



Promoting a ‘research active’ nation

Every citizen, by helping to design or take part in research, sharing their data, or fundraising for a medical research charity, is contributing to a ‘research active’ nation focused on best health for all through high quality research.

Background

Patients, carers and the public – citizens - are integral to the way in which the National Institute for Health Research (NIHR) will achieve its ambition of improving the health and wealth of the nation.

We wish to enable and empower patients, carers and the public to contribute to this ambition in the way that they feel most confident. This contribution can be defined in terms of five key policy objectives:

- Citizens defining health outcomes that matter to them
- Citizens helping to identify and deliver research of the highest quality
- Citizens being able to choose to take part in research
- Citizens being able to use the evidence on which their care is based
- Citizens having a good research experience and recommending it to others

Involvement

- Citizens defining health outcomes that matter to them
- Citizens helping to define and deliver research of the highest quality

Since 2006, the NIHR has established an internationally acclaimed reputation for its approach to public involvement working in partnership with INVOLVE and public involvement colleagues across its infrastructure. A summary of this work can be found in the NIHR’s annual report for 2012/13:

<http://viewer.zmags.com/publication/26f799ac#/26f799ac/1> and we have recently embarked on a strategic review: *‘Breaking boundaries: thinking differently about public involvement in research’* to set the tone and style for this work over the next decade: http://www.nihr.ac.uk/awareness/Pages/BreakingBoundaries_tor.aspx

In policy terms, less focus has been given to developing strategies for strengthening citizen engagement and participation in research across the health and social care system. Recent legislation and subsequent policy developments, however, mean the NIHR and its partners now have the ideal opportunity to address this.

Engagement and participation

- Citizens being able to choose to take part in research
- Citizens being able to use the evidence on which their care is based
- Citizens having a good research experience and recommending it to others

In December 2011, at the launch of the Government's *Life Sciences Strategy*, the Prime Minister spoke about wanting every patient to become 'a research patient' by sharing their personal data for research purposes.

Since then, the Health and Social Care Act 2012 has heralded new duties on health and social care organisations to promote and advance research. This provides us with a solid foundation on which to develop approaches to public participation and engagement that enable the willing patient to become an active research citizen, and willing patient populations to become research active communities.

Working with others

The strategic plan set out in this document highlights NIHR's aspirations for public participation and engagement in research and those areas where it has a clear leadership role to play. We hope that others will be excited by the opportunities it presents and join with us in co-producing innovative and creative solutions that will improve people's chances of benefiting from research.

In addition, where feasible, we look forward to being partners in strategic initiatives developed by others across science and our wider society with the intent of increasing citizen engagement and participation in research and innovation that will improve lives.

Accountability and responsibility

Recent issues such as care.data demonstrate the extent to which citizens rightly expect clarity and reassurance over the systems and safeguards in place as a pre-requisite to their taking part. We therefore have a responsibility to join with citizens and address this challenge together.



What is a research active community?

Parkinson's disease is a good example of a vibrant and growing 'research active community' where involvement, engagement and participation activities are actively promoted together. It has 1,000 people in the Parkinson's UK research network, a James Lind Alliance Priority Setting Partnership (JLA PSP) underway, national and regional research conferences, and study participation actively promoted across the nation.

The National Institute for Health Research (NIHR) can contribute to the building of such communities not least by promoting a health and social care system in which people can easily access information and potential opportunities to be involved, and take part in, research.

Our 2013 'Ok to ask' campaign was promoted across more than 150 hospital sites with almost 90% of patients rating the campaign as good or excellent. Although patient recruitment to studies through the Clinical Research Networks increased at that time it is difficult to determine how much is due to the campaign:

<http://www.crn.nihr.ac.uk/Resources/NIHR%20CRN%20CC/Document%20s/Corporate%20reports/Performance%20Report%20-%20April%20to%20June%202013.pdf>

Public involvement has an important role to play in addition to its contribution to the design of high quality research: namely, encouraging participation and engagement by building public trust. This has been demonstrated in both the Health Research Authority's (HRA) recent public dialogue exercise (<http://www.hra.nhs.uk/patients-and-the-public-2/how-the-hra-works-with-patients-and-the-public/what-patients-and-the-public-think-about-health-research/>) and to some extent the Department for Business' latest Public Attitudes to Science report <https://www.gov.uk/government/publications/public-attitudes-to-science-2014> .

Bringing it together

In time – and subject to the outcome of the 'Breaking Boundaries' review – the NIHR would anticipate integrating our public involvement, engagement and participation plans and their delivery into one strategy. But, in the meantime, the opportunities arising from the Health and Social Care Act 2012 require a specific and considered response as set out in this strategic plan.

