

NIHR patients and the public focus on I Am Research/NHS 70

July 2018

#IamResearch is a conversation opener for public involvement



'Wow, I never realised, that's really interesting,' said the BBC local radio presenter. I was doing a live interview for this year's NIHR 'I Am Research' campaign for International Clinical Trials Day (ICTD) in May. I had been explaining how people don't just take part in our research. They also help us to design and deliver studies. Our conversation continued off-air after he'd cued in the next piece of music. NIHR's campaign for ICTD has been going six years now. Each year it gets bigger and better. 2018 has been no exception with the NHS70 celebrations just adding to the fun (1). And patients, carers and the public have been front and centre.

Helping to organise hundreds of events around the country – from chocolate clinical trials to Open Days to information stands in hospitals and GP surgeries. Promoting our #IamResearch social media campaign which has reached millions of people. Telling their stories to national and local journalists for news stories covering an NIHR survey of 2000 people highlighting public misconceptions about research (2).

Which is why, as in previous years, I was in a London studio doing back-to-back interviews with over 20 local radio stations. It's something I love doing. Because in my head I imagine someone listening at home or at work who might just be persuaded to join research. Someone who had never thought of it before and whose life might be changed for the better as a result.

Plus it's always fascinating and challenging what radio presenters pick up on. This time around almost all of them asked whether people get paid to be in a trial. Most mentioned the events at Northwick Park over ten years ago in which six men who took part in a trial fell gravely ill. But more and more have – as the local BBC radio presenter – picked up on the fact that people are getting involved in research many different ways.

Public awareness campaigns like 'I Am Research' are getting a bit of a bad press at the moment – there's too many, what can they change in a week, in a day? But I think people are missing the point. Awareness campaigns need to be run over many years to begin to change public attitudes and behaviours.

Look at what's happened in dementia for instance where the first public awareness campaign was run in the early 90s. With NIHR about to report more people going into trials than ever I have no doubt in my mind that #IamResearch - and the 'OK to Ask' campaign before it - have contributed to this good news story for patients, carers and the UK.

In the public involvement community I think there's also some resistance to campaigns such as #IamResearch because they are seen to be more about 'engagement' or 'participation' than 'involvement.' Which is true, they are - although public involvement now has a higher profile in them. But, as my time in the studio shows, such campaigns are about beginning a conversation. A conversation opener that may well turn to discussing 'public involvement'. And who knows what might happen after that?

Simon Denegri - NIHR National Director for Patients, Carers and the Public

(1) 70 discoveries that have shaped the NHS: <https://www.nihr.ac.uk/news-and-events/support-our-campaigns/i-am-research/70-discoveries.htm>

(2) BBC Online News Coverage of #IamResearch: <https://www.bbc.co.uk/news/health-44238136>

Simon Denegri recognised in Queens' Birthday Honours

A number of NIHR leaders and researchers supported by the NIHR have been recognised for their achievements in the Queen's Birthday Honours 2018.

Dean of the [NIHR Faculty Trainees](#) Professor David Jones, who is also Professor of Liver Immunology at Newcastle University and lead for the liver disease theme with the [NIHR Newcastle Biomedical Research Centre](#), has received an OBE for services to liver disease and training.

Professor Jones said: "I am delighted, and very pleasantly surprised, to be awarded an OBE for my work in liver medicine and in academic training. My whole career has been focused on improving the lives of patients with the liver disease primary biliary cholangitis and in helping the next generation of medical researchers. It is nice to know your efforts are seen and appreciated.

"Everything has been done as part of teams and I acknowledge the support and contribution of my colleagues at Newcastle University, Newcastle upon Tyne Hospitals NHS Foundation Trust and the National Institute for Health Research."

Simon Denegri NIHR National Director for Patients, Carers and the Public, has been awarded an OBE for services to public health and social care research.

Professor Matthew Hotopf, Director of the [NIHR Maudsley Biomedical Research Centre](#) and Vice Dean of Research at the Institute of Psychiatry, Psychology & Neuroscience at King's College London, has been awarded a CBE for services to mental health research.

Professor Hotopf said: "I am deeply honoured to receive this award. It represents the contributions of a huge number of people in my research team, the NIHR Maudsley Biomedical Research Centre and the wider academic community at King's College London, working to improve the profile of mental health research and ultimately to benefit people with mental health problems."

