noted that by involving patients, researchers were more likely to address issues of relevance to those with direct experience of a condition, treatment and care. This emerged as an important issue for third sector organisations. Patient respondents with similar views reflected on how decisions are made about the allocation of research funding and the potential for and speed at which relevant research can be adopted into practice to benefit patients quickly.

Respondents describe aspects of personal transformation such as gaining new knowledge, changing attitudes and adopting different ways of doing things for example,

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'As an ex-clinician, since working in close association / collaboration with service users (mostly stroke survivors with aphasia) my perspectives on what is important to research and how to go about it have changed quite profoundly.' ID 283 Researcher/Academic

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'I think public involvement - lay review - has forced researchers to think more about the "patient journey". It's great to see proposals that will minimise the number of hospital visits and/or investigations. I do not think researchers would be aware of the anxiety caused by "waiting for results" if it were not for patient groups'. ID 28 Public

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'It has enabled increased recruitment through access to hard to reach and minority groups. It has ensured that public facing research materials are accessible and understandable for lay people - again, this increases recruitment. It has enabled evaluation of the experience of those participating in health research - and subsequent trial design has improved, again increasing recruitment. It has ensured where possible that research outcomes are disseminated in a timely and accessible way – resulting in a more informed patient population.' ID 91 Public Involvement Lead/Specialist

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'I have been involved in Focus Groups where people with a diagnosis have been very brave and spoken publicly of how they feel, how different drugs have affected them, how the public treat them. This has sometimes brought researchers up short, people are thought of differently not just as numbers or statistics'. ID 188 Public

Question 2 : what stops public involvement in research?

This question revealed familiar and persistent themes.

Public awareness

Although there is greater awareness of public involvement in research there is a sense that the opportunity is not accessible to all and that information was hard to find particularly for the wider population. Groups that were considered to be rarely involved included people who were identified as 'healthy' now but who may use health services in the future. Evidence submitted by those working in public health particularly emphasised the risk of reinforcing inequalities and missing opportunities to improve health in communities with the most to gain.

''I think the whole 'public involvement' side of things is very good at the moment. However, the information (online) about it, such as the opportunities available and how to apply, could be simplified'. ID 32 Public

Many commented on the need for a high profile communication campaign to raise awareness of health research and demystify the activity in a way that the general population could engage with;

'People don't know what research is or how it applies to them. This needs more promotion and better explanation. A lot of people ask me if my interviewing research will mean they get injected with things because they only know about clinical research' ID 285 Researcher/Academic

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'Red tape! And with that I mean the involvement of so many entities that need to be included on literature and outputs that it takes over the visual message to the public, it gets complicated, confusing and messy. People need to know what is out there, how they can get involved and why it's happening. The acronyms, that then need to be spelt out and explained along with the many avenues an opportunity comes from, suddenly gets too difficult to decipher unless you're an academic or a clinician.' ID 227 Other

Some respondents drew attention to the need to state the case for public involvement in research more clearly which they felt had been overlooked or underplayed in policy and procedural guidance.

Attitudes

In the main the attitude of respondents was positive and committed towards public involvement but some were sceptical and could not find any evidence that it made any difference. This influences how research and researchers are perceived for example,

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'Paternalism - the idea that those in charge know best, and the public shouldn't get involved and just leave things to "the professionals"'. ID 84 Public

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'Attitudes take time to change, and there are clearly still many academics, and institutions, who regard academic excellence as being in some sense 'above' the practicalities of everyday life. The emphasis on the 'impact' of research outside academia, introduced in the 2013 Research Excellence Framework, was not universally welcomed. For whatever reason, the quantity of funding achieved by an individual is now as important a criterion for promotion or salary increment as publications, teaching innovation or other academic excellence. This is an area where a widespread cultural change is needed. Research should be valued primarily for what it achieves, not for how much it costs'. ID 263 Researcher/Academic

Resources

The variable availability and allocation of resources was a common theme. Respondents reflected on this in different ways. For example, there is frustration that funding to support relationship building and partnership work ahead of preparing funding applications is often perceived to be hard to obtain and inadequate to support a minimum standard of good involvement practice.

The development of the cost calculator and budgeting guidance by INVOLVE was identified as being a very helpful practical resource. However there is concern that this is not widely known about and third sector representatives in particular were unfamiliar with it but could immediately see its benefits

Infrastructure

As public involvement has grown across the NIHR, variation in the infrastructure to support the activity has arisen across programmes, organisations, institutions and regions.

