

## Patient and Public Involvement Newsletter

Edition 2 — Autumn 2015

### Thames Valley takes two places in Health Services Journal top 50 Patient Leaders List



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### Podcast: What on earth is the point of doing research if it doesn't make the patient's life better?

In this podcast from *BioMed Central* you can hear from the authors, patients and carers involved in research, as well as journal editors, on involving patients and the wider public in research and how this can impact the clinical relevance of research.

[bit.ly/1NMebSy](http://bit.ly/1NMebSy)

### Carol Munt and Mark Stone from the Thames Valley named in HSJ top 50 Patient Leaders list

The *Health Service Journal (HSJ)* – a weekly news title about the NHS, healthcare management and health policy aimed at healthcare leaders – announced its first ever Patient Leaders list.

The Patient Leaders list recognises and celebrates the full breadth of patients and citizens' role in healthcare – from shaping national policy and influencing the NHS nationally, to individuals making waves through being involved in their own care.

Fifty individuals from across the spectrum of healthcare made the list, including patient leaders Carol Munt (third from left) and Mark Stone (fourth from left) from our Thames Valley Patient Experience Strategy Group.

Carol explains: "I believe that the NHS is a valuable national asset and it must

stay close to its origins as a public service. Yet the service also needs to adapt as demands on it increase. The choices our health commissioners make are influenced by patients, and we need more people to come forward and get involved."

Neil Churchill, NHS England's Director for Improving Patient Experience,

"This is well-deserved recognition – their impact has been immeasurable. They push us to work differently, challenge the *status quo* and ensure that new work includes patients from the beginning."

– DR SIAN REES, DIRECTOR PATIENT AND PUBLIC INVOLVEMENT, ENGAGEMENT AND EXPERIENCE OXFORD AHSN AND NIHR CLAHRC OXFORD

salutes the new awards recognising patient leaders.

"Patient leaders use their own personal experiences to campaign for better services for others; they provide a powerful voice from patient and carer groups and charities that agitate and inform; and they do all these things largely as volunteers, for no other reason than they want to make a difference and bring about change."

# healthtalk.org

## healthtalk.org provides free, reliable information about health issues, by sharing people's real-life experiences.

healthtalk.org was created in 2001 by Oxford GP Dr Ann McPherson CBE and Dr Andrew Herxheimer after their own experiences of illness.

Ann had been diagnosed with breast cancer and although she knew about the medical side, couldn't find anyone to talk to about what it was really like to have the disease.

This, and Andrew's experience of knee replacement surgery, prompted them to come up with the innovative idea of a patient experience website.

A small group of people from various backgrounds formed a steering group and, after many meetings around Ann's kitchen table, the idea developed into the website that later became healthtalk.org (formerly Healthtalkonline and Youthhealthtalk).

healthtalk.org provides free, reliable information about health issues, by sharing people's real-life experiences.

You can watch people sharing their stories about cancer, autism, motor-neurone disease, pregnancy, drugs,

depression, and much more.

If you, or someone you care about, is affected by any of the 85 health issues covered, you can find out what happened to around 40 other people in the same situation. You will find good advice and reassurance on topics such as:

- making decisions about health and treatment,
- talking to friends and family,
- practical issues like money and travel,
- emotional well-being,
- impact on work or education,

### Patient and public involvement in research on healthtalk.org

Find out about the experience of taking part in research as a patient or member of the public, by seeing and hearing people share their personal stories on

film.

healthtalk.org's researchers travelled all around the UK to talk to people in their own homes. Find out what people said about their reasons for getting involved, what activities and tasks are required, and the value of patient and public involvement in research.

- The PPI section of Healthtalk.org covers the following topics;
- what is involvement?
- deciding whether to get involved,
- being involved,
- debates surrounding involvement,
- the future.

• Later this year they will add PPI reflections from researchers.

• We believe this is a truly great resource, and hope you check it out.