Simon Denegri

NIHR National Director for Public Participation and Engagement in Research

April 2014

A strategic plan for increasing citizen engagement and participation in health, social care and public health research (2014-2019)

Our Aim

We wish to work with our partners to enable and empower patients, service users, carers and the public – citizens - to benefit from research as part of their care and treatment.

Our high-level policy objectives are:

- Citizens being able to choose to take part in research
- Citizens being able to use the evidence on which their care is based
- Citizens having a good research experience and recommending it to others

When asked, the vast majority of citizens say they would be willing to participate in health and social care research. For those who do take part, motivations range from wishing to benefit from new treatments and the care that goes with it, to wanting to help other people with their condition. There is now growing evidence of the link between research, quality of care and patient experience [[National Cancer Patient Experience \(NCPE\) 2013 Survey](#)].

However, most citizens are not given a choice to contribute to research during the course of their illness. It is an opportunity missed for them. It is also an opportunity missed for health commissioners and providers who wish to improve the quality of the care and treatment available to people using their services.

What does this look like?

From a citizen perspective this aim translates into people being able to be treated in a health and social care setting which is research active and where they can:

- Ask about research
- Choose to take part in research
- Champion research to fellow citizens, staff and health professionals
- Share their experiences with researchers, commissioners and providers
- Shape the way in which research is prioritised, designed and delivered
- Feel their contribution has made a difference and has been acknowledged
- Access and use research evidence to make decisions about their own care

From the perspective of condition-specific patient populations it translates into a clear sense that research is part of the care pathway that is considered by patient and doctor together. Some patient populations, such as cystic fibrosis, Parkinson's disease, dementia and cancer, are moving towards being research active communities where choice, participation, involvement, access to evidence and patient experience in research are becoming priorities.

How will we achieve this?

NIHR has developed a world-class infrastructure for research and we now wish to match this with a world-class approach to engaging the citizen and encouraging their participation. Our near-term strategy will focus on making the following happen across the health and social care system:

- Improving patient choice with accessible information for patients, professionals and the health and social care workforce
- Promoting participation by removing current barriers to research
- Learning from patient experience to improve access to research and research evidence
- Supporting patients to champion research in their locality

Citizens play a crucial role in prioritising, designing and delivering research in ways which lead to better engagement and participation. We look forward to the report and recommendations of the [NIHR Breaking Boundaries strategic review of public involvement](#) about how this can be strengthened and to incorporating their recommendations into this strategy.

Priorities

A number of priorities will underpin our work:

- We will seek to work with others and build partnerships with a range of other organisations who see citizen engagement and participation as a priority for UK research. We envisage both industry and medical research charities as integral to this partnership approach.
- We will seek to co-produce solutions and approaches with citizens, health and social care staff professionals and researchers.
- Each component part of the strategy will have a public delivery plan which will identify clearly the partners we hope to work with and how.

Supporting choice, promoting participation

- Improving patient choice with accessible information for patients, professionals and the health and social care workforce.
- Promoting participation by removing current barriers to research

In all our work we hope to strengthen public confidence in research by communicating the benefits and why participation is important, but also being candid about the risks and clear about the safeguards in place. Key initiatives in supporting choice and promoting participation are:

The UK Clinical Trials Gateway (UKCTG)

The UKCTG website (<http://www.ukctg.nihr.ac.uk/default.aspx>) and downloadable app is a key commitment to patients under the Government's Life Sciences Strategy. It is aimed at

helping patients find easy-to-use information about clinical studies in which they might participate. From April 2013 until February 2014, UKCTG had over 80,000 visits a month. A UKCTG Project Board chaired by the NIHR's National Director for Public Participation and Engagement in Research is now overseeing improvements to the Gateway with a focus on enhancing the quality of information available to visitors including lay summaries. A key priority is to promote UKCTG more widely to health and social care organisations and in contexts where patients and professionals will find it most helpful.

Ok to ask

Our 'OK to ask' campaign was rolled-out across the NIHR and the NHS for the first time on International Clinical Trials Day (ICTD) in 2013. It is the only national campaign of its kind in the world. Over 150 NHS Trust hospital sites took part and 80% of respondents to a follow-up survey about the campaign said it helped build momentum in their Trust about the importance of clinical research. We welcome the recent support and recommendations of the House of Common Science and Technology about 'Ok to ask.' Following transition to our new Local Clinical Research Networks (LCRN) structure in 2014, 'Ok to ask' will be an NIHR sponsored activity lead by the National Director and delivered by LCRNs working with local NIHR infrastructure and health and social care partners. In 2015 the priority will be to broaden the message and materials applicable and available for health professionals and the health and social care workforce. We will look to incorporate digital and social media methods of participation increasingly into our 'Ok to ask' campaign in future years without forgetting the importance of traditional techniques in helping us to reach the widest audience possible.

