NHS
National Institute for
Health Research

Senior Investigators
Leaders for patient and public involvement in research

April 2014

Contents

Examples

This paper should be referenced as:

INVOLVE (2014) NIHR Senior Investigators: Leaders for patient and public involvement in research, INVOLVE, Eastleigh

About this publication

The National Institute for Health Research (NIHR) Senior Investigators (SIs) constitute a network of approximately 200 pre-eminent researchers who represent the country's most outstanding leaders of clinical and applied health and social care research. SIs provide expert advice to the Department of Health's Director General for Research and Development as well as research leadership to the NIHR Faculty[1]. They are selected through a process of annual competition with advice from an independent expert panel currently chaired by Professor Melanie Davies.

This publication presents five examples of how Senior Investigators involve patients and the public in their work. It coincides with the launch of NIHR's Eighth Competition in May 2014 to:

- provide Senior Investigator competition applicants with clear examples of patient and public involvement practice at the level of Senior Investigator;
- encourage all NIHR Faculty members to integrate patient and public involvement into their own research career development; and
- give patients and the public an insight into the ways Senior Investigators involve people in their work.

[1] Visit the NIHR Faculty web pages for more information about NIHR Senior Investigators, including a directory: http://www.nihr.ac.uk/faculty/Pages/faculty_senior_investigators.aspx

Acknowledgements

We thank the project advisory group for their work on this publication:

Sarah Buckland, Director, INVOLVE Coordinating Centre – chair of the group;

John Hughes, INVOLVE Advisory Group member and former public member of the Senior Investigators panel;

Mary Ray, current public member of the Senior Investigators panel;

Maryrose Tarpey, Senior Advisor, INVOLVE Coordinating Centre and project manager; and

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

The advisory group gratefully acknowledge the skills and expertise of **Katherine Cowan** http://www.katherinecowan.net, who was commissioned by the INVOLVE Coordinating Centre to conduct and write up the interviews.

This was an NIHR-wide project funded by INVOLVE working with NIHR Faculty and the NIHR Central Commissioning Facility.

Foreword

In the past I have called on our NIHR Senior Investigators to help lead the way in embedding patient and public involvement into the culture and ethos of health and care research. Now, as the examplars in this publication confirm, Senior Investigators are indeed making a significant contribution to ensure we deliver on our commitment to fund and support research that is important to the needs of patients and the public by involving them every step of the way.

By their leadership, they are enabling the creation of the best possible environment for patient and public involvement in research to flourish. They are using their influence and conviction to place the interests of patients and the public at the heart of all our activity - from individual NIHR funded research projects, training programmes within the Faculty to arrangements within commissioning and infrastructure provision.

I recommend you read this publication, whether you are an aspiring Senior Investigator, at the start of your research career or are a member of the public interested in getting involved. There is much to learn from the experience and excellent practice of these inspirational individuals. They so clearly show what a massive difference patient and public involvement makes and why it remains fundamental to our success.

Professor Dame Sally C. Davies FRS FMedSci,
Chief Medical Officer and Chief Scientific Adviser,
Department of Health

Introduction

The National Institute for Health Research (NIHR) has built a world-leading reputation for the way it involves the public in the design, delivery and dissemination of health, social care and public health research.

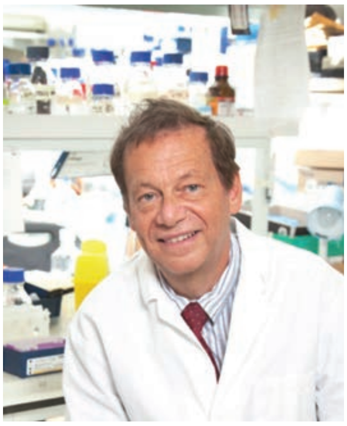
When it was established in 2006 the NIHR made a bold statement that public involvement would be a core principle in the way it worked. It signalled the beginning of a culture change in how UK health research is conducted. This transformation is ongoing and is actively supported by INVOLVE, NIHR's national advisory group for the advancement of public involvement.

Strong leadership has been crucial to promoting this culture change. NIHR is immensely fortunate in having a cadre of senior researchers who have led the development of public involvement over the years and now champion its value from first-hand experience. This publication gathers together the reflections of five of these leaders who are NIHR Senior Investigators.

Many themes emerge from their descriptions of public involvement: the sense of common purpose that develops between researchers, patients and the public; how this partnership can remove barriers to research – contrary to many people's expectations; and the benefits to research in having public champions that can speak from their own experience of being involved. Each of the senior investigators highlighted in this publication, convey powerful messages on the impact that public involvement has had on their work and the difference it has made.

