Strategies for engaging patients with participation in research

EULAR Registers And Observational Drug Studies, Prague, November 2013

Simon Denegri, Chair, INVOLVE; NIHR National Director for Public Participation and Engagement in Research (UK)
Public involvement in UK health research

• Core principle of National Institute for Health Research (NIHR) from day one
• NIHR leadership based on belief that public involvement helps drive research quality
• NIHR funding for national advisory group has ensured a sustainable movement
• Success built on ‘partnership’ working
• Clear expectation set with research community
• A ‘marriage maker’ or a ‘deal-breaker’
What we aspire to:
A dynamic partnership between the public, researchers and others, to advance NHS, public health and social care research and improve the health and well being of the population.

Established in 1996 INVOLVE is a national advisory group funded by, and part of, the National Institute for Health Research. [http://www.invo.org.uk/](http://www.invo.org.uk/)

How we do it?
- Leadership across NIHR
- Build and share the evidence base
- Develop capacity and capability
- Influence policy and practice
Setting research priorities

WHAT QUESTIONS SHOULD PARKINSON'S RESEARCH ANSWER?

We're asking people affected by Parkinson's and health and social care professionals to help us identify the top 10 unanswered questions they want Parkinson's research to address.

We need the input of people who have direct and personal experience of Parkinson's to make sure we are addressing the most urgent needs.

Complete the survey now

Your survey responses will help to guide Parkinson's research.

And we'll use the responses to make sure researchers address the things that make a real difference to people living with Parkinson's.

Tell us the questions you'd like to see answered by Parkinson's research - we need your input now!

http://www.netscc.ac.uk/news/item/08042013.asp
Ensuring value and efficiency

‘The aim of patient and public involvement is to improve the quality, feasibility and translational value of research...[This] is the first time we can see that patient involvement is linked to higher likelihood of reaching recruitment target – and as a result, study success.’

Professor Til Wykes, Director, MHRN

‘Patient involvement in research boosts success,’ The Guardian, 16/09/13

**Paper reference:** Ennis, L. et al. ‘Impact of patient involvement in mental health research: longitudinal study’ *British Journal of Psychiatry* (Sept 2013) doi: [10.1192/bjp.bp.112.119818](https://dx.doi.org/10.1192/bjp.bp.112.119818)
Work with Industry

Young people help researchers to "get real"

Clinical research is evolving. Increasingly, there is pressure on the research community to ensure that treatments are relevant and effective in daily life. This is driving more researchers to seek the input of service users in the development of their work, which is leading to a transformation of the cultural and regulatory environment for children's research.

The NHR Medicine for Children Research Network (MCRN) has been at the forefront of patient and public involvement in research and has long been involved with its first Young Persons’ Advisory Group in Liverpool since 2005. Many more have been established in London, Nottingham, Birmingham and Bristol. The initial remit of these groups was straightforward: to engage young people with research and to work in partnership with them, and offer support to researchers. Jenny Newman, MIB Medicines for Children Research Network Consumer Liaison Manager, explains how the work has evolved.

"We set up the group to provide a forum for young people to learn about, and comment on, various aspects of research and the identification of research questions to the dissemination of research findings. We are now working with national governing bodies and helping to remove the guidance that they provide to researchers to help them design and deliver ..." and influence.

Young people want to know what the study will mean to them.

Young people... want to know what the study will mean to them.

Group members felt that MREC guidance was producing study materials that failed to meet their needs. The first Young Persons’ Advisory Group in Liverpool was set up in 2005, and a member of the Liverpool Young Persons’ Advisory Group...

Young people help researchers to "get real"

Closing the gap between patients and the life-sciences industry

Delivering research on time and on target is essential to make sure that important research questions get answered in a cost-effective way and the findings can be used to improve healthcare. PCRN recently sought to find out how a patient’s perspective could help improve delivery of commercial research studies and avoid potential problems.

Young people help researchers to "get real"
Widening access to research
From willing to active research citizens

Public appetite

• 82 per cent of people believe it is important for the NHS to offer opportunities to take part in healthcare research.
• Less than 7% said they would never take part in a clinical research study.
  
  *NIHR Clinical Research Networks Survey May 2012*
• Over 70% of patients look for information about clinical trials
  
  *ecancer 5 235 2011 ‘Information needs of cancer patients’*

Patient experience

• National Cancer Patient Experience Survey 2012
  — 1 in 3 patients had a discussion about research with a health professional
  — > 53% who were not asked, would like to have been
• Discussion much less likely if happening at all for patients with other conditions (i.e. 1 in 5 for type 1 diabetes)
• 91% of Trusts do not provide information to support patient choice in research: NIHR CRN CC Mystery Shopper 2013
### Q4.
There are opportunities for NHS patients to get involved in research. Please imagine that you have a health condition such as heart disease or cancer, which affects your day-to-day life.

