

INVOLVE



*National Institute for
Health Research*

Taking stock

INVOLVE Coordinating Centre
March 2015

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INVOLVE (formerly Consumers in NHS Research) was established by the Department of Health in 1996 to ensure that public involvement in research and development improves the way that research is prioritised, commissioned, undertaken and disseminated.

In 2015 there is a clear commitment to public involvement in research across the National Institute for Health Research (NIHR) with an increasing acceptance of the value, importance and need for public involvement in research. There is a growing expectation from research funders and commissioners that public involvement is an integral part of the research that they fund. Since 2011, researchers have been required to outline their plans and budget for public involvement in their research and all parts of the NIHR are required to have strategies for their public involvement.

Whilst the involvement of the public is not yet universally accepted and there are constantly new challenges to address, the extent of public involvement and the influence of the public on research have grown considerably in the last 20 years. INVOLVE and the Coordinating

Centre have played a central role throughout in influencing the reach and involvement of the public in research.

This report outlines some of our recent activities and achievements in supporting and promoting public involvement, working in partnership with our NIHR colleagues and the public.

Sarah Buckland

Director INVOLVE Coordinating Centre

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What we have achieved

This report provides a broad overview and snapshot of some of our recent work (2013-2015) and our 'reach' in 2015. We reflect on who we are working with and influencing.

Resources and activities:

We develop all of our resources in collaboration with researchers and members of the public.

We continue to **build** on our resources and our core publication on how to involve members of the public in research 'Briefing notes for researchers' (2012).

Recent activities include:

- leading on the development of the [Benefits Advice Service](#) for involvement, in partnership with NHS England, the Health Research Authority (HRA), Social Care Institute for Excellence (SCIE) and Involving People Wales (February 2015) – a free, confidential service, run by Bedford Citizens Advice Bureau, offering personal advice and support on how payment of fees and expenses for public involvement might affect people in receipt of state benefits
- publishing guidance and examples for researchers on using [social media for public involvement in research](#) (November 2014)
- running a series of [joint webinars](#) with the NIHR School for Social Care Research (2014) on:
 - an overview of public involvement in adult social care research
 - research with black and minority ethnic people using social care services
 - end of life care research methods and public involvement in end of life care research
 - user controlled research

- publishing guidance for researchers on [budgeting for public involvement](#) supported by an online calculator – a joint project with the NIHR Clinical Research Network: Mental Health (2013).

We **support and influence** policy and practice on public involvement in research.

Recent activities include:

- working with the NIHR public involvement leads within the funding programmes (e.g. NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) and Central Commissioning Facility (CCF)) to revise the questions on public involvement in the Standard Application Form (2015)
- developing and consulting on a [draft framework for values, principles and standards for public involvement in research](#) which went out for public consultation (November 2014)
- publishing a joint INVOLVE and Health Research Authority (HRA) report on [public involvement in research applications to the National Research Ethics Service](#) (November 2014)
- membership of the National Institute for Health Research (NIHR) wide group discussing, Adding Value to NIHR-funded research, (2014)
- leading on the work to introduce a good quality plain English summary as a requirement of funding across the NIHR (2013- 2014).

We bring people **together** by organising events and meetings to share perspectives and experiences:

- over 530 people attended our 9th conference **INVOLVE 2014** (November 2014)
- public involvement leads across the NIHR met to discuss public involvement in research (2014)
- INVOLVE advisory group members have regular meetings (ongoing)

We **raise awareness** of public involvement in research.

Recent activities include:

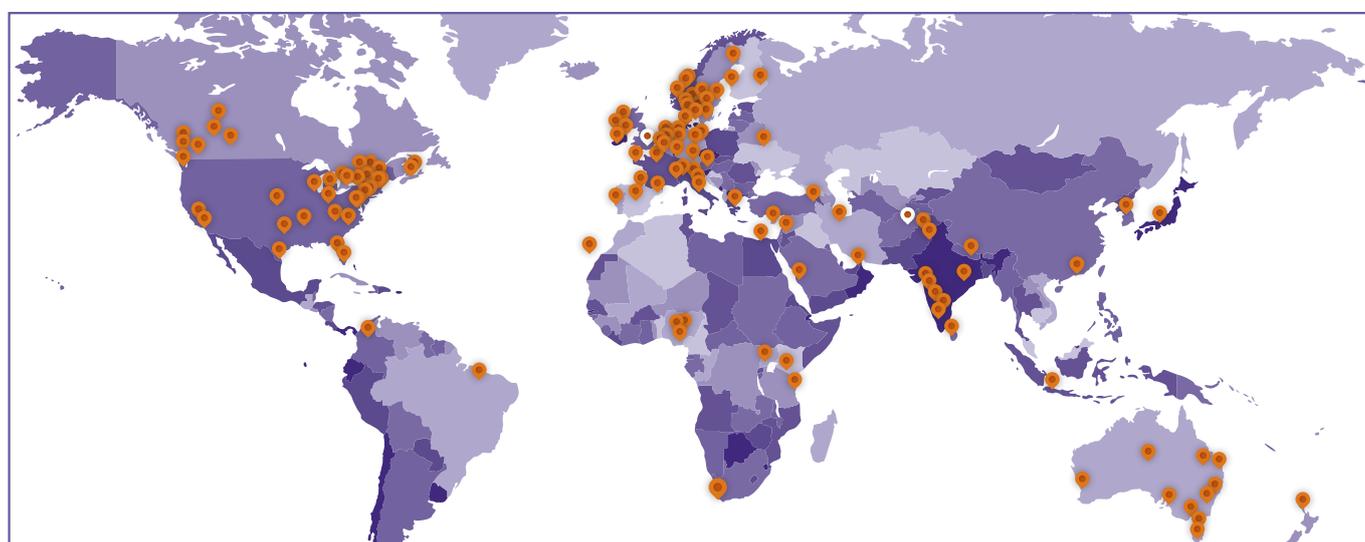
- developing ‘**This is my story**’ an animation of a young man’s journey to becoming involved in research (January 2015)
- developing **invoDIRECT** – an online directory of networks, groups and organisations that support active public involvement in NHS, public health and social care research (2013)
- redeveloping **People in Research** – a website for advertising opportunities for public involvement in research (2014)
- publishing our **INVOLVE quarterly newsletter** and sending regular email alerts (see diagram 1 for distribution)

