

Patient and Public Involvement Newsletter

Edition 4 — Spring 2016

Queen's Anniversary Prize for Oxford's innovation in biomedical engineering



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Oxford University's pioneering work in biomedical engineering has been recognised with a Queen's Anniversary Prize.

Awarded every two years, the Queen's Anniversary Prizes recognise universities and colleges which have demonstrated excellence, innovation, impact and societal benefit.

Oxford's Institute of Biomedical Engineering (IBME), which is a

research institute in the Department of Engineering Science, has been at the forefront of innovation in medical technology for the past seven years, hosting world-leading projects such as the first human liver to be kept alive at body temperature outside the body.

Research carried out at the IBME has led to the establishment of nine commercial spinout companies, including OxSonics (ultrasound therapy), Oxehealth (cameras as health monitors), Intelligent Ultrasound (quality assurance of imaging services), and CN BioInnovation (fast-tracking of new drugs).

Professor Lionel Tarassenko CBE FREng FMedSci, Head of the Department of Engineering Science and member of NIHR CLAHRC Oxford's theme 5 team, said: 'Oxford is leading the world in showing how engineers can work together with clinicians to address unmet needs in the prevention, diagnosis and treatment of major diseases and conditions.'

Read more at: www.ox.ac.uk/news/2015-11-19-queens-anniversary-prize-oxfords-innovation-biomedical-engineering

Leading the fight
against dementia

Alzheimer's Society

Top 10 dementia research questions

The Alzheimer's Society led a Dementia Priority Setting Partnership with the James Lind Alliance to identify some of the priorities for dementia research.

Through extensive engagement with people with dementia and their carers, health and social care practitioners, and organisations that represent these groups, over 4,000 questions on the prevention, diagnosis, treatment and care of dementia have been whittled down to a top 10 list.

Read more at: www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804

Healthtalk.org

Ever wondered what researchers really think about PPI?

You can find out about the experiences of health researchers of involving patients and members of the public in their research, by seeing and hearing people share their stories on film.

The researchers travelled all around the UK to talk to 36 people working in health research, including clinical and scientific researchers, social scientists, and people with

a specific role coordinating patient and public involvement in research.

Find out what people said about their reasons for involving people, the impact it has made, what some of the problems have been, and how involvement can be better implemented and supported.

Professor Carl Heneghan (pictured) is one of the contributors.

Researchers were asked how they viewed the purpose of involvement. A common answer was that only people who had experienced a particular condition could really understand it, so the aim of involvement was to bring that expert knowledge to the table alongside researcher knowledge.

Bringing this expert insight to individual



research projects could make them better: more relevant to patients, more likely to be funded, more likely to recruit participants, and, in the end, more likely to improve clinical practice

and patient experience.

There are sections on definition and purpose, recruitment, the value of PPI, measuring impact, training needs, learning from experience, the attitudes of colleagues, organisational support and leadership,

doubts and worries, practical advice, payment, long term involvement and 'professionalisation', 'representativeness' and feelings and emotional impact.

It ends with messages for other researchers, for people who get involved in research and for NHS, universities & funders.

You can view the researchers' experiences of PPI here: www.healthtalk.org/peoples-experiences/medical-research/researchers-experiences-patient-public-involvement/topics

New research exploring how frontline staff use patient experience data for service improvement

University of Oxford and Picker Institute Europe have announced that they have been awarded £786,880 by the National Institute for Health Research (NIHR) to investigate how NHS frontline teams use different types of patient experience data for improvement.

The project aims to build an understanding of which types of data or quality improvement approaches are more or less likely to be useful with frontline teams in making health care more person-centred.

The project's Chief Investigator; Louise Locock, Director of Applied Research, Health Experiences Research Group at the University of Oxford's Nuffield Department of Primary Care Health Sciences said: "Improving patient experience is currently a high



priority for the NHS but change has been slow. There is an awareness of the importance of patient experience and we need to learn lessons about what works in which contexts and share learning across the NHS".