• [www.healthtalk.org](http://www.healthtalk.org)

### Register to become a patient reviewer for the *British Medical Journal*.

• If you're a patient living with disease, a carer of

• a patient, a patient advocate acting on behalf of a patient group, or you play a leading part in advocating for patient participation and partnership in healthcare the we would like to invite you to take part in a unique initiative.

• The BMJ has committed to improving the relevance and patient centredness of its research, education, analysis, and editorial articles by asking patients to comment on them. Patient review is a new initiative for the *BMJ*. They are taking the lead and hope other publishers will follow.

• [Click here \(bit.ly/1i5DDEc \)](http://bit.ly/1i5DDEc) to register.

### Research results

• Oxford makes a difference!

• Development of New Models for Collection and Use of Patient Experience Information in the NHS by the Picker Institute.

• Visit [bit.ly/1FSxwQJ](http://bit.ly/1FSxwQJ) to read more



# Beating dementia through research



**If it is true that today's research is tomorrow's treatment, then it is also true that tomorrow's treatments rely upon people volunteering to take part in research.**

It is hugely encouraging that figures by the National Institute for Health Research show a 60% jump in people signing up (for research) in the past year.

Finding out about research opportunities has become a lot easier, thanks to Join Dementia Research (JDR). Join Dementia Research is a service that allows people - both with and without dementia - to register their interest in participating in research and is being used within the Thames Valley ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)).

Dr Rohan Vanderputt, consultant psychiatrist and speciality dementia lead for the Thames Valley says: "We are lucky in Oxford and Buckinghamshire to have access to a lot of high quality research. There are studies for different types and severity of dementia, with options that can be done at home or in the clinic. JDR will allow people to learn about what is available locally, to register their interest in research and to help to develop better treatments for themselves and future generations."

Alison Nicolson, whose husband Norman has dementia, says: "Supporting my husband to take part in dementia research has helped both of us to feel that something good can come out of what is happening... I want to encourage others to help so that we can beat this disease."

If you would like to find out more about dementia research please email [dementia.research@oxfordhealth.nhs.uk](mailto:dementia.research@oxfordhealth.nhs.uk) or call 01865 231556

**What sort of research could I be volunteering for?**

'Join dementia research' is designed to match people to appropriate research studies using their personal information and interests.

Current research ranges from clinical studies of new treatments to surveys about what works in improving quality of life for people with dementia and their carers.

**Who can register with 'Join dementia research'?**

Anyone, with or without dementia, can register their interest as a volunteer. Volunteers must be over 18 years old and people from all ethnic backgrounds and cultures are welcome. You can also register someone else, providing you have their consent.

**How will registering benefit me?**

- 'Join dementia research' will reduce the time it takes to find research studies that interest you.
- It will help you learn more about research in your local area or in other parts of the country.
- If you do take part in a study, you will have the satisfaction of knowing you could contribute to future insights into dementia and its causes as well as early diagnosis, better treatment, and quality of care.



We are always looking for new opportunities to publicise the research going on in Oxford with the hope of encouraging more patients and members of the public to either participate or get involved.

Our PPI Coordinator, Lynne Maddocks,

joined with other agencies on National Clinical Trials Day this year at Temple Cowley shopping centre to help promote the OK to Ask campaign.

If you are involved with events or activities which could be a publicity opportunity, then please let us know.

## Meet a researcher: Dr Helen Atherton

### Tell us about the research you are currently working on?

My research interests are in the use of the internet and communications technologies in healthcare settings.

I am currently conducting research that is exploring the experiences of general practices in offering different types of consultation to patients; telephone, email and even Skype.

### What was your childhood ambition?

To be an actress performing on stage – I envisaged a more mainstream audience than you will find at most academic conferences....

### What do you like most about working at Oxford University?

Being part of a large and lively department in a beautiful city. I don't live in Oxford, so every day when I arrive at the train station and cycle

to the office I feel lucky to be in such amazing surroundings.