For each of the types of research I’m about to read out, taking the answers from this card, would you like your doctor to tell you about research that you would be able to take part in?

<table>
<thead>
<tr>
<th>If the research would involve...</th>
<th>Yes, definitely %</th>
<th>Yes, probably %</th>
<th>No, probably not %</th>
<th>No, definitely not %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trialing a new medicine or treatment</td>
<td>35</td>
<td>37</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Taking a sample of your blood and testing it in a laboratory</td>
<td>60</td>
<td>28</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Talking to researchers about your family history to help them understand if there are any factors that may be passed down in your family</td>
<td>60</td>
<td>28</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Allowing a researcher confidential access to your medical records but no other involvement</td>
<td>46</td>
<td>34</td>
<td>11</td>
<td>6</td>
</tr>
</tbody>
</table>

IPSOS MORI Poll for Association of Medical Research Charities, 2011
Making research accessible

‘OK to Ask’ campaign: International Clinical Trials Day 2013

- Clear, simple message
- Patient-facing
- Easy to deliver
- NHS Trust focus

- Encouraging patients and carers to ask their clinician about clinical research (and log response/suggestions)
- Encouraging clinicians to consider their response if a patient does ask: how to channel interest
Feedback

WWW.SURVEYMONKEY.COM/S/NIHROKTOASK

WE ASKED CLINICAL RESEARCH NETWORK STAFF, TRUST AMBASSADORS AND PATIENTS WHAT THEY THOUGHT ABOUT THE CAMPAIGN

77% RATED THE OVERALL CAMPAIGN AS GOOD OR EXCELLENT

80% SAID THE CAMPAIGN HELPED TO DEVELOP SOME MOMENTUM FOR RESEARCH AWARENESS IN THEIR TRUST

71% RATED HOW WELL THE CAMPAIGN WAS RECEIVED BY PATIENTS AS GOOD OR EXCELLENT

98% SAID THEY WOULD CONTINUE TO PROMOTE THE OK TO ASK MESSAGE
Patient ambassadors in research

Involvement4Access
Partnering with patients to improve research engagement in the NHS

We want to embed a patient-centred research culture in the NHS. To do this, we need to engage with patients with research more effectively.

Many patients and carers are already Patient Research Ambassadors. They feel passionate about research and are prepared to talk about it, both with each other, and NHS care professionals and managers.

Involvement4Access is a resource for the research community, which contains guidance and examples of best practice on how to engage and empower Patient Research Ambassadors.

By "research community" we mean everyone involved with research: from nurses to patients, from carers to trial coordinators and from family members to Trust Boards. You’ll find guidance below for key groups within this community. You’ll also find top-tips, useful links and examples of best practice which will increase as the project develops.

We all have a role to play in ensuring patients are aware of, and engaged with research. Please start the I4A conversation by telling us your plans/initiatives and help others benefit from your good practice.

I4A activity map
Take a look at the patient-partnership work taking place in England. Let us know what you’re up to, and get your activities on the map!
Citizen driven health and wealth

“In the future the public will be more technically sophisticated, inquisitive and informed than ever before.”

Professor Samuel Thier, Harvard University
Speaking at the launch of the UK eHealth Informatics Research Centres and Network, May 2013
Digital platforms: UK Clinical Trials Gateway

The UK Clinical Trials Gateway provides easy-to-understand information about clinical research trials running in the UK, and gives you and others access to a large range of information about those trials. It is designed to help you understand clinical trials and potentially find a trial that is of interest to you or your clinician that is taking place in the United Kingdom.
UKCTG Public and Patient Feedback

- Only 28% had taken part in a clinical trial
- 38% knew little or nothing about clinical trials and would like a clear and reliable source of information to learn more;
- **64% would like to find out about trials recruiting in their local area**
- 66% found UKCTG ‘easy’ or ‘very easy’ to find their way around
- 67% found the information provided on the site ‘very clear’ or ‘fairly clear’
- 72% said that UKCTG should help them make direct contact with a clinical trial without going through their doctor
- 88% said the site should provide relevant links to patient groups, medical researchers and funders
- 88% would recommend the site to others.
Thank you

Simon.Denegri@nihr.ac.uk
www.invo.org.uk
Twitter: @SDenegri
Blog: http://simondenegri.com/