In early 2018 the researchers will produce a practical toolkit for the NHS on strategies for making patient experience data more convincing, credible and useful for frontline teams and Trusts.

Could you help Oxford Health NHS Foundation Trust improve the care environment?

Oxford Health 
NHS Foundation Trust

This local NHS Trust is looking for people to take part in their PLACE assessments – Patient-Led Assessments of the Care Environment.

The PLACE assessments involve teams made up of patient representatives going into hospitals to evaluate hospital buildings, cleanliness, food, and how the environment supports patient's privacy and dignity. It focuses entirely on the care environment and does not cover clinical treatment or how well staff are doing their job.

The assessments take place every year, and results are reported publicly to help drive improvements and show how hospitals are performing.

Who can be a PLACE assessor?

You don't need any qualifications or experience, just a genuine interest in taking part.

Assessment teams are a collaboration between staff and patient assessors, so patients must make up, at least, half of the assessment team. Anyone who uses the service can be a patient assessor, including current patients, their family and visitors, carers, or patient advocates. If you work for the Trust or have worked for them in the last two years you are not able to take part. This is to make sure assessors are independent.

What does taking part involve?

Taking part in PLACE means giving up a half-day or day to take part in the visit to the hospital. The Trust will prepare you for taking part in assessments by providing information and training so that you feel confident in taking part.

Oxford Health NHS Foundation Trust first PLACE assessment is on 10 March 2016

Contact Jennifer Acourt on 07881 506799

or via email Jennifer.acourt@oxfordhealth.nhs.uk

Interested but no experience of this Trust?

PLACE assessors are needed in all NHS Trusts—get in touch with the Trust where you have the most experience.

Free Quality Improvement training

Devised by the NIHR CLAHRC North West London this resource gives you an introduction to a systematic approach for quality improvement.

Once registered click on the Patient and Public Engagement/ Involvement module.

Register at qi4u.ocbmedia.com/login

Future Learn: Improving healthcare through clinical research course

FutureLearn's 'Improving Healthcare Through Clinical Research' course will be starting on 6 June 2016. It is a free, four week online course.

It is open to everyone; from patients, the public, to carers and healthcare professionals.

You will find out how medical treatments are discovered, tested and evaluated, to improve healthcare for all.

You can sign up to register for the June course now, by going to www.futurelearn.com/courses/clinical-research



PPI Opportunities

Opportunities to get involved, for funding, to give feedback, or just find out more about PPI.

Patient Opinion

Patient opinion is an independent site about peoples experiences of UK health services, good or bad: www.patientopinion.org.uk.

Passing your stories to the right people to make a difference.

If you have an experience of health care in the last three years, either as a patient yourself or as a carer or friend of someone else, patient opinion would like to hear about it. What was good? What could have been better?



Public Open Day – Celebrating Medical Research

The NIHR Oxford Biomedical Research Centre will hold a public open day “Celebrating Medical Research in Oxford” on Thursday 21st April from midday to 5pm at the John Radcliffe Hospital.

The event, at Tingewick Hall in the Academic Block, will include interactive stands, lectures, debates and tours about the work of the Oxford BRC, which funds medical research across seven areas including cancer, diabetes, stroke and genetics.

More here: oxfordbrc.nihr.ac.uk/event/public-open-day-celebrating-medical-research

Recruitment opportunity to shape primary care services



The NHS England Primary Care Oversight Group (PCOG) is looking for two patient and public voice members to join the group. The PCOG oversees the effectiveness of primary care commissioning; making sure it is patient focused and clinically led.

Candidates need to have a genuine commitment to developing excellent primary care services, as well as an understanding of national strategy development.

Details and application information can be found at: bit.ly/1QBoue7

Applications close 23 March 2016.