'Firstly, the NIHR could be more transparent, use less acronyms, be more open to public involvement, and develop ways of supporting public involvement in the various groups, committees and constituent parts of the NIHR. The impression given, rightly or wrongly, is that PPI is not really embraced in the working of the various arms of the NIHR. This may relate in part to the impression of heavy performance management - with these in mind it is difficult for the public and patients to see how they have a place.' ID 230 Researcher/Academic

'There is far too much duplication, working in silos and re-inventing the wheel. We need to free ourselves up to enable more time and resources for innovation and creativity. This needs to be joined up with academic and NHS public involvement strategies so that patients have one gateway into involvement opportunities and clear signposting from there'. ID 526 Public Involvement Lead/Specialist

Public involvement posts may be full time, part time, an element in other posts or devolved across research teams. It would be premature to draw conclusions about what this may indicate but it raises questions about how infrastructure decisions are made, what evidence is available about effective models and to what extent public involvement practice across the NIHR and the NHS can be aligned.

Recognition, reward and payment

Another significant element in this area is the vexed issue of recognition, reward, reimbursement and payment. Despite the availability of guidance, local NHS and Higher Education Institutional policies and administrative practices are obstacles which slow down prompt reimbursement and payment. The current financial status across all public services and the impact of austerity policies on our society are adding additional challenges. There is a risk that those who get involved are those who can afford the time and money to do so, compounding issues of exclusion that are identified by respondents. This area merits further investigation but is unlikely to be straightforward because of the tension between financial and social capital in this activity.

'Established groups can provide a wide range of support (research design, pre-funding through to dissemination). The University of Hertfordshire group has nearly 10 years of expertise, members are trained in research methods so can provide quick responses to researchers' requests. However, finance for groups such as these is precarious and without sustained and adequate funding it is difficult for groups to continue to develop and expand their contribution despite the increased requirement for PPI if bids are to be successful. Core funding is needed to fund administrative support of the group as well as advertising, outreach work, mentorship and training of current and new members.' ID 29e Researcher/Academic

Training and support

Many respondents commented on training and support for public involvement. This aspect is already identified by INVOLVE as an area that required specific attention. There is broad agreement that a basic level of support should be available to anybody who becomes involved and a minimum skill level and knowledge about public involvement should be incorporated into researcher training. Ideas and observations about what is required were offered by respondents:

'I attended the RAPPORT (Research with Patient and Public Involvement – a realist evaluation) study feedback. It made me think about levels of training required. Currently the training provided is basic, to explain what PPI is and help researchers plan how to proceed (I have taught on such workshops)'. ID 74 Researcher/Academic

'Training early career researchers in good involvement practice would help increase confidence and understanding of public involvement and reduce the likelihood of bad involvement experiences. We think that the experience of members of the public who have been involved in research should be drawn upon within such training, and that two-way mentoring between researchers and lay representatives should be encouraged'. ID 19e Charity

Inconsistent expectations and approaches

Some respondents expressed difficulty in understanding clearly what is required for public involvement and how to deliver it. Because there is no consensus on 'why' or 'how' to do it nor widespread use of existing guidance there are inconsistencies in expectations for those who are invited to be involved and for those who wish to involve.

There seems to be difficulty in translating evidence into practice and as a consequence evidence is not routinely tested in the real world and practice evolves in an ad hoc way. Many individuals and teams work independently of each other even within the same organisation, institution or region although there are areas where a more collaborative approach is emerging, notably in the West of England. For some there is a desire to introduce standards whilst for others a systematic but flexible approach which addresses key elements such as 'why', 'how' and 'who' are more palatable.

'Making all involvement opportunities task specific, time-limited, with clear expectations and guidance on what people should expect from being involved and how their input will be qualified (e.g. two-feedback/appraisal process on how people are performing). Providing information on outcomes of previous, relevant research and examples of how PPI was crucial to the effectiveness of the research trial. Create an agreed glossary of lay wording e.g. health research rather than clinical trial.' ID 91 Public Involvement Lead/Specialist

Frameworks do exist to support evaluation but they may be designed for specific programmes, publications, groups and individuals when in fact the difference public involvement makes may manifest at multiple levels and can be taken from a variety of perspectives for example;

'One would be at the start of a study, to plan ahead how to evaluate the impact of PPI on the research, and on the contributors (cf. the PiiAF – Public Involvement Impact Assessment Framework document). The second would be, with other researchers and PPI representatives acting as 'critical friends', to reflect on a study at the end and thus to work out what to do better next time.' ID 74 Researcher/Academic

Some respondents highlight increasing pressure to evidence and demonstrate impact for example through the Research Excellence Framework (REF).