They show what can be achieved when the active involvement of the public is embedded into research practice. We hope they will inspire and encourage those applying to be NIHR Senior Investigators to lead from the top in continuing to make public involvement happen in the future.

Simon Denegri
Chair, INVOLVE
NIHR National Director for Public Participation and Engagement in Research



Dr John Bradley

Director, NIHR Cambridge Biomedical Research Centre

> "There's no doubt that you can do laboratory-based research without patient and public involvement. But, if you do involve people, and you involve them early, you will reap the benefits as a research programme evolves."

NIHR Senior Investigator John Bradley has undertaken many different types of study, but his research is primarily laboratory-based, looking at the cardiovascular aspects of kidney disease. His experience suggests that most people, both healthy volunteers and patients, want to support health research and want a greater involvement than simply participating as subjects. Dr Bradley has found that patient and public involvement (PPI) in his work has positively influenced the development of questions and outcomes, has enhanced recruitment and increased the retention of participants in trials.

In his research on kidney care, Dr Bradley chaired the Advisory Board for a Kidney Research UK study looking at different interventions within primary care that would help doctors and patients achieve better blood control. Patients influenced the study design and helped identify the interventions to test. They attended the interview for the award with the funding body, emphasising the research team's aspiration to conduct research with patients, for patients. They held the researchers to account, monitoring progress and acted as critical friends. This study led to the Engaging with Quality in Primary Care (ENABLE) study coordinated by Kidney Research UK and funded by the Health Foundation, for which a patient advisory group contributed to all parts of the study process, such as the development of patient materials, practitioner training and advice and evaluation tools.

It is important to note, suggests Dr Bradley, that the nature and design of patient and public involvement inevitably varies between studies. It will look very different in a study examining the direct care of patients to a laboratory-based study. However it still has applications in both settings. At the Cambridge Biomedical Research Centre (BRC), where the work is divided into themes, there is an expectation that PPI will be on the agenda for any key meetings with theme leads. If patients and the public are appropriately involved by theme leads, Dr Bradley suggests, it is more likely that the value and application of PPI will filter down into the research teams. The BRC has set up a panel of around 40 people who provide feedback on the BRC's research proposals and patient information and consent forms, making sure that materials are appropriate and terminology accessible.

A children's research board has been established at the NIHR/Wellcome Trust Cambridge Clinical Research Facility (CRF) for Experimental Medicine which supports the work of the BRC, where paediatric studies are carried out, many involving blood sampling. Children who had been or were likely to be involved in studies were invited to spend a morning reviewing the facilities at the CRF and made suggestions to help researchers provide an environment where children would like to spend time and participate in research.

Dr Bradley emphasises that PPI is essential for the development of gene and DNA research to ensure the public understands the issues around DNA collection and analysis. As with research requiring blood or tissue samples, patients are at the heart of it. They need to be involved to help find ways to ensure all of the issues are fully considered, explain the processes and address the ethical implications.

A major challenge for PPI, according to Dr Bradley, is convincing all types of researchers of its importance. There is no doubt that it requires planning, time and effort. However, in a world where researchers already have significant levels of bureaucracy to manage, Dr Bradley believes that PPI will ultimately help rather than hinder the process.

> "You might think that because you're studying a molecular signalling pathway, PPI is not important, but it is still about patients. PPI is essential for genomic research, to ensure all of the concerns are fully understood and ethical issues are properly addressed."

NIHR Cambridge Biomedical Research Centre: http://www.cambridge-brc.org.uk/public

Loud F (2012) INVOLVE Conference presentation about public involvement in the ENABLE study: http://www.involve.nihr.ac.uk /wp-content/uploads/2013/01/3.8-Loud.pdf

Professor David Gunnell

Professor of Epidemiology, School of Social and Community Medicine, University of Bristol

> "We involve patients to understand what they want, to understand their needs, to ensure that what we research is directly relevant and will make a difference. We're doing it to make a difference to the patient and to population health."

NIHR Senior Investigator David Gunnell was the co-Principal Investigator on an NIHR Programme Grant for Applied Research (PGfAR) in support of the National Suicide Prevention Strategy for England. His research focuses on strategies for improving mental health and preventing suicide.

To plan and agree priorities for this suicide research programme Professor Gunnell and his team convened a workshop that included patients, representatives from the Samaritans (the national suicide prevention charity) and policy makers. Their views and input were key to ensuring this very challenging programme of work was designed appropriately and sensitively with the needs and concerns of service users and population health policy at its heart. One service user became a co-applicant, advising the research team and assisting with the recruitment of patients who self-harm to the study.