Have your say: Patient Reported Outcome Measures (PROMs) public consultation

Patients are asked to complete questionnaires (PROMS) to assess the improvement in their health from their own perspective. For example, before and after hip or knee replacement, groin hernia or varicose vein surgery.

NHS England is consulting on the current PROMs collections and the future for PROMs, regarding options around how to use resources most effectively to understand the outcomes which matter to patients.

The consultation will run until 28 March 2016.

Contribute here: www.engage.england.nhs.uk/consultation/proms-programme/consultation/intro/view

Patient Research Ambassadors Initiative

The Patient Research Ambassadors (PRAs) Initiative is a project which aims to improve how NHS patients can find out about and participate in research in their local NHS care organisation.

Find out more about the role of a PRA at: www.brighttalk.com/community/medical-research/webcast/6833/189051

Does your community group need financial support for a project or event?

The University of Oxford has a small community grants scheme, which since 2013 has provided funding for over 50 local projects, from Oxford Open Doors to the Cowley Road Carnival, with grants ranging from £300 to £15,000.

More at bit.ly/1X6oWBD

Sign up to the Lay Members Network.

If you're a CCG Patient & Public Involvement Lay Member you can sign up to a Lay Members Network to support you in your role.

Visit these sites to find out more:

www.england.nhs.uk/ourwork/patients/public-voice/lay-members

pplaymembers.wordpress.com

bit.ly/1p7SgfU

PPI in action

PPI really can make a difference

Patient leader Michael Seres had an idea—the research was done and now there is a device in production.

The device is a sensor that warns when a stoma bag is at risk of overflow or spillage.

Read more here: bit.ly/24LGkkW

Depression: ARQ

The Depression: ARQ project captured approximately 10,000 questions about depression from more than 3,000 people with some experience of depression.

These questions were then condensed into a 'Top 10' priorities for research.

The primary aim is for the 'Top 10' to inform researchers and funders so that they can focus on priorities set by patients.

You can read the top ten here: www.depressionarq.org

Community groups showcase successful participation projects.

Films, posters and comic books are just some of the innovative resources that have been created by groups who received an NHS England Celebrating Participation in Healthcare grant.

Find them here: www.england.nhs.uk/ourwork/patients/public-voice/comm-grant

How patient and carer leaders can make a difference

NHS England commissioned a study to explore how patient leaders can play a more prominent role in defining, assessing and improving patient experience.

The researchers worked with patients and system leaders to assess which elements of patient leadership were most important and should be explored further.

Not surprisingly, the study was co-designed with patient and carer leaders.

You can find out more here: www.england.nhs.uk/wp-content/uploads/2013/08/imp-exp-care.pdf

Oxfordshire GP practice wins Research Engagement Award

We are really pleased to announce that the winner of the National Association for Patient Participation (N.A.P.P.) Research Engagement Award is White Horse Medical Practice in Faringdon, Oxfordshire.

The practice, working with their Patient Participation Group, community groups and other local organisations, has run a survey on maternity service needs across their geography and beyond.

Case study of Patient Partnership

The Health Quality Improvement Partnership have produced a case study of a GP Practice Patient Participation Group.

It demonstrates the requirement for PPG governance arrangements, challenges in achieving diversity and inclusivity, and reporting and data clarity to meet the needs of lay members.

Read more here: www.hqip.org.uk/resources/case-study-gp-practice-patient-participation-group-gpp

Auditing the effectiveness of patient and public engagement

The Royal Marsden NHS Foundation Trust specialises in cancer care, treatment, research, training and education.

Keen to assess the level of engagement of patients, their carers and families in making decisions about the development of services, and how they can be improved, their quality assurance department developed and shared a questionnaire, and analysed feedback for action.

You can find the results here: www.hqip.org.uk/resources/case-study-auditing-the-effectiveness-patient-and-public-engagement/

Stroke patients

Sentinel Stroke National Audit Programme (SSNAP) has launched two new reports.

The first details the findings of their first ever audit on care organisation for stroke survivors, and the second is their annual report.