### Tell us about when you most successfully worked in partnership with patients or public representatives on your research. Why did it work so well?

Some of the best involvement has happened when we have been developing applications for research funding. In devising the research questions we want to answer, public involvement has been vital.

We were recently funded to conduct a programme of research on improving NHS quality using internet ratings and experiences.

In developing our research questions we engaged two patient representatives who co-ordinated our public events and helped us to obtain valuable perspectives from the public



on what was important to research e.g. how the public use the internet to decide on where to access healthcare.

Our representatives will now work with us on the entire project, being fully invested in the work we are doing.

### What would be your dream holiday, and who would you go with?

At the moment, with a 17 month old son, my dream holiday would involve sleeping for a fortnight.

Failing that I would love the opportunity to take my family to visit friends who live in Malaysia and Brunei and at the same time visit the rainforest in Borneo.

### You can read more about Dr Atherton's research at:

[www.phc.ox.ac.uk/team/helen-atherton](http://www.phc.ox.ac.uk/team/helen-atherton)

### Recent health research publications from at Oxford University

- Using the nose to inflate a nasal balloon helps heal glue ear in children, researchers have said in the *Canadian Medical Association Journal*. ([bit.ly/1GskPHI](http://bit.ly/1GskPHI))

- More can be done to improve the way GP practices deal with patients suffering stroke symptoms, research has shown. *Research published in the British Journal of General Practice* highlights the important role of GP receptionists in directing stroke symptoms. ([bit.ly/1VBhXPk](http://bit.ly/1VBhXPk))

- Extracts from the Mexican poppy found in Mali have been found to treat malaria ([bit.ly/1VBhXPk](http://bit.ly/1VBhXPk)) as reported on BBC Radio 4's Health Check ([bbc.in/1J5N308](http://bbc.in/1J5N308)).

- Find out more about the work that is going on in the NIHR CLAHRC Oxford with their *Bites* ([bitesized information](http://bitesizedinformation.com)). Current topics are Early Intervention in Psychosis and Back Skills training. ([bit.ly/1MUk4vx](http://bit.ly/1MUk4vx))



## Meet a PPI rep: Derek Jerome

### Tell us about the projects you are currently involved with?

StemBANCC's (Oxford Centre for Diabetes, Endocrinology and Metabolism, Radcliffe Department of Medicine, one of the NIHR CLAHRC Oxford's partners) goal is to generate 1,500 iPS cell lines from 500 people, characterise them in terms of their genetic, protein, and metabolic profiles, and make them available to researchers.

iPS (induced pluripotent stem) cells, like embryonic stem cells, are able to generate any kind of cell in the body; as such, they offer researchers a potentially limitless supply of different kinds of human cell that can be used in research and drug development.

PiNS (Nuffield Department of Clinical Neurosciences) is examining a cohort of patients with both painful and painless neuropathy to investigate the relationship between sensory symptoms, altered sensory processing, cutaneous denervation and ultimately genotype.

In a sub-set of patients, functional MRI will be performed to investigate pain in the brain.

### Why did you first get involved in medical research?

Both my parents have/had type 2 diabetes and it was found early on that I had diabetic-related tendencies. As an engineer, I also worked for a number of medical companies and have gradually moved from the design and development of medical devices to now mostly working clinically in a training role.

### What do you like most about being involved in medical research?

The chance to interact and learn. I believe that everyone involved in medical research of course hopes to help with some ground breaking research, but also recognise that it is through slow and steady process that most things are overcome.

There is something very rewarding about supporting people who are dedicating their lives to medical



research; most of the doctors, researchers and nurses involved are sacrificing time and the potential to earn more by working in research. The little I can offer to assist them is something that I would encourage more people to do.

### Tell us about when you have felt most that your contribution to a medical research project was valuable and why you felt that was?

I was a participant in a clinical trial some time ago that had 3 arms; a drug, a placebo and diet and exercise; I had the latter. I think my arm of the trial helped increase the body of evidence that strengthened the push to get people to have more healthy and active lives.