Improving patient recruitment

We will continue to work closely with the Health Research Authority (HRA) to improve the regulatory environment so that it does not place unnecessary barriers in the way of public engagement as can happen now. . It will also be important to include clinicians, Clinical Research Nurses and other health and social care staff in this dialogue and development. We will also work with patients, the public and researchers to identify and publish exemplars of public engagement and participation strategies that have made a difference to clinical trial delivery and, in particular, the recruitment and retention of patients. Particular areas of focus will be young people, rare diseases and models for charity and industry funders.

Building research active communities

Our Stroke Research Network has shown how long-term focus on involvement and engagement can lead to better participation, having grown the research participation rate in the stroke population from 1% to nearly 10%.

The Mental Health Research network has similarly shown how patients and researchers working together can lead to more effective recruitment strategies meaning that studies are four times more likely to recruit to time and to target. **Paper reference:** Ennis, L. et al. 'Impact of patient involvement in mental health research: longitudinal study' *British Journal of Psychiatry* (Sept 2013) [doi: 10.1192/bjp.bp.112.119818](https://doi.org/10.1192/bjp.bp.112.119818)

Raising the level of conversation

The National Cancer Patient Experience Surveys of 2012 and 2013 show that only 1 in 3 cancer patients are having a conversation with their doctor about research. In diabetes the level is 1 in 4. In other conditions the conversations are non-existent.

<http://www.jdrf.org.uk/news/latest-news/survey-reveals-people-with-type-1-diabetes-denied-chance-to-take-part-in-trials->

Supporting innovation

We believe there is scope to prompt and support innovation in engagement activities that lead to greater research participation through an open call for local or regional pilots of such work, projects that that are measurable and have the potential for wider adoption.

We recognise the tendency to fund engagement and participation work in the clinical research arena and will explore with the NIHR Schools for Primary Care, Social Care and Public Health respectively the scope for joint activity that will establish NIHR leadership in these spheres. We would also expect to engage and work with appropriate partners to set a new benchmark for engagement and participation activities in the area of innovation and diffusion.

Accessible information for all

Finally, we will look to refresh and upgrade the materials that NIHR makes available to citizens about research, data use, and research opportunities, and alternative formats in which it is provided to make it accessible to different communities. This includes working with young people to help design and develop a range of research 'apps' that will help enthuse young people about research and encourage their participation in research studies [See also the recommendations of the Chief Medical Officer's annual report for 2013:

<https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays/cmos-annual-report-2012-our-children-deserve-better-cmos-summary-as-a-web-page>]

Learning from patient experience

As more citizens enter research, it is going to be increasingly important to think about how this experience feels from a consumer's perspective and to strengthen practice accordingly. We want those who have taken part in research to continue to be our best advocates to other citizens.

Developing the evidence base on patient experience

We propose conducting an NIHR wide satisfaction survey of patients in research similar to that recently conducted by NIH in the United States [ref]. We also think there is scope to work with LCRNS, NHS England, charities and other partners to

Measuring patient experience

NIHR Clinical Research Facilities (CRFs) are conducting a 'Friends and Family' test with participants during 'Ok to ask 2014' that has been designed by patients.

The image shows a survey form titled "Clinical Research Facility Open Day 2014". At the top, there are logos for CHIEF SCIENTIST OFFICE, UKCRF NETWORK, and National Institute for Health Research (NIHR). The survey contains four main questions:

- 1) Would you recommend taking part in research to your friends and family? (please tick)
 Yes No
- 2) Was everything explained thoroughly to you on the day of your visit? (please tick)
 Yes No
- 3) Why did you decide to take part in this research study? (please tick)
 Personal benefit
 Family member illness
 Financial gain/payment
 Altruistic reasons/helping others
- 4) We are grateful that you have taken part in our research today. We have opportunities for patients/participants and their families to get more involved in our work. When patients/participants and families team up with us, it makes our research better. There are many ways to help out - some examples are:
 - ▶ help research nurses and staff decide which research should take place
 - ▶ help research nurses and staff review and make patient information sheets
 - ▶ help research nurses and staff by providing comments or input about the research facility
 - ▶ join research nurses and staff on research study groups to give the patients/participants point of viewIf you would like to learn more about this please provide your contact details to a nurse here today. Thank you

At the bottom, there is a "Thank you" message: "Thank you for completing this service evaluation survey. Please hand in to a member of the research team." and a website link: "For more information on clinical research visit www.nihs.uk/conditions/clinical-trials". There is also an "OK to ASK" logo.