View them here: www.hqip.org.uk/news-events/news/ssnap-annual-report-2015

Meet a researcher: Dr Sara Ryan



Tell us about the research you are currently working on?

I'm currently working on several projects which makes for an interesting working life. I'm interviewing learning disabled mothers about their experiences of pregnancy and maternity care, people with rare diseases about their experiences of genomic research, I'm doing a secondary analysis of autistic people's experiences of primary care and working with colleagues on projects around experiences of skin conditions, domestic violence and a rare condition called Alport syndrome.

What was your childhood ambition?

Ha! I had three main ambitions across my childhood. To be a writer, a

photographer and a tennis player.

My work involves writing so I've sort of achieved that. I'm always taking photos which I still love.

My tennis playing went from quite good to mediocre (or worse).

What do you like most about working at Oxford University?

I enjoy the work I do which largely focuses on exploring people's experiences of health and illness. I like the flexibility around working hours and I work with a good bunch of colleagues. I live in Oxford so it's also convenient.

Tell us about when you most successfully worked in partnership with patients or public representatives on your research.

Why did it work so well?

I've worked with a local self-advocacy group, My Life My Choice, for around seven years now.

I find working with them a very positive experience and learned an awful lot from them. I find not only are they professional, fun and committed to research around learning disability issues, but they also make the research much more robust by bringing back the ideas, or research we do, to something relevant to them.

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

It would involve a dramatic train journey somewhere with my partner, Rich (who unfortunately isn't that keen on train travel).

Training and seminars for PPI contributors

The NIHR CLAHRC and the Nuffield Department of Primary Care Health Sciences are running some training seminars for local (Thames Valley) patient and public contributors.

These are not intended to make researchers of you, simply to help you feel fully able to contribute and better placed to ask questions.

Lunch or tea will be provided at the start of each seminar

and you can claim travel expenses.

There is still time to sign up:

To book onto one or more of the seminars simply email Lynne (ppi@phc.ox.ac.uk) who will register you and will give you details of the location, which is in central Oxford.

Date	Time	Title	Host
22 March	12.30pm to 2pm	Understanding ethics and what is meant by 'informed consent'.	Dr Andrew Papanikitas
11 April	5.30pm to 7pm	What is a systematic review? Some explanation of commonly used research terminology	Dr Nicola Lindson-Hawley
18 May	5.30pm to 7pm	How can we work together to improve PPI?	TBD

Meet a PPI contributor: Alan Chant

Tell us about the projects you are currently involved with:

I am currently involved in an exciting project called PIRIST – standing for Patient and public Involvement intervention to enhance Recruitment and Retention in Surgical Trials – being led by Joanna Crocker at the Nuffield Department of Primary Care Health Sciences. It started life with a broad remit to demonstrate the impact that PPI has in research. The research then narrowed to a specific examination into how PPI could result in improvements in recruitment and retention in surgical trials – an area with relatively limited PPI involvement. We are hopeful (fingers crossed!) that the results will demonstrate the positive impact that involving patients and the public can bring to research.

Why did you first get involved in medical research?

In 2011, I was suddenly struck down with myeloma cancer, and a spinal operation led to 2 years of intensive

in-patient and out-patient treatment in Thames Valley hospitals. In particular, the care that I received at the Churchill Hospital was exemplary, and, although it is a cliché, I wanted to give something back as a patient to say “thank you”.

I am now a PPI rep on 8 other bodies, including NICE, Cancer Research UK, UK Clinical Research Collaboration and Oxford BRC, so you could say that research projects have become something of a passion!

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

Advancing knowledge is a crucial area in driving change and so the outcome of research is rewarding in itself. There is also the benefit of working alongside enthusiastic and passionate researchers, clinicians and specialist health workers.

I also find demonstrating the benefit of PPI both challenging and rewarding and have seen the benefits at first hand of the patient perspective making a significant difference to the development and outcomes of the final research.



