

# From subjects to partners: putting patients at the heart of medical research

Report of a roundtable on 12 June 2019

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The Academy of Medical Sciences is the independent body in the UK representing the diversity of medical science. Our mission is to promote medical science and its translation into benefits for society. The Academy's elected Fellows are the United Kingdom's leading medical scientists from hospitals, academia, industry and the public service. We work with them to promote excellence, influence policy to improve health and wealth, nurture the next generation of medical researchers, link academia, industry and the NHS, seize international opportunities and encourage dialogue about the medical sciences.

### **National Institute for Health Research**

The National Institute for Health Research (NIHR) is the nation's largest funder of health and care research. The NIHR:

- Funds, supports and delivers high quality research that benefits the NHS, public health and social care.
- Engages and involves patients, carers and the public in order to improve the reach, quality and impact of research.
- Attracts, trains and supports the best researchers to tackle the complex health and care challenges of the future.
- Invests in world-class infrastructure and a skilled delivery workforce to translate discoveries into improved treatments and services.
- Partners with other public funders, charities and industry to maximise the value of research to patients and the economy.

The NIHR was established in 2006 to improve the health and wealth of the nation through research, and is funded by the Department of Health and Social Care. In addition to its national role, the NIHR supports applied health research for the direct and primary benefit of people in low- and middle-income countries, using UK aid from the UK government.

### **NHS England and NHS Improvement**

NHS England oversees the budget, planning, delivery and day-to-day operation of the commissioning side of the NHS in England. In January NHS England published the Long Term Plan to ensure that in 10 years' time we have a service fit for the future. From 1 April 2019, NHS England and NHS Improvement have come together to act as a single organisation. Our aim is to better support the NHS and help improve care for patients.

**Opinions expressed in this report do not necessarily represent the views of all participants at the event, the Academy of Medical Sciences or its Fellows, the National Institute for Health Research, or NHS England and NHS Improvement.**

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## Contents

Executive summary .....	4
Introduction .....	5
Summary of discussions .....	6
Next steps .....	11
Annex 1: Participant list.....	12

# Executive summary

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**Patients and carers have been a prominent voice in advocating for increased participation and involvement in research.<sup>1,2</sup> However, there remains a lack of opportunities for them to engage with the research agenda. This comes at the detriment to patient and carer outcomes, especially since there is increasing evidence that patients in research-active healthcare settings have better outcomes and receive better care.<sup>3,4,5</sup>**

On Wednesday 12 June 2019, the Academy of Medical Sciences co-hosted a roundtable with the National Institute for Health Research (NIHR) and NHS England and NHS Improvement on 'Enabling research in the NHS – patient perspectives'. The roundtable, chaired by Professor Dame Jessica Corner FMedSci, convened patient leaders and patient advocates to explore the opportunities for, challenges to, and next steps needed to place patients at the heart of research in the NHS.

The following key themes emerged from discussions at the meeting:

- **Equitable access to research at the point of care:** To increase patient participation in research, more should be done to ensure that research opportunities are highlighted during consultations with healthcare professionals. Efforts are also needed to provide equitable research opportunities across the UK. The use of new technologies to increase opportunities to undertake research remotely through apps and wearables should be explored.
- **Patient and public involvement across all stages of the research and development (R&D) pipeline:** Early involvement of patients and carers should be a priority. Partnerships between patients, carers and researchers are vital to develop treatments that consider patients' expectations and can help to inform research designs that are suited for patient participants. Patients can also provide valuable insight into funding allocations.
- **Meaningful and effective patient and public involvement (PPI):** PPI should be a core skill that is included in undergraduate health curricula and considered in all research studies. The value of research should also be communicated more broadly to patients, carers and members of the public to create a more receptive environment for research. Case studies and exemplars would be helpful in this regard.
- **Accessible research:** Research findings should be produced in ways that are easily accessible and understandable so that patients, carers and the public can use them to inform decisions about treatment, care and wellbeing.