### What would be your dream holiday, and who would you go with?

Touring New Zealand with my wife. The chance to share this wonderful country for a few months with my wife would be fantastic and really two or even three months would still not do it justice!

## Influencing decision makers and commissioners - Free online course

Through this practical four-part course, funded by the Cabinet Office, you will learn how to influence decision makers and commissioners.

The National Council for Voluntary Organisations (NCVO) will support you in defining your approach, identifying your target audience and evaluating your progress.

### Learning outcomes - By the end of the course you will:

- feel confident about putting together a plan of action for influencing
- get more clarity on your target audience
- be able to tailor your message as appropriate and evaluate your progress.

### Course structure:

- What you want to influence and why?
- Who you want to influence?
- Connecting with decision makers and commissioners
- Communicating and tailoring your message

For more information and to see additional content, visit:

[bit.ly/1HILBNP](http://bit.ly/1HILBNP)

## How PPI is influencing our research

### Experiences of Patient and Public Involvement (PPI) in health and medical research

We aimed to explore the perspectives and experiences of patients and members of the public involved in health and/or medical research as advisors. We set up an advisory panel which comprised patients and members of the public, representatives of organisations that support or facilitate involvement, and academics.

The panel was responsible for providing advice on the types of people we should interview for the research, refining the semi-structured interview guide, discussing emergent themes arising from the data as analysis progressed and reviewing the reports written for [healthtalk.org](http://healthtalk.org). Some of the PPI advisors are currently involved in co-authoring academic publications based on the data.

Patient and public involvement had a significant effect on the research process. Here are some of the effects we noted as the research progressed:

- gave us permission to challenge the current involvement orthodoxy (beliefs and practices),
- provided ideas for recruitment,
- validated some of the views proposed by both the professionals and other lay members,
- questioned some of the proposed understandings of the data,
- allowed us to feel we could be flexible with the agenda for meetings,
- encouraged a great deal of enthusiasm and validated our initial data.

**Dr Anne-Marie Boylan, CLAHRC Research Fellow**

**Dr Caroline Jones, Senior Researcher**

### People's willingness to accept overdetected in cancer screening

PPI input was very important in our project on overdetected in cancer screening. Overdetected is detecting cancer that would not have otherwise caused any symptoms. This can lead to unnecessary treatment of patients, causing harm, but no benefits, since the patients is unaffected by detected cancer. It could also divert healthcare activity from patients who genuinely need it

We wanted to survey members of the public, to see how much overdetected they think is acceptable in cancer screening.

The research team designed a survey for members of the public, and we asked our PPI group to try out the survey and tell us how easy it was to understand and answer, and to suggest ways we could improve it.

We were then able to improve the survey, making sure that it was accessible to the public, and would produce valid results. This led to us publishing the results in the *British Medical Journal*.

## The Healthcare Quality Improvement Partnership



# HQIP

Healthcare Quality  
Improvement Partnership

### Do you have any examples of Patient and Public Involvement in quality improvement to showcase?

### Would you like to see your achievements highlighted in HQIP (Healthcare Quality Improvement Partnership) guidance on PPI?

HQIP is looking for new and innovative examples of patient and public involvement in quality improvement initiatives, from which to create case studies to use within forthcoming refreshed and renewed PPI guidance and online resources.

This especially includes best practice around Co-participation and Patient-led quality improvement projects.

If you would like to share your work and are interested in proposing a case study example, please email [kim.rezel@hqip.org.uk](mailto:kim.rezel@hqip.org.uk) with your contact details.

CRGs are responsible for providing NHS England with clinical advice regarding specialised services, and for the delivery of key 'products', such as service specifications and commissioning policies, which enable the NHS to commission services from specialist service providers through the contracting arrangements overseen by its area teams.