Professor Paul Little, former Director of [NIHR Programme Grants for Applied Research](#) and Professor of Primary Care at University of Southampton, has likewise been awarded a CBE for services to general practice research.

Other NIHR leaders who have been recognised in the Queen's Birthday Honours include:

- Professor Sian Ellard, Panel Member at the NIHR Trainees Coordinating Centre
- Professor Paul Emery, Director of the [NIHR Leeds Biomedical Research Centre](#)
- Professor Anne-Maree Keenan, Assistant Director of the NIHR Leeds Biomedical Research Centre, Panel Member at the NIHR Trainees Coordinating Centre, NIHR Infrastructure Training Lead and NIHR Senior Investigator
- Professor Jane Marshall, Panel Member at the NIHR Trainees Coordinating Centre
- Professor Laura Serrant, Panel Member at the NIHR Trainees Coordinating Centre
- Professor Charles Wolfe, Director of R&D at [NIHR Guy's and St Thomas' Biomedical Research Centre](#)



Help celebrate the NHS 70th Birthday with the I Am Research and NHS 70 campaign!

The **NHS** turned 70 on 5 July 2018, and to mark the occasion our [I Am Research and NHS70 campaign](#) has been encouraging patients, carers and the public to get involved in research and help shape the next 70 years of the NHS.

Our survey has revealed only 14% of people have ever taken part in a clinical trial, despite 85% saying they want to help the NHS find better treatments. Based on this data from 2,000 UK adults, we have issued a call for more people to join clinical trials and get involved in research.

Simon Denegri, NIHR National Director for Patients, Carers and the Public, said: “Research has played a massive part in transforming the healthcare that patients have access to today – from the discovery of penicillin to the production of the contraceptive pill – and it remains one of our best chances to develop the care and treatment we receive in the future.”

Three patients, Carlene Coda, Steven Burgess and Mohsan Akhtar share their personal journeys of participating in clinical research - they explain their reasons for taking part and how research has helped them in our <https://www.nihr.ac.uk/patients-and-public/documents/HelpCelebrateNHS70IamResearchCampaign.pdf>

If like Carlene, Steven and Mohsan, you would like to participate in health research, you can visit the [UK Clinical Trials Gateway](#) to find out about studies of interest. In addition to helping to recruit patients and healthy volunteers onto clinical trials, the NIHR provides many other opportunities for people to become involved in research, this could be as a [Patient Research Ambassador](#), [advising researchers on improving patient experiences](#), [signing up for mailings](#), or simply talking about research.

The Great Untold Story of Research

Simon Denegri, national director for patients, carers and the public at the National Institute for Health Research (NIHR), advocates closer public involvement in NHS research and innovation. The British people have high hopes for their healthcare. They believe that the NHS will throw ‘everything’ at it if they or a loved one is unwell. That ‘everything’ includes the very latest that research can bring to their hospital bedside, GP surgery or their home. It’s a belief fuelled not only by their own experiences but by newspaper headlines and fly-on-the-wall TV documentaries showing health professionals battling against the odds with the help of amazing technological advances – all to turn those odds in favour of patients and families.



Time and time again, surveys show that the vast majority of the British public believe health research is important and a vital part of what the NHS does. When the Association of the British Pharmaceutical Industry (ABPI) recently asked people to identify the main reason for the UK's lead in medicine and medical technology, the most popular answer was the NHS, followed by the UK's scientific heritage.

They are also justifiably proud of the NHS's track record. It is, after all, world-class. When asked in the same ABPI survey which British innovation in the last 70 years has had the biggest impact on health and medicine, 21% of people chose the first liver, heart and lung transplant, closely followed by the structure of DNA and the development of the CT scan.

To tie in with the NHS's 70th birthday, the NIHR is showcasing how research has improved health and care over the past 70 years, as well as how our research is helping to shape the future. This includes spotlighting 70 discoveries – starting with penicillin – that have transformed outcomes for patients and the way the NHS works, and highlighting seven research legends whose findings have transformed care in our health service.