The roundtable was held to inform the Academy's wider project on 'Enhancing the NHS-academia interface'.<sup>6</sup> This project aims to address how the interface between academia and the NHS can be enhanced to accelerate the translation of research into patient benefit and population health, and to increase the appeal of the UK to the life sciences industry.

# Introduction

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The UK has a world-class environment for medical research, underpinned by outstanding academic institutions, a vibrant pharmaceutical and medical technology industry, and a unified healthcare system with significant research capabilities and access to a diverse patient population. Surveys have shown that patients would like to be offered opportunities to be involved in clinical trials and that the public believes that the NHS has an important role to play in supporting research into new treatments.<sup>7,8</sup> However, despite the increasing evidence that patients in research-active healthcare settings have better outcomes and receive better care, current opportunities for patients to engage in research remain limited.<sup>9,10,11</sup>

To explore opportunities for, challenges to, and next steps needed to place patients at the heart of research in the NHS, the Academy of Medical Sciences, the National Institute for Health Research (NIHR) and NHS England and NHS Improvement (NHSE/I) convened a roundtable on 'Enabling research in the NHS – patient perspectives' on 12 June 2019, chaired by Professor Dame Jessica Corner FMedSci, Pro-Vice-Chancellor (Research & Knowledge Exchange) at the University of Nottingham. The meeting convened patient advocates and patient leaders (see Annex 1) to:

- Explore the opportunities for and challenges to research in the NHS from the patient perspective.
- Identify best practice examples and understand how these could be implemented more widely.
- Consider the next steps needed to place patients at the heart of research in the NHS.
- Seek the patient perspective to inform the Academy's vision to enhance the NHS-academia interface.

The discussions focussed on increasing access to research at the point of care, enabling research across the whole of the UK, engaging patients at all stages of the R&D pipeline, and the benefits of communicating the value of research to health researchers, patients and the wider population.

This report provides a summary of the discussions that took place at the meeting. It does not represent the views of all participants at the event, the Academy of Medical Sciences or its Fellows, the NIHR or NHSE/I.

# Summary of discussions

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The roundtable provided an opportunity for patient leaders and patient advocates to discuss:

- **Equitable access to research at the point of care.**
- **Patient and public involvement throughout the research and development (R&D) process.**
- **Meaningful and effective patient and public involvement (PPI).**

Participants stressed that the UK is one of the best places in the world to undertake research and has a solid foundation in PPI thanks to progress over the past two decades. 2018/19 saw an unprecedented amount of research in the NHS, with 100% of Trusts in England involved in research and 875,250 participants taking part in studies across the country.<sup>12</sup> This provides an excellent platform, but increased efforts are needed to provide all patients with opportunities to participate in research.

## Equitable access to research at the point of care

### *Accessing research at the point of care*

Surveys show that only 15% of patients have discussed clinical research with a healthcare professional in their lifetime.<sup>13</sup> Participants agreed that more should be done to provide access to research at the point of care to increase awareness across all patient demographics and thereby increase engagement. This could include, for example, the availability of relevant and up to date lay literature in consultation spaces, or conversations between patients and medical staff about relevant research opportunities. Patients and carers could also be empowered with questions to ask healthcare professionals about research or treatment options within a consultation.<sup>14</sup>

Participants noted that discussing research opportunities in an accessible way and allowing patients to reflect on the options provided takes time. The increased time commitment required by healthcare staff compared to proceeding with a conventional treatment was highlighted as a key barrier to conveying research opportunities, a situation that is unlikely to improve given current pressures facing the NHS workforce. Participants suggested that, in the long term, the integration of research into all aspects of treatment and care could reduce the added time commitment. The mandatory collection of smoking cessation data provides an example of how research can be integrated into service delivery (Box 1).<sup>15</sup>

## Box 1: Routine data collection for smoking cessation

Four-week quit rates, both self-reported and carbon monoxide-verified, in addition to demographic and treatment data are collected routinely by local stop smoking service providers and submitted to NHS Digital. The resulting data are then used to evaluate the effectiveness of stop smoking services and the relative success rates of different demographic groups. This is an example of integrated research at the point of care to improve service delivery and enhance patient outcomes.