Above all, CRGs are driven by a commitment to ensure equity across specialised services. This means ensuring that patients who require treatment from any of the specialised services have equitable access to those services, regardless of where they live, and that each of the services is of the highest possible quality.

CRGs are also at the forefront of the drive to spearhead innovation, working with clinical leaders, patients and suppliers to identify and promote best practice; scanning the horizon for new treatment approaches; and taking action to improve patient experience and outcomes in the NHS.

### The following groups are still recruiting patients and members of the public:

**INTERNAL MEDICINE:** Morbid Obesity Surgery, Specialised Imaging, Cardiac Surgery, Heart & Lung, Transplantation

**CANCER AND BLOOD:** Specialised Cancer SCR, Haemophilia & other Bleeding Disorders, Infectious Diseases, Specialised Immunology, Upper GI Surgery, Sarcoma, Chemotherapy, Complex Head and Neck

**MENTAL HEALTH:** Specialised Services for Eating Disorders, Specialised Mental

## Apply to be a Patient or Carer member of a Clinical Reference Group (CRG)

Health Services for the Deaf, Tier 4 Child & Adolescent Mental Health Services, CAHMs Secure

**TRAUMA:** Cleft Lip & Palate, Specialised Orthopaedic Services, Hyperbaric Oxygen Therapy, Specialised Ophthalmology, Complex Spinal Surgery, Major Trauma

**WOMEN AND CHILDREN:** Medical Genetics, Paediatric Surgery, Metabolic Disorders, Paediatric Intensive Care, Complex Gynaecological Service, Specialised Maternity Services.

### If you'd like to apply, contact:

**0113 825 086 or**

[england.voice-crg@nhs.net](mailto:england.voice-crg@nhs.net)

## Bits and bobs

### Did you know that the Nuffield Department of Primary Care Health Sciences is part of the School for Primary Care Research?

Read more about the work of the School at: [bit.ly/1RqUbVI](http://bit.ly/1RqUbVI)

### Healthwatch Oxfordshire



Healthwatch Oxfordshire has a **Project Fund for Oxon voluntary and community organisations**

([bit.ly/1Mbaj9x](http://bit.ly/1Mbaj9x)) to do short-term projects to explore the health and social care needs of their clients or local community.

The maximum amount of funding awarded is £5,000.

The deadline for the first round of applications is October 16th 2015.

### Latest results of the GP Patient Survey

NHS England has published the latest results of the **GP Patient Survey**.

The survey seeks the views of over two and a half million people every year about their experience of GP services and NHS

dentistry. The survey produces a database that can be used to identify good practice and opportunities to improve patient experience across a range of local services.

The results for every individual GP practice in England can be found, with a new practice comparison tool, on the GP Patient Survey website ([bit.ly/1LtI7oU](http://bit.ly/1LtI7oU)).

### Get the McPin bulletin on involvement in psychiatric research



**These bulletins** provide news about mental health research and advertise any relevant user and carer involvement in research opportunities and events within the McPin Foundation or other organisations. Visit: [bit.ly/1R7o7K5](http://bit.ly/1R7o7K5)

### The next stage of NHS Citizen Gather

[www.nhscitizen.org.uk](http://www.nhscitizen.org.uk)

NHS Citizen Gather is an opportunity to talk to other citizens about how the NHS in England can improve and how everyone can contribute to making those improvements happen.

Gather enables you to start and join conversations, share your ideas and suggestions and vote to support the discussions you think are important.

A Citizens' Jury will then choose five issues to go to an NHS Citizen Assembly meeting in November 2015.

### There is a new journal written with patients at its heart:

Research Involvement and Engagement

Visit [www.researchinvolvement.com](http://www.researchinvolvement.com)

### And finally...

A big 'thank you' to all who contributed ideas for the name of our PPI newsletter.

We hope you like the choice of PPI Pulse, with its medical connotations, but also a sense of pace and importance!

Lynne Maddocks,

Coordinator of Patient & Public Involvement

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