In previous research, Professor Gunnell and colleagues tested a contact-based intervention – a letter and the provision of sources of information and help – aimed at reducing the incidence of self-harm in the period after psychiatric hospital discharge. Every aspect of this was shaped by patient and public involvement (PPI). There were two service users and a Samaritans' representative on the steering group. One of the service users became a co-author of a resultant paper.

The design of the intervention was determined through research interviews with service users. This enabled the team to assess how patients preferred to be contacted, how useful they might find the letter, how to word it, how often to contact them and any other issues they felt were relevant. The letters and protocols for patient contact following psychiatric hospital discharge were co-produced with a service user member of the research group and had input from a number of patients who had recently been discharged from a psychiatric inpatient unit. Service users commented on the design of the study and provided ideas that were incorporated into the final letters to patients and the interview guide to follow up on the intervention.

A similar approach was adopted in the development of the second intervention within the research programme: a contact-based intervention aimed at reducing the risk of repeat self-harm among people presenting to hospital following self-harm.

Professor Gunnell and his team worked closely with their Service User Adviser to ensure people were adequately briefed and supported before, during and after the process of being involved. As well as the adviser, there were always at least two service users involved, to encourage peer support and to minimise the pressure a lone individual could feel.

Professor Gunnell believes that a key determinant of successful PPI in research is collaboration. Research is enhanced through the sharing of knowledge, insights and experience. In particular he credits the Service User Adviser, Rosie Davies, with playing a key role in terms of contacting patients to be involved, helping the research team to communicate with them and supporting them to remain involved.

For Professor Gunnell, patient and public involvement is not an optional extra: it is part of the research process, ensuring that the evidence discovered is meaningful, relevant and useful to a particularly vulnerable group of patients.

> "Patient and public involvement is about collaboration. It is not about the work of one individual but rather groups of patients and researchers coming together and contributing to a wider body of work."

Gunnell D et al (2013) A multicentre programme of clinical and public health research in support of the National Suicide prevention Strategy for England, Programme Grants Appl Res 2013:1(1) http://www.journalslibrary.nihr.ac.uk/pgfar/volume-1/issue-1

INVOLVE (2013) Examples of public involvement in research funding applications: Example 9 http://www.invo.org.uk/resource-centre/examples/exploring-public-involvement-in-nihr-research-funding-applications a multi-centre programme of clinical and public health research to guide health service priorities for preventing suicide in England.

Professor Elaine Hay

Director, Institute of Primary Care and Health Sciences Centre,
Keele University

> "As researchers I think we sometimes lose sight of the fact that the reason we do research is for the benefit of patients. Patient and public involvement brings us back to that."

NIHR Senior Investigator Elaine Hay's research area is musculoskeletal conditions. She is interested in improving doctors' and patients' capacity to manage the conditions in primary care and through self-care.

Professor Hay was introduced to the concept of patient and public involvement (PPI) through an osteo-arthritis programme which was seeking to understand the differences between patients' and researchers' priorities for research. Like many researchers, she was acutely aware that funders increasingly wanted to see evidence of PPI in research proposals. However, Professor Hay suggests that she soon started to see the benefits of PPI to all aspects of her research and the benefits to the patients themselves.

At the Primary Care Centre, the 60 members of the Patient and User Group are involved in prioritising research questions, advising on appropriate methodologies, devising effective and ethical recruitment strategies, interpreting findings and disseminating results. Patient involvement in the development of fibromyalgia research questions has changed the researchers' focus from cause to day-to-day coping with the condition which causes widespread muscular pain. Much arthritis research is looking for a cure. However, patient involvement has encouraged researchers at the Centre to also look at how to help them cope psychologically. Professor Hay says that researchers should not make assumptions about what patients want or need.

Integrating patient and public involvement into the end stages of the research process has also been a focus for Professor Hay, to ensure appropriate communication with trial participants. Patients have helped the researchers translate the results of trials into accessible language. Additionally, they have advised on communication with the control group participants, who may become anxious that they have missed out on treatment opportunities.

Professor Hay has committed core funding to ensure the Centre's Patient and User Group is run effectively. Organising the members, allocating them to projects and supporting their involvement is resource-intensive. It is important to recognise that different people will have different interests, skills and availability. Some may want to contribute to work which concerns their condition while others may carry out wider strategic activities. Two patients are now employed to coordinate this work, ensuring that everyone involved is supported, as well as being clear about their role and responsibilities. Professor Hay believes that patients know and will disengage when PPI is being carried out in a tokenistic or half-hearted way.