We aim to publish the results of a survey currently underway across all our CRFs in July, to see what they gather in terms of data about - and current approaches to - ensuring the experience of participants is a good one.

measure people's access to research through other survey work, the best example being the National Cancer Patient Experience Survey (NCPE).

The clear focus on patient experience in the new operating framework for LCRNs is welcome. This data will help us develop a clear map of the patient pathway to research, identify key barriers to participation and appropriate strategies for overcoming them.

Dignity and respect: An NIHR 'commitment to patients'

This commitment will be based on patient priorities identified through the work currently underway across NIHR Clinical Research Facilities (NIHR CRFs), healthtalkonline, James Lind Alliance (Priority Setting Partnerships (PSPS) and elsewhere. The 'commitment' would be given to all patients taking part in NIHR-supported research and cover information, consent, use of data, feedback and access to trial data. With growing numbers of people taking part in research as part of their care and treatment, we must also be transparent and honest about what they can expect.

Supporting citizens to champion and lead research

Research ambassadors

NIHR's Involvement4Access (I4A) initiative has enabled us to define patient leadership in research within an NHS Trust environment and bring together a network of Trusts interested in its practical application. We intend to pilot our 'Research ambassadors' model in a number of areas first, with a view to expanding it to all research intensive Trusts after this and, subsequently, other appropriate health and social care settings. Our research ambassadors would be supported by their local NHS Trust but also play an important leadership role in their surrounding geography working with other parts of NIHR and the health and social care system.

Local partnerships

We will work with and encourage Local Clinical Research Networks (LCRNs) - together with other parts of the NIHR infrastructure in their geography - to develop public involvement, engagement and participation in research strategies with their local health and social care partners.

Measurement

We have set out some strategic goals for this programme of work for 2014 to 2016 in Appendix I. One of these goals will be to work with citizens, researchers and professionals to develop a dashboard of performance indicators for engagement and participation. It would be our intention to show progress against these indicators in an annual 'Patient Prospectus.'

Leadership

The development and implementation of this strategic plan will be led by the NIHR National Director for Public Participation and Engagement in Research, assisted by a small team and in keeping with the NIHR's core principles on public involvement. The strategic plan will

have the status of an NIHR programme – called 'PROACTIVE' for short - with an annual plan
and budget.

Appendix I: 2014-2016 Strategic Goals

1. Supporting patient choice in research with accessible information for patients, carers and professionals	<ul style="list-style-type: none"> • Improve the quality and presentation of the information contained on the UK Clinical Trials Gateway (UKCTG) and promoting usage through the NHS and NIHR partners • ensure updated materials about clinical trials are available via the new NIHR website
2. Promoting patient participation by increasing the visibility of research in health and care settings	<ul style="list-style-type: none"> • Work with Local Clinical Research Networks (LCRNs) to support 'Ok2Ask' campaign in provider settings for ICTD in May 2014
3. Involving patients, carers and the public in research development, innovation and diffusion	<ul style="list-style-type: none"> • Publish exemplars of how public involved has improved patient access to research including in rare diseases and young people - Winter 2014
4 Using patient insight to remove barriers to participation and improve their experience of being in research	<ul style="list-style-type: none"> • Publish results of NIHR CRF survey of how we gather and use patient insight in trial units - June/July 2014 • draft NIHR commitment to patients in research - January 2015
5 Promoting patient leadership in research in local health and social care settings	<ul style="list-style-type: none"> • Establish patient research champions in 1/3 of NHS Trusts under the Involvement4Access project by Summer 2015
6 Developing and supporting collaborative working between NIHR, NHS and other organisations to improve patient participation and engagement in research	<ul style="list-style-type: none"> • Publish NIHR's strategy on public participation and engagement in research on International Clinical Trials Day (ICTD), 20 May 2014
	<ul style="list-style-type: none"> • Establish a joint forum between NHSE and NIHR to focus on delivery of patient choice in research - Spring 2014
7. Strategy dashboard developed with citizens, professionals and researchers	<ul style="list-style-type: none"> • Publish a final set of performance indicators by the end of 2014
8. Alignment with patient choice sections of NHS England research strategy and areas of joint working established.	