What is less recognised is the role that has increasingly been played by patients, carers and the public in this innovation story. Over three million patients, carers and healthy volunteers alone have taken part in clinical trials since NIHR was established in 2006. Many thousands have helped us identify research priorities and design and deliver the best research to meet people's health and care needs. Up and down the country, citizens are actively co-designing the future of health and care alongside NIHR research, health professionals and NHS staff.

People like mother and daughter, Sophie and Sammy Ainsworth. Sophie was diagnosed with the life-changing condition lupus as a young girl and is now studying for her university degree. As well as taking part in clinical trials, Sophie is a member of our GenerationR movement of young people helping researchers design studies. Meanwhile, Sammy's experience has led her to become a patient research ambassador at her local Preston hospital – being the face of research with other hospital users, raising awareness, helping to recruit patients to trials, and lending her insight and experiences to researchers.

I Am Research

NIHR has been at the forefront of the movement to involve the public in research over the last decade. It is the recognised world leader for the way in which it has made public involvement 'business essential' to the delivery of clinical trials. Now, charities and industry are catching up fast, and public involvement is becoming an important part of local innovation partnerships led by Academic Health Science Networks as part of the Life Sciences Strategy. But at the end of the day, it's the contribution of people like Sophie and Sammy from which we should draw inspiration. The NIHR aims to highlight this in its annual 'I Am Research' campaign, timed to coincide with International Clinical Trials Day which took place on 20 May.

The campaign is both a cause for celebration and a call to action. According to a new NIHR survey of 2,000 members of the general public, just over 10% of people have taken part in a clinical trial; it is important that more people not only join us in this enterprise, but also understand that routine activities such as sharing patient data are essential to research into future treatments.

Dispelling myths – and becoming proactive

The challenge confronting NIHR, its NHS partners, industry and research charities is not that people are not willing – over 80% of respondents to the survey said they wanted to help the NHS develop better treatments – but that common misconceptions about research persist, and we are not making research part of the routine care and treatment that most people can expect when using their health service.

Those misconceptions include the fact that they have to be invited to take part rather than ask about opportunities; that research is not happening near them even though nearly all hospitals are research-active; and that whole groups in society, such as children, cannot take part in a trial.

Approximately 80% of people have never been invited to take part in a trial and many have not seen information about research in their local hospital or GP surgery. In fact, people are more likely to have seen information about clinical trials on the web than they are in their local NHS.

There is now growing evidence of the link between research-active hospitals and quality of care. This evidence suggests that the public's gut instincts about what research means for the NHS and their own care has always been spot on. Perhaps, as in many other things, the public have been ahead of us all the time.

What seems clear is that they can have a bigger role to play in the innovation story ahead by taking part in studies and developing research that matters to them and the nation.

But first, we need to let them.

The public as our partners' highlights report

The NIHR Central Commissioning Facility (CCF) has recently published its PPI highlights report for 2017-18. This year, they have opted to report against the new national standards for public involvement <https://sites.google.com/nihr.ac.uk/pi-standards/home>. The report covers different aspects of work in line with the 6 standards: inclusive opportunities, working together, support and learning, communications, impact and governance. As you might imagine, there was more to report under some standards than others! You can access the report through this link: The public as our partners 17/18 www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/Documents/CCF_PPIreport17_18SHORT.pdf. Get in touch with the CCF PPI team <https://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/ccf-ppi/ccf-ppi-team.htm> if you would like to know more.

Patient experience survey results to improve research practice

Over 4,300 research participants (or their carers) have had their say in the Patient Research Experience Survey.

The NIHR Clinical Research Network has been working on ways to collect and understand patient feedback so the insight can be used to continuously improve clinical research practice.

During 2017/18 a patient survey was carried out by Local Clinical Research Networks across England and core feedback was collated and analysed nationally:

- 87 per cent of patients said they had a good experience of participating in research
- 83 per cent said they would be happy to take part in another study

In his recent blog about the survey, Simon Denegri OBE, NIHR National Director for Patients, Carers and the Public, said:

"The high positive ratings on overall experience (80+ %) are consistent with every survey I've seen in this field. But the report includes a neat synopsis of the recurrent themes in the data about what's high on the priority list for patients."