At the Centre's annual PPI meeting Professor Hay is conscious of being visible as a leader, demonstrating to patients, the public and the research community that PPI is a vital part of their work. Indeed, an evaluation of the PPI programme found that the Patient and User Group had provided invaluable opportunities for the researchers to discuss their ideas and modify and validate their approaches, as well as enhancing the Centre's ability to attract research funding.

> "Our patients, the PPI group, they're our ambassadors, they can help us get messages about research out into the public domain. What I would love is for patients to go to their GP and say, 'Have you seen this research?"

Institute of Primary Care and Health Sciences: http://www.keele.ac.uk/pchs/involvingthepublic

Professor Hywel Williams

Professor of Dermato-Epidemiology and Director,
Centre of Evidence-Based Dermatology, University of Nottingham

> "I don't actually think of the patients who work with us as PPI members: they're colleagues, they're people with good ideas. To me, they're part of the team like the statistician or the qualitative researcher or the clinician. I don't see a boundary. Patient and public involvement is essential, integral and natural to what we do."

NIHR Senior Investigator Hywel Williams has involved patients and the public in his research for over 20 years and considers it to be an essential mechanism for bridging the gap between the researcher's ideas and the reality of the patient's experience.

Patient and public involvement (PPI) is a key feature in a wide range of Professor Williams' activities. This includes initiatives to set priorities for research into various skin conditions, identifying patient-important outcome measures for eczema research and supporting a patient, Maxine Whitton, to become lead author on the Cochrane systematic review of interventions for vitiligo (a condition that causes white patches on the skin).

The NIHR Health Technology Assessment (HTA) programme-funded HI-Light Trial, which is about testing handheld ultraviolet devices for vitiligo, originated from a suggestion put forward by patients and clinicians working together in a James Lind Alliance Vitiligo Priority Setting Partnership. This was an exercise that developed out of an NIHR Programme Grant for Applied Research (PGfAR) coordinated by the Centre of Evidence-Based Dermatology. This input has changed the focus of vitiligo research from a hospital-based intervention treating the whole body to testing a treatment that can be used at home to repigment the visible areas on the hands and face that matter most to patients. Again in vitiligo, finding out how patients conceptualised successful treatment has led to the development of a new primary outcome measure of asking patients how noticeable their vitiligo is after treatment as opposed to the traditional measure of percentage of skin repigmentation. Patient involvement has also ensured participant information and recruitment materials for vitiligo studies are accessible and appropriate to people from different ethnic groups.

Professor Williams attributes a culture change in dermatology research to the involvement of patients. He suggests that in the past, research was dominated by basic science and the patient voice was rarely heard. Now he feels that there is greater acknowledgement of and response to the patient as the user of research.

The presence of patients on, for example, clinical trial steering groups, in network meetings and funding meetings reminds the researchers to maintain their focus on the ultimate beneficiaries of the research.

According to Professor Williams there is still some way to go. He is aware of those within the clinical research community who are not yet comfortable with the notion of involving patients and the public. He says it can be helpful to observe a team which is confident about PPI, where patients are empowered to contribute and where adequate time and resource have been allocated to support this.

Professor Williams believes that when patients feel valued and respected while undertaking PPI activities, they become the greatest allies of the researchers and the most powerful advocates for the research.

> "Good patient and public involvement comes from the top. If you're the chair, phone your PPI reps before the meeting, meet up with them, make them feel relaxed, introduce them, bring them in. The chair must demonstrate that the patients' opinions are valued and hopefully other researchers will pick that up and take it back into their work."

Centre of Evidence Based Dermatology:
www.nottingham.ac.uk/research/groups/cebd/get-involved.aspx

Projects: Interventions for vitiligo – Cochrane review
http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD003263.pub4/abstract

Eczema outcomes project
http://www.homeforeczema.org

Vitiligo PSP
http://www.lindalliance.org/Vitiligo_Priority_Setting_Partnership.asp

HI-light trial
http://www.trialsjournal.com/content/15/1/51

Professor Sue Ziebland

Director, Health Experiences Group, Nuffield Department of Primary Care Health Services, University of Oxford

> "A lot of research is funded by public money, so it's a no-brainer that the public should be involved in defining it. It's important for science, it's important for public understanding and ethically it's important. Patient and public involvement helps make research better."