Leadership

A supportive, competent and influential leader was perceived as critical to the successful delivery of involvement. Respondents commented on the value of experiential knowledge of public involvement in leaders.

Conversely, perceived lack of first–hand experience of PPI and limited or absent empathy with patients were thought to diminish the status of some research leaders. There was a sense that champions of involvement are required from outside established involvement teams to promote changes in organisational and institutional culture for example:

'Getting a wider range of people involved, in particular reaching out to seldom heard groups as they are disproportionately affected by health inequalities. Learning and good practice must be collected and continued to be disseminated through organisations like INVOLVE. Also, leadership for users and carers in positions of research needs investment so that they can manage themselves better, manage their peers and colleagues into research projects, and encourage others to be involved.' ID 170 User Researcher

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'I have been in many groups where a positive effort has been made to be inclusive, but where, once on board, some people are then unable to contribute because of the leadership of the group. Diversity does sometimes need a perceptive and sensitive leader to work'. ID 132 Public

Question 3 : doing public involvement differently

This question was designed to encourage people to share new ideas and suggest new ways of approaching involvement. There were many detailed submissions demonstrating the wealth of experience that is now emerging across NIHR representing the wealth of experience to be drawn from in the future. Broadly, respondents described ideas in the following areas.

Practice standards

There is a sense that practice has developed but the time has come to consolidate, use the available evidence base and identify gaps in knowledge. Raising practice standards may require a continuous improvement approach that generates evidence of what works more quickly so modifications can be made and adopted to avoid duplication and waste. Peer review, performance management and regulation – self or independent - were suggested as potential approaches to improving practice and raising standards.

Promotion and outreach

As identified earlier, there is a desire to reach further into the general population about health research and the opportunities for involvement and to link this with wider societal trends;

'Need local dedicated co-ordinators for national campaigns. People with 'research in their veins' whose job it is to be at the end of 'OK to ask ' , who can meaningfully answer queries and deal with the questions that a national research awareness campaign should raise; who can raise awareness locally e.g. in care homes and other areas that sit outside the system.' ID 240 Other

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'The sense that getting involved in medical research is an aspect of being a good citizen. I think we should foster a sense that the public have a right to participate and, at a minimum level, perhaps even a duty...I think we should build a sense of reciprocity. The public help by volunteering for trials so what does the public get back? …The public pays the going rate for the medicines via the tax system and the NHS. Further, the better job the public does in getting involved in medical research and drug development, the lower the cost of development for Pharma (e.g. trials recruit faster) yet this is not reflected in lower drug prices. So I think the reciprocity should come in the form of a bigger say in the direction and shaping of research.' ID 216 Public Involvement Specialist/Lead

Learning from other sectors and disciplines

Respondents provided useful examples from other academic disciplines, public services and from business about how to engage and involve more effectively. For example young people are researchers and patients of the future and are likely to have very different expectations for public involvement so working with them now can help to anticipate future needs and aspirations.

Inclusion and diversity

Current practice was perceived as being exclusive and not always fully meeting the requirements and goals of equality legislation. There is a real risk that unless inclusion in public involvement is addressed, inequality and discrimination will worsen and there will be negative health and wealth outcomes. Suggestions were made for improving access;

'Shorter interactive and more accessible involvement so that everyone can join.' ID 525 Young People Advisory Group Researcher Adviser

'The key issue for me is that there is a growing acknowledgement of the specific practical, legal and ethical issues around involving children and young people in research, which need to be considered alongside adult PPI. Generic PPI guidance on support, while aiming to be for everyone, often does not address these issues and is therefore really only for adults.' ID 10e Researcher/Academic

'This is difficult for many organisations. Seeing role models like themselves - old/young, non-white, not wearing grey suits - all these would help. People from unrepresented areas may believe that it's not for the likes of them to get involved so showing people who are like them, getting on and making a difference, is likely to be helpful.' ID 29 Public