### *Equity of access to research*

Recent data from the NIHR Clinical Research Network showed that 100% of NHS Trusts in England took part in research in 2018-19, involving 870,250 participants across 2,194 studies.<sup>16,17</sup> While these figures are encouraging, participants noted that there remains a disparity in the concentration of research activity across Trusts, with the majority clustered around centres of excellence, often in the south east of England.

Trust-specific cultures and the distribution of funding were cited as two of the main reasons for the disparity in research activity across the country. To improve attitudes towards research, participants suggested asking patients and healthcare professionals about their motivations to engage with research. This information could then be used to inform strategies to further promote research within Trusts.

Participants also suggested that research funding is commonly awarded to outstanding academic institutions, often with follow-on funding to the same groups. Participants called for a coordinated strategic approach across the life sciences funders to increase research capacity across all healthcare settings, accompanied by a coordinated nationwide approach to PPI to ensure equity of access to research across the UK.

### *Use of new technologies*

To enable greater participation in research, some participants stressed the need for studies to better integrate into patient and carers' lives and minimise disruption to their daily activities. It was suggested that services could increasingly be accessed remotely as has already been seen in other settings, such as banking and online shopping. Technology was thought to play a crucial role in increasing access to research and care, including through app-based data recording and wearables, such as the MoleScope outlined in Box 2.<sup>18</sup>

However, while the use of new technologies could help to improve geographical access to research by taking the research to patients, some participants cautioned that it could also negatively affect equity of access. For example, the low prevalence of smart phones among patients with severe mental health disorders or elderly individuals could lead to exclusion of these groups. Furthermore, participants emphasised the value of face-to-face interaction in certain settings, such as mental health research. As such, the deployment of technology-based research should be carefully considered and alternatives provided as appropriate.

## **Box 2: At home surveillance of moles**

The MoleScope™ by MetaOptima is a smartphone attachment to image moles through magnification and specialised lighting. The device can be used to scan moles at home to check for warning signs and to support doctors to make an accurate diagnosis, or to help inform any next steps.

## **Patient and public involvement throughout the R&D process**

Participants called for a greater democratisation of research with a shift away from assumed views, expectations and goals, and towards greater involvement and engagement of patients. Platforms already exist to involve patient and carer voices and views in the R&D pipeline; however, participants called for earlier involvement to influence the design and implementation of studies, and to enhance data-driven research.

In the development of therapeutic agents, for instance, early involvement of patients in the R&D process would help to

identify and clarify patient priorities and inform more relevant research outcomes. For example, whether individuals would value a less effective drug with fewer side effects over a more effective drug with more side effects, or whether patients would prioritise a cure over targeting the most limiting symptoms of disease. By highlighting the value of the patient voice to those involved in R&D, including the pharmaceutical sector, it was hoped that closer partnership working could be established.

Patient and carer views should also be reflected in study designs to ensure that research processes are not overly onerous and are practical to patients (for example, the frequency or timing of hospital visits). Patient and carer involvement in research design was highlighted as being particularly important in data-based research, where standards around data usage and ownership are still in development. Box 3 illustrates how these standards and practices can be co-developed with patients and the public.<sup>19,20</sup>

## Box 3: The 100,000 Genomes Project Participant Panel

Participants that have donated their genome as part of the 100,000 Genomes Project have the opportunity to influence and challenge the direction of the project. Established in 2016, the Participant Panel oversees how their data is being used and by whom. The Panel can invite any member of staff from Genomics England and NHSE/I to explain the elements of the project that they are responsible for, and can suggest improvements to ensure that participants' interests remain at the heart of their decision-making. Issues that the Panel influences include decisions around access to project data, ethics and engagement with commercial partners. The Panel also listens and responds to feedback from wider participants to inform future user service design from their experiences.

Participants also believed that patients, carers and members of the public could provide important insight into funding allocations to disease areas. Increased transparency in funding mechanisms and decision-making was seen as a key priority, with a need to align research funding and innovation in the UK with disease burden.