NIHR Senior Investigator Sue Ziebland is a medical sociologist who specialises in qualitative narrative interview methods. Her research and interviews with service users provide the content for Healthtalkonline, a website offering information about health issues. She therefore uses patient and public involvement (PPI) as a means of generating effective public engagement tools.

Professor Ziebland has involved patients and members of the public in her research for many years and believes it has had positive impacts. When recruiting a researcher to carry out interviews with people with schizophrenia, having a service user on the panel was an effective way to identify the candidate with a demonstrable ability to build rapport with that specific participant group. On the steering group for a study on the ethical dilemmas of carers of people with dementia, three carers contributed to every stage, from designing interview tools to helping researchers interpret the results. They were engaged, enthusiastic, supportive and challenging, offering a fresh perspective and views on the presentation of findings which the researchers had not anticipated. The project led to a Healthtalkonline module about caring for dementia which was honest and upfront about carers' positive and negative experiences.

In other projects, patients' connections and insights into community dynamics have helped Professor Ziebland and her team involve so-called 'seldom heard' groups and recruit them to studies. This has included taking advice on how and where to communicate appropriately, including with people who are unable to read. Through PPI they have gained access to Irish travellers and have worked with young men, including those from black and minority ethnic communities, both groups which researchers often struggle to include in health research.

Professor Ziebland notes that patient and public involvement brings the authority of experience but that people will only feel confident expressing that if their contribution is clearly valued by the research team. This requires researchers to be explicit about the purpose of a PPI activity, the specific requirements of a task and the role of each individual in relation to the wider research programme.

Supporting patients to be involved is important and may need to include offering training or mentoring – either formally or informally. Researchers should also plan for illness and absence when working with patients and not rely on sole individuals. Professor Ziebland takes a reflective approach to PPI and considers it to be a continual learning process. She suggests that researchers who are new to PPI may find it helpful to visit the Healthtalkonline PPI module in which patients talk about being involved in research. A module describing researchers' experiences of PPI will follow in 2015.

Professor Ziebland believes that patient and public involvement enhances public knowledge of research and makes people more favourably disposed towards it and to incorporating findings into their lives. More widely, it contributes to public understanding of science and enhances people's ability to interpret headlines about research findings.

> "It's important to communicate to patients that they are there because we recognise that they can do something which we can't do. If you're involving them in the right way, you ought to be surprised by the things they can contribute."

Healthtalkonline
http://www.healthtalkonline.org

Carers of people with dementia module
http://www.healthtalkonline.org/peoples-experiences/nerves-brain/carers-people-dementia/topics

Patient and Public Involvement experiences module
http://healthtalkonline.org/peoples-experiences/medical-research (available from July 2014)

Further information: Patient and public involvement in research

INVOLVE describes ‘patient and public involvement’ as an active partnership between patients, members of the public and researchers in the research process. This can include, for example, involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

INVOLVE’s definition of the term ‘patients and public’ includes: 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 and research. (INVOLVE, 2012)

For a more detailed explanation of involvement, how it links to and differs from engagement and participation in research see http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2

NIHR organisations providing useful resources, advice and support on patient and public involvement in research include:

NIHR Research Design Service (RDS) http://www.ccf.nihr.ac.uk/Pages/RDSMap.aspx provides advice and support to researchers developing research proposals for submission to the NIHR and other national, peer-reviewed funding competitions for health and social care research. This includes resources, advice and support on patient and public involvement in the development of proposals.

INVOLVE http://www.invo.org.uk provides advice and a range of resources on patient and public involvement in research.

These include:

- a directory of research networks and organisations supporting involvement invoDIRECT.
- resources which include briefing notes for researchers on what is public involvement and how to involve people in research; an involvement cost calculator to help with budgeting; searchable databases including an evidence library and other resources.
- a website http://www.peopleinresearch.org provides information for patients and the public about current opportunities for getting involved in research. Researchers and funders can use People in Research to advertise and invite patients and the public to get involved in their research.

The **James Lind Alliance** (JLA) http://www.jla.nihr.ac.uk has a guidebook with step-by-step guidance on involving patients and clinicians in the identification and prioritisation of search topics and questions.

INVOLVE

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development.

If you would like to know more about what we do, please contact us:

INVOLVE
Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD

Web: **www.involve.nihr.ac.uk**
Email: **admin@invo.org.uk**
Telephone: 023 8065 1088
Twitter: @NIHRINVOLVE

If you need a copy of this publication in another format please contact us at INVOLVE.

Email: **admin@invo.org.uk**
Telephone: **023 8065 1088**

This publication is available to download from:

www.involve.nihr.ac.uk