'Not take a tokenistic approach. Speak to people from minority groups and ask how people might be engaged with rather than using tired old methods. Go and sit in a supermarket and tell people what you do or go to a community centre and run an event. Don't wait for people to come to you and even if they do don't assume they can speak for everyone in their community.' ID 75 User Researcher

People commented that the NIHR needed to more closely reflect diversity in the population. It was felt that if leaders and role models were promoted and recruited from varied backgrounds, this would encourage more people to become involved;

'Be more aware of community centres, faith centres as sources of research participants. Acknowledge public health expertise in their local communities; community support officers etc. Get Healthwatch involved. Local radio stations (e.g. we have had health / health research message put over local Punjabi radio) Research in the evenings? Weekends? Think differently about when research is done and where it is done. Think who are we going to get participating at that time? The times are usually convenient for the researchers rather than the participants. Make it clear that research studies welcome those with access and mobility difficulties.' ID 240 Other

Question 4 : how do we do it? The future design and delivery of public involvement in NIHR

Coordinate and collaborate

The NIHR is a complex network and could benefit from a shared aim that underpins the development of local practice. Some regions are already moving to a position where individuals from different organisations and programmes are joining together to share knowledge and resources.

'Real progress in PPI will not be achieved without an effective mechanism for coordinating PPI efforts across the now many NIHR bodies that have a role in developing, fostering, or implementing PPI. It is essential there is a central body that will coordinate these efforts and will be responsible for ensuring that gaps do not occur, nor needless duplication. This body would need to be national and have the necessary structure to carry out its functions. At present, a major change in the role of INVOLVE would be the most promising means of achieving this.' ID 24e Public

Flexible and evidence based mechanisms

Some respondents suggested that the mechanisms for involvement should be more closely scrutinised for effectiveness. For example, the common practice of inviting patients and carers to join committees and steering groups was perceived by some to be of limited value and likely to become less attractive as an approach. Other sectors, for example the third sector, ecology and private companies could offer alternative approaches to learn from.

Within social science and humanities departments there are well-established teams with experience of participatory research methods from which others could learn. There is unlikely to be a single mechanism to recommend but there is evidence emerging about the important 'ingredients' of effective involvement and more could be done to work from this evidence to test and refine mechanisms in practice and to inform future research priorities for involvement.

Respondents commented on the necessity of including patients, in the design of new approaches.

'Involve in the design and delivery as wide a constituency as possible - those with 'knowledge', 'experience' and 'expertise', but also those who may be able to assist by asking questions, because they have different backgrounds.' ID 23e Researcher/Academic

Better identification of when there can be more public influence especially at critical decision making points for example identifying research priorities, making decisions about funding and translating findings into real benefits for patients. We also need involvement to understand why some research falters. Greater openness and transparency could facilitate conversations with the public to better understand how they see the possibilities for involvement.

'One of the most widely mentioned 'metrics' of improved Public Involvement (PI) would be a growth in collaborative or user-led research. Suggestions for other specific indicators included: routine PI sections in annual reports and evaluation of PI in NIHR funded research project reports; increased representation of people from minority groups; and better recruitment to trials (the latter two suggestions being offered by public contributors). ID 15e RDS collective

Third sector representatives and community voluntary organisations were identified as potential partners who could more effectively engage with people locally and nationally;

'The voluntary sector could play a key role in both the design and delivery of NIHR funded research. NIHR could establish much stronger links between research charities (such as the Wellcome Trust, Cancer Research UK, the McPin Foundation) and NIHR funded bodies in order to jointly commission and fund research.' ID 35e Voluntary Sector

Continuous improvement

Views were also expressed about how well routinely collected information about public involvement in the NIHR is used to inform strategy and delivery in research. More could be done to think strategically about collecting data for different reasons, for example, understanding the difference between collecting data for performance management or for continuous improvement and how this contributes to a stronger evidence base. For example,

'PPI work can and should be quality assessed, fortunately more tools are now available to do this (e.g. the CASP - Critical Appraisal Skills Programme PPI tool, GRIPP – Guidance for Reporting Involvement of Patients and Public checklist and new models for conceptualizing PPI. What is required now is a national framework which sets minimum standards for PPI quality, against which funding and ethical approval decision making can be made. There should also be a move towards making incorporation of quality PPI work into funding application bids standard for all reviewing bodies (as done by NIHR).' ID 51e Other