## Meaningful and effective PPI

Participants suggested that effective partnerships between patients, carers and researchers are underpinned by a mutual desire to improve patient outcomes and advance treatments. Participants believed that a further cultural shift is needed in how patients, carers and the public view health research and similarly, how researchers see the role of patients in delivering the best research.

### *Health researchers*

To ensure that PPI is a key priority for health researchers across all disciplines and research institutes, participants called for PPI to be integrated within undergraduate education. It was suggested that this would encourage PPI to be viewed as a central component of research rather than a 'nice to have', as well as a cultural shift within the next generation of researchers. Participants suggested that PPI could be included in research projects undertaken as part of health research degrees, which would provide students with the basic skills and experience to further engage with patients and the public. Participants indicated that case studies and exemplars in PPI would be valuable to communicate the benefits of PPI to researchers and how it translates to patient benefit, and to provide guidance on how it can be effectively undertaken.<sup>21,22,23</sup>



### *Highlighting the value of research to the public and patients*

Participants voiced a need to raise awareness of the value of research from a young age to equip patients, carers and members of the public with the skills to navigate treatment and research opportunities. Informing the public about the fundamentals of research could enable them to make more informed decisions about, and to take ownership of, their care and associated research opportunities. This might also mitigate patients and their family being overwhelmed when research options are presented alongside a diagnosis. Outreach activities, such as the Centre of the Cell science education centre (Box 4), can help to demystify research and provide a conduit for communication between researchers and the public.<sup>24</sup>

## Box 4: Centre of the Cell science education centre

Centre of the Cell is the world's first science education centre to be located within working biomedical research laboratories. A distinctive orange pod suspended above laboratories at the Blizzard Institute, the centre provides interactive sessions for schools and families run by students and early career researchers. Visitors can observe genuine research taking place and learn about cells, the human body and advances in medical research.

Performance indicators and metrics were discussed as a way to communicate the value of research. Participants welcomed the recent inclusion of research performance indicators as part of the Care Quality Commissioners (CQC) well-led framework to incentivise research in the NHS.<sup>25</sup> Building on these, participants discussed the value of research metrics: on the one hand, they can raise the importance of research and help to stimulate a culture change; on the other, there is a risk that, if implemented incorrectly, they could provide perverse incentives to undertake research in a way that is not meaningful or effective. Participants agreed that metrics were valuable and had a role in raising the profile of health research in NHS Trusts; however, metrics were thought to be largely inaccessible by the patient community and therefore an ineffective way of communicating the value of research to them. Rather, narratives were thought to be much more impactful due to their accessibility and relatability. Publicising research narratives on social media and news stories was encouraged. To depict a more realistic picture of research, participants called for the media to highlight smaller, more gradual successes and advances, as well as those focussing on potential cures.

### *Access to research outcomes*

Access to study findings is not only important for researchers and regulators to inform further research and regulatory decision-making, but also for trial participants and the patient and carer community who value being informed of the results of the research in which they participated or have an interest in. This includes communicating the outcomes of the trial, ongoing studies and the potential impact on disease management.

Participants supported the transition to open access to research, as well as the inclusion of lay summaries to broaden access to research findings (see Box 5).<sup>26,27,28</sup> Participants noted that health information needs to be tailored to the literacy and numeracy levels of the wider patient population as current levels in many medical information sources are not appropriate for the general public.<sup>29,30</sup> It is estimated that two-fifths (43%) of adults do not have sufficient health literacy to fully understand typical text-based health information, a figure that rises to three-fifths (61%) if materials include numerical information.<sup>31,32,33</sup>

## Box 5: Enhancing access to research findings

### **Pfizer publication of lay summaries**

As part of their policy to make clinical trial data accessible and transparent, Pfizer produce lay summaries of trial findings to share with trial participants and interested bodies. These accessible documents are supported by publications in peer-reviewed journals within 18 months of study completion, and online clinical study report synopses on Pfizer's website with links to datasets on [clinicaltrials.gov](https://clinicaltrials.gov).