We **build** knowledge and understanding of public involvement by:

- maintaining the **Evidence library** – a database of references and abstracts of research with over 280 entries (ongoing)
- publishing **Bibliography 5** – a summary of references on public involvement in NHS, public health and social care research (2014)
- publishing a series of examples of public involvement in research:
 - **NIHR Senior Investigators** – leaders for public involvement in research (2014)
 - **Exploring the impact of public involvement on the quality of research** (2013)
 - **Exploring public involvement in research funding applications** (2013)
- holding an **invoNET** round table discussion on ‘Taking stock of the evidence base for the impact of public involvement in research’ (March 2014)

invoDirect has 107 listed organisations

Diagram 1 Where our newsletter travels



Our reach

April 2014 – March 2015

Visitors to the website



Over 1.2 million

Twitter



Tweets **3,600**
Followers **2,630**

Mailing list



email alerts and newsletters go to **4,900** people

International



225 subscribers from **46** countries

INVOLVE
2014-2015

People accessing our Briefing notes



54,600

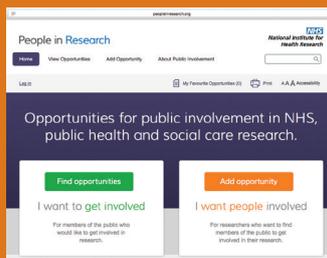
Conference



530 delegates

92 presentations
85 posters
1,700 tweets

People in Research



83 new opportunities
8,300 visits

Evidence Library



33,600 visits

Our communication

We **reach out** to our audience in different ways:

Our **website** is the hub of our communication – over 1.2 million people visited it in the last year. All of our publications are free to download and we have a diverse selection of publications, resources and libraries of articles and references on public involvement in research.

**Over 900 organisations
link to our website**

Our **twitter feed** was started in 2012 and we have solidly built our presence to reach 2630 followers.

Our **mailing list** of nearly 5,000 people receive our online quarterly newsletter and regular email alerts of news on public involvement in research.

We **speak** at meetings and events such as:

- EUPATI (European Patients' Academy on Therapeutic Innovation) Conference Patient involvement in medical research and development (2014)

- Four Nations (Involving People) Conference, Cardiff (2014)
- Great Ormond Street Hospital and Biomedical Research Centre Guy's and St Thomas' event (2014)
- NIHR Trainees Coordinating Centre Conference (2014)
- NIHR School for Public Health scientific meeting (2014)
- UK Clinical Research Facility (CRF) Annual Conference (2014)

We **share** our publications and answer questions by having stands at conferences and events, such as:

- NIHR School for Social Care Research (SSCR) Conference (2015)
- NIHR themed call on multi-morbidities in older people (2015)
- Health Services Research Network (HSRN) Annual Conference (2014)
- Public involvement in research conference, Newcastle (2014)

We **answer** email and telephone enquiries that come into the Coordinating Centre, nearly 400 in 2014.

Who we work with

We work with others to produce, contribute to and share information. We value the relationships, shared learning and skills we develop.

We are committed to making our events and meetings accessible. We have ground rules and a clear payment and recognition policy.

NIHR-wide groups and meetings

We facilitate the following groups of public involvement leads to discuss public involvement in research, address common concerns, exchange ideas and share information:

- **Public Involvement Collaboration Group** – NIHR Research programmes (Central Commissioning Facility (CCF), Evaluation, Trials and Studies Coordinating Centre (NETSCC), Trainees Coordinating Centre (TCC)) and public involvement leads from other research commissioning and funding organisations such as the Medical Research Council and the Economic and Social Care Research Council.
 - **NIHR Collaborations for Leadership in Applied Health Research and Care** – public involvement leads from across the 13 regional organisations in England
 - **NIHR Research Design Services (RDS)** – public involvement leads from across the 10 regional centres in England (from February 2014 this group has been facilitated by the RDS)
 - **NIHR-wide public involvement, engagement and participation strategy forum** – this group considers NIHR-wide issues on public involvement in research. It is attended by members of the INVOLVE Coordinating Centre, INVOLVE public advisory group members and public involvement leads from across the NIHR.
- We **initiated and facilitated** two, time-limited, groups for partnership working across the NIHR:
- **Learning for involvement** – a NIHR-wide group of public involvement leads established to explore approaches to support learning and development for public involvement in research across the NIHR. We are currently finalising a report and recommendations to present to the Department of Health (2013-2015)
 - **Implementation Group for plain English summaries in NIHR funded research** – a NIHR-wide group to implement a good quality plain English summary as a requirement of funding for NIHR research. (2013-)