Wrap up of the ‘Co-producing research: How do we do it?’ Event, London July 5th

The first week of July is national ‘co-production week’ as designated by the Social Care Institute of Excellence (SCIE). It is a week to celebrate all things co-production related. This year the week fell during the NHS at 70 celebrations.

The INVOLVE/ Research Design Service (RDS) South East Partnership (led by Gary Hickey & Duncan Barron) teamed up with UCL Centre for Co-production in Health Research, Centre for Public Engagement (Kingston and St George’s, Joint Faculty), RDS London, Academic Health Sciences Network Kent, Surrey, Sussex and the international journal *Health Expectations* to put on a regional event to celebrate both NHS at 70 and co-production.

Using examples from London and the South East we sought to:

- Explore how co-producing research is different from other approaches involving patients and public in research
- Identify factors which enable the co-production of research
- Raise awareness of the National Institute for Health Research (NIHR) approach to co-producing research including the recently published ‘Guidance on co-producing a research project’

The Centre for Public Engagement hosted the event which was co-chaired by Duncan Barron and Gary Hickey.

Tina Coldham, Chair of INVOLVE, kicked off proceedings with a short history of co-production and with a particular focus on the NIHR’s interest in how it might help us to evolve and improve patient and public involvement in research.

Gary Hickey (INVOLVE) and Kati Turner (St George’s University) then outlined the guidance on co-producing research <https://www.nihr.ac.uk/patients-and-public/documents/CoProJuly.pdf> that has been co-produced by NIHR. The focus was on the five key principles that have been developed:

- Including all perspectives and skills
- Respecting and valuing the knowledge of all those working together on the research
- Reciprocity
- Building and maintaining relationships

They stressed that the guidance could be used as a first step for starting on the co-production pathway. They also raised some of the challenges in co-producing research. They noted that further guidance from INVOLVE is due in October 2018 which will highlight examples of co-produced research.

Building on the opening sessions the rest of the morning focused on some of the challenges involved in co-producing research. Sam Robertson (Sussex Partnership NHS Foundation Trust) gave a personal account of her experiences of being a public member involved in co-produced research as well as being an academic. In particular, she talked about her experiences of Participant Action Research (PAR) as a means of co-producing research. Benefits of using PAR were that participants become co-researchers who can help determine the focus of the work. Using focus groups as an approach has the potential, via debate and discussion, to ensure public views help generate new meanings and understanding. Additionally focus groups can provide an environment in which less vocal members can gain confidence and find a voice. Challenges included the ethical issues of involving more vulnerable people in focus groups, having the resources to ensure the involvement of co-researchers and the commitment required of co-researchers in co-produced research.

The morning ended with an interactive session run by Prof Mary Chambers (Editor, *Health Expectations* and Director, Centre for Public Engagement) during which delegates explored, in groups, the challenges and solutions to co-producing research for different parties.

For example, challenges for funding bodies included how to measure the quality of co-produced research and ensuring that adequate resources were allocated to enable co-produced research. Challenges for universities and researchers included the pressures on researchers and universities in publishing articles in high ranking journals which may lead a) to issues about ownership of research and b) to researchers generating knowledge that does not involve and/or is of less concern to the public. Another challenge was a perceived lack of expertise and/or confidence amongst researchers to undertake co-produced research.

In terms of solutions it was suggested that awareness of co-production needs to be raised via for example training and/or the development of 'co-production departments' in organisations. It was also suggested that the public should be involved in priority setting and commissioning. The need to develop an evidence base for co-produced research was also a suggested solution.

After lunch attendees listened to a recorded message from Simon Denegri (NIHR National Director for Patients, Carers & the Public) in which he referred to the NHS at 70 and gave an inspiring message in support of the event and co-production in health and social care research in general. The first session in the afternoon was another interactive session led by Niccola Hutchinson-Pascal (UCL Centre for Co-production in Health Research) and Gary Hickey (INVOLVE). Niccola is collaborating with a group of patients, healthcare professionals and researchers to co-produce the development of the Centre for Co-production. As part of this work, one of a Series of Pilots <https://blogs.ucl.ac.uk/public-engagement/2018/07/02/the-co-pro-pilots-are-here-funding-available-from-the-ucl-centre-for-co-production-in-health-research/> involves testing how to establish a network that enables co-production. The session involved delegates exploring some of the barriers and possible solutions to setting up such a network.