### **The BMJ's Patient and Public Partnership**

In 2014, The BMJ introduced internal editorial changes aimed at better integrating patient partnerships in its ways of working. Its patient partnership strategy, devised with an international patient advisory panel, introduced changes such as patients reviewing all relevant research papers alongside its standard scientific peer review processes, publishing a monthly patient-led and -written series called 'What your patient is thinking', and appointing patient and carer editors as members of the editorial team. In 2015, The BMJ was the first medical journal to receive a 'Patients Included' certificate in recognition of its work to promote patient partnerships.

In addition to being mindful of language when communicating research, exploiting a range of platforms was encouraged, including online resources, such as Mental Elf (see Box 6).<sup>34,35</sup>

## Box 6: The Mental Elf

The Mental Elf is an online resource with blog posts produced by mental health experts. These reliable posts are free and contain succinct summaries of academic articles of evidence-based research relevant to mental health practice. The ambition of Mental Elf is to stimulate conversations between patients, health professionals, carers, policy makers and clinicians. Mental Elf is now part of a wider 'National Elf Service' that provides accessible information on a variety of health topics, including The Social Care Elf, The Dental Elf and The Education Elf.

# Next steps

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The UK has a strong foundation in patient and public involvement and engagement in research, which now needs to be expanded to provide greater opportunities for all patients to contribute to research. The roundtable provided valuable insight into the next steps needed. These included:

- Providing access to research opportunities routinely at the point of care and equitably across the UK. The role of new technologies in enabling this should be explored.
- Greater involvement of patients and the public at all stages along the R&D process, including early engagement in research priorities and research design, through to implementation and dissemination of research findings.
- Better training of health researchers in PPI so that it is included as a central component in designing, delivering and disseminating research studies.
- Better communicating the value of research to patients and members of the public to encourage greater participation. Also ensuring that research findings are accessible and understandable so that patients and carers can use them to inform decisions about treatment and care.

# Annex 1: Participant list

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## *Participants*

**Dr Adrian Baker**, Research and Innovation Senior Manager, NHS England and NHS Improvement

**Sally Brearley**, Chair, Royal College of Physicians Patient and Carer Network

**Aisling Burnand MBE**, Chief Executive, Association of Medical Research Charities

**Dr Catherine Calderwood**, Chief Medical Officer, Scottish Government

**Alan Chant**, Patient Representative, UK Clinical Research Collaborative Board

**Tina Coldham**, Chair, INVOLVE

**Professor Dame Jessica Corner FMedSci (Chair)**, Vice Chancellor, Research and Knowledge Exchange, University of Nottingham

**Simon Denegri OBE**, National Director for Patients, Carers and the Public, National Institute for Health Research

**Eric Desson**, Member of the Lay Research and Strategy Sounding Board, Cancer Research UK

**Jillian Hastings-Ward**, Patient advocate, Genomics England Participant Panel

**Jacob Lant**, Head of Policy and Public Affairs, Healthwatch UK

**Professor Susan Michie FMedSci**, Professor of Health Psychology, University College London

**David Montgomery**, Director of Research, Prostate Cancer UK

**Dr Siân Rees**, Director of Patient & Public Involvement, Engagement & Experience, Oxford Academic Health Science Network

**Dr Jonathan Sheffield OBE**, Chief Executive Officer Clinical Research Network, National Institute for Health Research

**Adrienne Skelton**, Director of Policy Health and Social Care Improvement, Versus Arthritis

**Richard Stephens**, Patient advocate

**Derek Stewart OBE**, Director for Patient Involvement, National Institute for Health Research

**Dr William van't Hoff**, Clinical Director for NHS Engagement, National Institute for Health Research

**Professor Dame Til Wykes DBE FMedSci**, Professor of Clinical Psychology and Rehabilitation, King's College London

## *Secretariat*

**Dr Claire Cope**, Policy Manager, Academy of Medical Sciences

**Holly Rogers**, Communications and Engagement Manager, Academy of Medical Sciences

**Dr Amy Slater**, Policy Officer (Careers), Academy of Medical Sciences

**Dr Naho Yamazaki**, Head of Policy, Academy of Medical Sciences

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