'It is an ongoing challenge to ensure that PPI does not become an end in itself or a route to a credible story for funders. It is important that researchers have a clear idea of the purpose of PPI and relevance to their work, but this requires resources. For researchers working to tight deadlines and juggling teaching commitments, time and funds to develop appropriate involvement are often scarce.' ID 23e Researcher/Academic

'By using a recognised continuous improvement paradigm (Plan/Do/Study/Act) there is much that can be achieved in the next 10 years provided this is based on sound and coherent partnerships under a national strategy. This would also need to be active locally, regionally, and nationally.' ID 11e Public Involvement Lead/Specialist

Question 5: Where should we be with public involvement in NIHR in the next 10 years?

Many respondents expressed the desire to be ambitious and work from progress made to date. For some this means refining practice and for others reframing the purpose of involvement, working differently to recognise connections between engagement, involvement and participation and re-balancing approaches to take better account of how people are realistically going to get involved.

Valued practice

The debates about the need for public involvement should mature into conversations that focus more on what works. Individuals noted how they wanted to devote energy to getting better results both in terms of improved health and higher quality, relevant research.

'PPI should be routine – how things are done, not an optional extra. This should be embedded throughout the NHS so that all users of NHS services can expect that research evidence (is) supported by robust PPI. PPI isn't simply an issue for research but for patient care, too.' ID 15e RDS collective

'By ten years, public involvement should have a much greater profile than what it has now. Members of the public and patients should know that we actively do research in an array of disease areas or conditions and that there are many opportunities for them to take part in this. Not only should NHS employees be aware of opportunities of public involvement in research but other professions should know these exist and the reasons why.' ID 20e Public Involvement Lead/Specialist

'Realistically I would hope that there will be a significant cultural shift and a reversal of the current self-perpetuating cycle of undervaluing PPI. I see more investment in PPI; this does not need to be financial, information, skills, access are often more important than money to individual; to be valued and know that your contribution has made a difference, that something positive could come from a devastating event because of new knowledge or systems.' ID 36e Public Involvement Lead/specialist

The desire to make a difference together was a motivating element for many patients and researchers. This can be forgotten in the noise of semantic and theoretical discussion and where institutional priorities and values may differ for example between the NHS and Higher Education Institutions.

Better evaluation and evidence

How best to evaluate public involvement is a persistent theme in submissions. Not surprisingly there is no consensus and it is outside the scope of this report to explore in detail here. It is not always clearly stated or explored what the overall purpose of involvement is at the start of an activity.

Many factors influence the outcome of successful research studies and the relationship between public involvement and other factors is worth further consideration. Evaluation of public involvement should be an integral part of research activity.

There is a need to more systematically collect evidence on the changes that involvement makes to research across the NIHR. The collection of case studies could be one approach that could be considered as well as research impact / outcome studies.' ID 35e Voluntary Sector

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The evidence base would be substantially enhanced so that there was a consensus between NIHR, senior researchers, the public and other stakeholders on the value of public involvement and the key factors necessary to ensure effective involvement. We will have an agreed set of methods and indicators for assessing the impact of public involvement that will have contributed to building a convincing evidence base. Public involvement would be so embedded in the culture of NIHR that new staff or new researchers coming into the field would naturally take on the values and practices of effective public involvement. ID 40e Researcher/Academic

This concludes the summary of our findings.

Appendices

Review Panel Terms of Reference and Membership

The Breaking Boundaries strategic review of public involvement was commissioned by the NIHR and announced on March 31st 2014. It has been an opportunity to assess how far the NIHR has been successful in achieving this original goal. Also to set a clear direction for the NIHR for the future that builds on these achievements. The review panel was asked to make a report and recommendations to NIHR according to the following terms of reference:

- A compelling vision and clear objectives for NIHR's leadership in public involvement.
- Areas where NIHR should be looking to maximise the public's contribution to health, social care and public health research in the future.
- Ways in which NIHR organisations should be thinking about, linking, planning and executing public involvement, participation and engagement activities.
- Options for the future support and organisation of public involvement across NIHR so that it is embedded in policy and practice.
- How NIHR can grow a diverse and inclusive public involvement community.
- Innovations and new thinking in public involvement in health, social care and public health research.