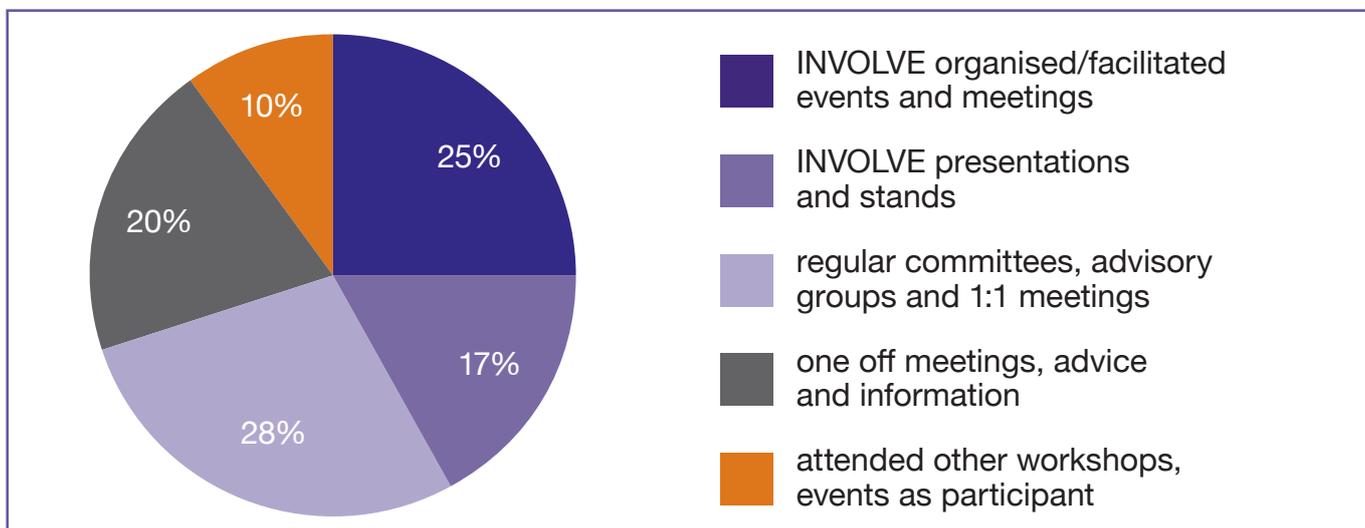
Examples of organisations we have worked with in the last year include:

- INVOLVE advisory group
- NIHR partners and infrastructure
- Academic Health Science Networks (AHSNs)
- Athena Institute, VU University of Amsterdam
- Bedford Citizens Advice Bureau (CAB)
- Consumer and Community Participation Programme – the University of Western Australia
- Health Research Authority (HRA)
- Involving People Wales
- James Lind Alliance (JLA)
- NHS England
- The Patient-Centered Outcomes Research Institute (PCORI) USA
- Social Care Institute for Excellence (SCIE)
- University of Southern Denmark
- Voluntary sector shared learning group
- ZonMw The Netherlands

We sit on a number of NIHR boards and committees such as the NIHR Strategy Board, Design Authority Data Standards Board, Adding Value group and Programme Managers group. In the last year we have also been members of other groups and committees such as the:

- Health Research Authority (HRA) Patient and Public Involvement Steering Committee
- UK Clinical Research Collaboration Research and Governance Forum
- NETSCC Patient and Public Involvement Reference group
- Research Excellence Framework sub group panel
- Theatre of Debate project group – patient and public involvement in research
- UK Clinical Research Facility Patient and Public involvement workstream
- Children’s Policy Research Unit Advisory Board, University College London
- Centre for Public Engagement Advisory Committee, Kingston University and St George’s University of London

Diagram 2 illustrates the range of events and meetings we attended during 2013 and 2014



Looking to the future

During the next year and beyond we will:

- embrace and welcome working on public engagement in research
- reflect on how best to continue to develop an evidence base
- forge new alliances and collaborations
- work with others on involving children and young people in research
- raise awareness of public involvement and engagement in research
- consider issues around diversity and inclusion in public involvement in research
- explore how best to work with and support regional networks
- develop our database of examples of public involvement in research.

The team:

These results could not have happened without the hard work and collaboration of the whole team:

Sarah Buckland (Director)

Sarah Bayliss

Sarah Bite

Paula Davis

Erica Ferry

Helen Hayes

Martin Lodemore

Marisha Palm

Maryrose Tarpey

Gill Wren

INVOLVE

INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

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

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