There followed three presentations of co-production in action in London and the South East. First up was Duncan Barron (RDS South East), Victoria Hamer (lay panel member, RDSSE) and Kate Sonpal (INVOLVE) who explained how they had helped (with a larger group of partners in the SE) co-design a young person's advisory group (YPAG) aged 8-18yrs and a parallel Parent and Carers (PaC) group in Kent, Surrey and Sussex. The group, funded by the charity Rockinghorse, works with researchers on their research ideas. The group have begun to co-produce their own ground rules and some 'Top Tips' for researchers which they see as an evolving process that will be regularly re-visited. Some of the Young People have also been keen to co-facilitate sessions and educate the adults in the benefits of using pictorial mind maps to capture ideas and feedback for researchers. A recent article highlighting the work of the YPAG can be found on pages 6-7 at: https://www.rds-se.nihr.ac.uk/wp-content/uploads/NL_126684_RDS-SE-Spring-Summer-2018_v5_web.pdf.

This session was followed by a presentation by James Byrne (Sussex Partnership NHS Foundation Trust) and Anna Verey (East London NHS Foundation Trust) who spoke about co-production in the The ENhanced dischaRge from Inpatient to Community mental Health care (ENRICH) study. This is a NIHR funded project investigating the effectiveness of peer support offered to people who are discharged from being in hospital as a mental health in-patient. They spoke about the challenges and opportunities of addressing the co-production principles of sharing of power, including all perspectives and skills and building and maintaining relationships. Power sharing provided the opportunity for a more democratic approach to decision-making with each voice being valued. It also provided opportunity for people to take on different roles in meetings and therefore increase skills and confidence. Challenges were occasional loss of direction and progress in meetings and the difficulties of keeping everyone informed.

Involving all perspectives and skills provided the opportunity of a 'richer' team because people with lived experience as well as researchers were present. Challenges included: developing trust amongst the group, integrating newcomers into established teams and getting a balance between authentic sharing and overwhelming self-disclosure and ensuring diversity and how to address the issue of different levels of expertise within the team. Finally, building and maintaining relationships provided the opportunity to develop induction training for all, peer support and to give consideration to language that enabled a respect for differences.

The presentations closed with a session from Charlotte Brigden (Pilgrims Hospice) and Graham Silsbury (public co-applicant) on the OPEL (Optimum 'Hospice at Home' Services for End of Life Care) study. The study is investigating what are the features of hospice at home that work for whom and in what circumstances? They outlined how various stages of the project were co-produced including deciding which data collection tools to use, the development of topic guides for interviews, interpretation of data and training for patient and public co-applicants.

For the final session the group logged on to a webinar hosted by the Social Care Institute for Excellence on 'Breaking down barriers to co-production' <https://www.scie.org.uk/co-production/breaking-down-barriers> which touched on many of the issues also raised at this event.

In conclusion, Mary Chambers (Centre for Public Engagement and Editor *Health Expectations*) highlighted an opportunity for people to submit papers to a 'co-production special' to appear soon in *Health Expectations*. Anyone interested can find out more here <https://onlinelibrary.wiley.com/page/journal/13697625/homepage/forauthors.html>

Feedback on the event from attendees was overwhelmingly positive. One person said that they had found the event "*Welcoming, inviting and hospitable*" and had enjoyed the "*Interactive nature*" and had left with a "*Better understanding of co-production research*".

Other written feedback included:

"I liked the opportunity to network with fellow passionate co-producers and in particular seeing innovative examples of co-production..."

"Interesting and intelligent conversations about co-production."

"This was a good consolidation of the principles in the new INVOLVE co-production guidance; showed we're all facing similar challenges and was a great opportunity to network and learn what others are doing"

For further information on this event please and to request copies of the presentations please contact: Gary.Hickey@nihr.ac.uk or d.barron@brighton.ac.uk

#I Am Research <https://tinyurl.com/y96nsz5q>

Birthday Honours <https://tinyurl.com/ydxwgve7>

Untold Story of Research <https://tinyurl.com/yc2hm5cd>

NHS 70 Birthday <https://tinyurl.com/y8qqgbdv>

Co-Production <https://tinyurl.com/y7zsqtgn>

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