Simon Denegri
Chair of Review and NIHR National Director for Patients and the Public / Chair, INVOLVE, NIHR

Tina Coldham
Mental Health User Consultant, Trainer & Researcher / Member of INVOLVE

Dr Stuart Eglin
Regional Director, NHS Research and Development North West, Honorary Visiting Professor, Institute of Psychology, Health and Society, University of Liverpool, Associate Member of INVOLVE

Dr Robert Frost
Policy Director, Medical Advocacy and Policy, GSK

Lynn Kerridge
Chief Executive, NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)

Rachel Matthews
Theme Lead for Patient and Public Engagement and Involvement NIHR CLAHRC North West London

Dr Virginia Minogue
Research lead, NHS England

Tara Mistry
NIHR Advisory Board and Member of INVOLVE/NIHR

Dr Sophie Staniszewska
Vice-Chair of the Review, Associate Member of INVOLVE, Senior Research Fellow, Patient and Public Involvement and Patient Experiences, Warwick Medical School, RCN Research Institute, University of Warwick

Dr Claire Stephenson
Research Support Network Manager, Parkinson's UK

Derek C. Stewart, OBE
Associate Director for PPI, NIHR Clinical Research Network,

Philippa Yeeles
Head of Patient and Public Involvement, NIHR Central Commissioning Facility (CCF)

Sarah Buckland
(Observer), Director, INVOLVE Co-ordinating Centre

Kay Pattison
(Observer), Research Programmes and Contracts Senior Manager Research and Development, Department of Health

Kathy Mann
(Secretariat), NIHR Research Programmes Officer, Research and Development, Department of Health

references

All Party Parliamentary Groups on Global Health; HIV/AIDS; Population, Development and Reproductive Health; Global Tuberculosis; Patient and Public Involvement in Health and Social Care (2014) *Patient empowerment for better quality, more sustainable health services globally.* London

Association of Medical Research Charities (2013) *Our vision for research in the NHS* [Online] Available from http://www.amrc.org.uk/publications/our-vision-research-nhs [Accessed 30th January 2015]

Association of Medical Research Charities (2014a) AMRC's 2014 Annual Conference [Online] Available from http://www.amrc.org.uk/tags/amrcs-vision-research-nhs [Accessed 30th January 2015]

Association of Medical Research Charities (2014b) *An essential partnership. A guide for charities working with industry.* AMRC, London

Boyle, D. Harris, M (2009) *The challenge of co-production. How equal partnerships between professionals and the public are crucial to improving public services.* NESTA, London

Boyle, D. Slay, J. Stephens, L. (2010) *Public Services Inside Out. Putting co-production into practice.* NESTA, London

Boyle, D. Coote, A. Sherwood, C. Slay, J. (2010) Right Here, Right Now. T*aking co-production into the mainstream.* NESTA, London

Cook, T. (2012) Where Participatory Approaches Meet Pragmatism in Funded (Health)Research: The Challenge of Finding Meaningful Spaces [60 paragraphs]. *Forum QualitativeSozialforschung / Forum: Qualitative Social Research, 13(1)*, Art. 18,

Coulter, A. (2011) *Engaging Patients in Healthcare.* McGraw Hill/Open University Press, Maidenhead

Department of Health (2006) *Best Research for Best Health.* London

Ennis, L. Wykes, T. (2013) Impact of patient involvement in mental health research: longitudinal study. *The British Journal of Psychiatry* 203: pp 381-6

Foot, C. Gilburt, H. Dunn, P. et al (2014) *People in control of their own health. The state of Involvement.* London, The King's Fund

GOV.UK (2014) *Major investment in life sciences* [Online] Available from https://www.gov.uk/government/news/major-investment-in-life-sciences [Accessed 30th January 2015]

Hanney S. Boaz, A. Jones T. Soper, B. (2013) *Engagement in Research. An innovative three stage review of the benefits for health care performance.* Health Services and Delivery Research Vol.1 Issue 8

Hubbard, G. Venning, C. Walker, A. Scanlon, K. Kyle, R.G. (2014) *Supportive care needs of women with breast cancer in rural Scotland,* Support Care Cancer

KPMG Global Healthcare (2014) *Creating new value with patients, carers and communities.* KPMG International cooperative.

