

Patient and Public Involvement Newsletter

Edition one — SUMMER 2015

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CHAIN PPI Resources

The Contact, Help, Advice and Information Network (CHAIN) is another Network that members might be interested in joining.



CHAIN is an NHS online mutual support network for people working in health and social care.

You can join its special interest group on Patient and Public Involvement / Improving Patients Experience at:

<http://chain.ulcc.ac.uk/chain/index.html>



Going the Extra Mile is a strategic review of public involvement in the National Institute for Health Research (NIHR).

The review of public involvement in the NIHR, commissioned by the Director General Research and Development/Chief Medical Officer in March 2014, provided an opportunity for an independent review panel to assess how far the NIHR has been successful in achieving public involvement across its activities to date and to recommend a direction for the NIHR for the future that builds on these achievements.

You can find the Extra Mile report here: bit.ly/invoxtramile

**Professor
Dame Sally
Davies, Chief
Medical
Officer**



“ No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective. ”

Opportunities to get more involved

The *PATIENTS ACTIVE IN RESEARCH* site promotes partnerships between patients, carers, other members of the public, and medical researchers.

It was developed with patients, and aims to ensure that medical research focuses on what really matters to those affected by ill health and is carried out in ways that encourage them to take part.

Opportunities to take part in medical research studies can also be found at:

<http://patientsactiveinresearch.org.uk/opportunities/>

Opportunities for Patient & Public Involvement at the Nuffield Department of Primary Care Health Sciences: bit.ly/OXPPI

Opportunities for Patient & Public Involvement at the National Institute for Health Research NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford: bit.ly/CLAHRCPPPI

Funding for Research

“The University of Oxford has secured over £139m in research funding from the Higher Education Funding Council for England (HEFCE) for the academic year 2015-2016 - more than any other institution.

This represents an increase of 1.7 per cent on the current year and follows Oxford's success in the 2014 Research Excellence Framework (REF), the official UK-wide assessment of the quality and impact of all university research, which found that Oxford has the largest volume of world-leading research in the country.”

Patient Research Ambassadors



• Patients, carers and interested members of the public who have experienced research can often be the best 'Research Ambassadors' in their local NHS care organisation.

• They can help ensure that people using local NHS care have the best opportunities and choices about taking part in research studies.

• The **Patient Research Ambassador Initiative** aims to promote the role of Patient Research Ambassadors (PRAs) in local NHS services. It provides a resource for the research community to take action.

• Visit bit.ly/PRAmbInI for more details.

NHS England Patient Involvement Newsletter

• NHS England has a new monthly Patient and Public Newsletter.

• It's a really useful digest of national patient and public voice news together with opportunities for people to get involved. It is available online anytime at:

• bit.ly/NHSIntouch

Roll up to support the OK to ask campaign

This years 'OK to ask' campaign has officially launched, with the aim of encouraging more patients or carers to ask about research opportunities that could be available to them or their loved ones.

Clinical research is thriving in the NHS with

more than 600,000 patients taking part in clinical research studies in 2013/14. We also know that it's mostly through a clinician-led approach that patients are recruited into studies and that research overall has a low visibility in the NHS. Research organisations would like this to change and to ensure that patients are more aware that research takes place in all settings of the NHS.

A recent survey conducted by the NIHR Clinical Research Network (CRN) showed that 95 per cent of people surveyed said it was important to them that the NHS carries out clinical research, but less than 21 per cent said they would feel very confident about asking their doctor about research opportunities.

While the campaign is primarily aimed at encouraging more patients to ask about research opportunities, it's also about reminding all healthcare professionals, from consultants and GPs to nurses and midwives, whether research-active or not, to be research-aware.



Want to be involved in developing PPI training for researchers and members of the public?

We are setting up a group to develop something for the Thames Valley and would love to hear from you if you are interested.

Contact Lynne Maddocks on:

Tel: 01865 617198

Email: lynne.maddocks@phc.ox.ac.uk

Support the campaign on social media

Join us in raising awareness of the campaign.

You can find us on Twitter ([#nihroktoask](https://twitter.com/nihroktoask)) and you'll find us on Facebook (www.facebook.com/NIHROKtoAsk), where you can get regular updates on what's happening.

Become a James Lind Alliance Affiliate



The James Lind Alliance (JLA), a non-profit making initiative established in 2004, brings patients, carers and clinicians together to identify and prioritise the top 10 uncertainties, or 'unanswered questions', about the effects of treatments that they agree are most important.

This information will help ensure that those who fund health research are aware of what matters to both patients and clinicians.

The James Lind Alliance Affiliates programme is for organisations and individuals who want to express support for, be involved in or simply be kept informed of the JLA's activities.

It's quick, easy and free to become a JLA Affiliate. You'll receive a bi-monthly newsletter and will become part of an ever-expanding network of decision-makers, influencers and pioneers committed to involving patients and clinicians in research priority setting.

Find out more at bitly.com/JamesLAA

The first prize for the 'Research Engagement Award' was presented to Holycroft Surgery's Patient Council at a recent event held by the award sponsors, the NIHR CRN in partnership with the National Association for Patient Participation (N.A.P.P.).

The award, launched last year to recognise the efforts of patient participation groups in primary care settings, aims to raise awareness of research with patients and the wider public, as well as promoting local opportunities for research studies.




Holycroft's Patient Council received first prize of £400 for their interest and involvement in clinical research which has helped to change the culture of the surgery to one where research is part of everyday clinical practice.

Dr Patricia Wilkie, Chair of NAPP said that the award was really important and commended Holycroft's Patient Council: "It was an extremely innovative grass roots approach with the PPG encouraging the practice rather than the other way around. It's

interesting how the project developed to include other practices, local communities and charities. A great example of how PPGs can raise awareness of research."

Research Engagement Award



Please contact us
if you could help
promote our research
with this postcard

For example, by leaving some in
your doctors surgery waiting room,
community hall/notice board, or even
in the pub!

Naming Competition

Get involved - make a difference

Like the writing through a stick of rock,
we place public involvement at the centre of our research.

We need your help to name this Newsletter!

A small prize will be available to one person who chooses the most popular title for the next edition, or comes up with the best new idea (editor's decision!)

Here are some of our ideas to get you started:

- **PPI Pulse**
- **Involvement Matters**
- **Involvement Illuminated**
- **Incredible Involvement**

You can vote for these, or come up with your own, by emailing lynne.maddocks@phc.ox.ac.uk.

We would also welcome **any feedback** on this newsletter, whether on this edition or thoughts for ideas to include in future editions. Thank you.

Please email lynne.maddocks@phc.ox.ac.uk with your thoughts.

Contact Us

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