NIHR (2013) Annual Report 2012-2013 http://www.nihr.ac.uk/about/nihr-publications.htm

NIHR Clinical Research Network (2014a) *Nine out of ten people would be willing to take part in clinical research.* [Online] Available from http://www.crn.nihr.ac.uk/blog/news/nine-out-of-ten-people-would-be-willing-to-take-part-in-clinical-research/ [Accessed: 30th January 2015]

NIHR (2014b) *Promoting a Research Active Nation* [Online] Available from http://www.nihr.ac.uk/documents/get-involved/Promoting%20A%20Research%20Active%20Nation_NIHR%20Strategic%20Plan_May%202014.pdf [Accessed 17th March 2015]

NHS England (2014) *Five Year Forward View*

Nuffield Council on Bioethics (2015) *The collection, linking and use of data in biomedical research: ethical issues*. [Online] Available from http://nuffieldbioethics.org/wp-content/uploads/Biological_and_health_data_web.pdf [Accessed 17th March]

Robert, G. (2013) Participatory action research: using experience-based co-design to improve the quality of healthcare services. Chapter 14 in *Understanding and Using Health Experiences*. Ziebland, S. Coulter, A. Calabrese, J. Locock, L. (eds) Oxford, Oxford University Press

Rome Declaration on Responsible Research and Innovation in Europe (2014) [Online] Available from: http://ec.europa.eu/research/swafs/pdf/rome_declaration_RRI_final_21_November.pdf [Accessed 20th January 2015]

Somekh, B. (2002). Inhabiting each other's castles: Towards knowledge and mutual growth through collaboration. In Christopher Day, John Elliott, Bridget Somekh & Richard Winter (Eds.), *Theory and practice in action research: Some international perspectives* (pp.79-104). Oxford: Symposium Books

Tarpey M and Bite S (2014) Public involvement in research applications to the National Research Ethics Service: Comparative analysis of 2010 and 2012 data, INVOLVE Eastleigh

Further reading

Boaz, A. Biri, D. McKevitt, C. (2014) Rethinking the relationship between science and society: Has there been a shift in attitudes to Patient and Public Involvement and Public Engagement in Science in the United Kingdom? *Health Expectations*

Beresford, P. (2013) From 'other' to involved. User involvement in research: An emerging paradigm. *Nordic Social Work Research* 3 (2) 139-148

Boote, J. et al (2012) Talking the talk or walking the walk. A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectations*.

Cahn, E. (2001) No More Throwaway People: The Co-production imperative. Washington DC: Essential Books cited in Boyle D, Harris M (2009) The Challenge of Co-production. *How equal partnerships between professionals and the public are crucial to improving public services*. London, NESTA

Evans, D. (2014) Patient and public involvement in research in the English NHS: A documentary analysis of the complex interplay of evidence and policy. *Evidence and Policy*, 10 (3) pp 361-377

INVOLVE (2013) *Exploring the impact of public involvement on the quality of research: examples*. Eastleigh: INVOLVE

Kline, R. (2014) The 'snowy white peaks' of the NHS: a survey of discrimination in governance and leadership and the potential impact on patient care in London and England. Available from Middlesex University's Research Repository http://www.england.nhs.uk/wp-content/uploads/2014/08/edc7-0514.pdf

Mathie, E. Wilson, P. Poland, F. McNeilly, E. Howe, A. Staniszewska, S. Cowe, M. Munday, D. Goodman, (2014) Consumer Involvement in health research: a UK scoping and survey. *International Journal of Consumer Studies* vol 38, no1, pp 35-44

Petit-Zeman, S. Locock, L. (2013) Bring on the evidence. Nature 501 (7466) pp 160-161

Shippee, N. et al (2013) Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expectations*

Staniszewska, S. Churchill, N. (2014). Patients' experiences in the UK: Future strategic directions. *Patient Experience Journal*, 1 (1), Article 18

Staniszewska, S. Boardman, F. Gunn, L. Roberts, J. Clay, D. Seers, K. Brett, J. Avital, L.Bullock, I. O'Flynn, N. (2014). The Warwick Patient Experiences Framework: patient-based evidence in clinical guidelines. *Int J Qual Health Care*

Turner, S. Wright, D. Maeso, R. et al (2013) Publication rate for funded studies from a major UK health research funder: a cohort study. *BMJ Open* 3:e002521.

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