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

One project that I have been involved in with Cancer Research UK has been as a PPI representative on an Early Diagnosis Advisory Group. Survival rates for cancer in the UK are poor in the international league table, and late diagnosis is an important contributor to this. The group has funded many research projects, and added to the understanding of why this should be so, and I have enjoyed playing a part.

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

I'm not big on holidays, and travel insurance is an issue with my current condition. However, hypothetically a trip to Seattle and Vancouver would be great – for the coffee and the scenery respectively. And, I'd better take the wife!

eLearning for healthcare improvement

An eLearning package is available to support people who wish to become involved in quality improvement work in healthcare.

By the end of this e-learning package, you will be familiar with:

- Your vital role in improving healthcare quality
- Quality improvement principles
- Quality improvement data

Find out more at: www.hqip.org.uk/resources/introduction-to-quality-improvement-for-patients-and-public/

NHS England final Statement on involving patients and the public in commissioning

Commissioning is the process for deciding which NHS services will be paid for and covers all NHS primary care services.

This document explains what the NHS' legal duties are in this area and how they implement them in practice.

Read the statement here: bit.ly/1pxigBU

The 'Leading together' programme



LEADING TOGETHER PROGRAMME
Patients, professionals and the public working together to improve care

There are opportunities throughout 2016 for patients and health professionals to come together and build effective partnerships through a unique 'Leading Together' programme.

Working in partnership with patients and the public is key to the NHS's Five Year Forward View, and to creating services that are truly person-centred.

It is often said that a shift in culture is needed to achieve this and the Leading Together Programme is part of this shift.

Delegates will learn new approaches to collaborative working and to what it means to co-create services that support high quality compassionate care.

Leading Together will support 120 health professionals and lay people to develop real partnerships that make a difference to their local health organisations and communities.

The programme aims to create increasing numbers of lay partners and professionals who can work together strategically to build a culture of involvement. It will be designed and delivered by leadership professionals and people who have regularly used health services.

The workshops will be delivered in groups of around 20 at different times and venues.

Each workshop lasts three days, spread over three months.

Application for the following areas remains open:

Tunbridge Wells	May/June/July 2016
Aylesbury	June/July/Aug 2016
Reading	July/Aug/Sep 2016

Subject to the co-design process we anticipate the programme will offer participants an opportunity to:

- develop knowledge and understanding of the benefits of working collaboratively
- share expertise and experiences to support learning for others in the group
- build collaborative networks
- develop leadership skills for influencing change
- put learning into action through projects that benefit your organisation and community

Applications are invited from patients, carers, clinicians, and members of the public (the Programme is free of charge).

For more information you can visit the [Leading Together webpage](#), or email leadingtogether@oxfordahsn.org

Major roll-out of NHS Right Care

- The [NHS RightCare programme](#) uses data on what Clinical Commissioning Groups are spending on patient care and the health outcomes patients get for that spend, to highlight "unexplained" variations compared to other CCGs. The programme then helps CCGs to drill-down into the local health system to understand why there is variation and what needs to be changed to improve value for patients and commissioners.
- Across the country, tackling variations in healthcare has the potential to, for example:
 - Save 5,000 more lives every year across the major conditions
 - Screen 100,000 more women for breast cancer
 - Provide 60,000 more diabetics with the full eight care processes recommended by NICE
 - Identify 100,000 more patients with hypertension and 60,000 more patients with heart disease earlier in the course of their disease and allow earlier intervention
- RightCare will roll out across all CCGs over the next two years, starting with the first wave of 65 CCGs covering over 18 million people, and expanding to cover all 211 CCGs over the next two years.

The Health Inequalities Commission: Call for evidence

The Commission has been asked by the Oxfordshire Health and Wellbeing Board to consider what actions could be implemented in Oxfordshire, which would result in a sustainable reduction in health inequalities. In particular, it will focus on how we can improve the delivery of health and social care functions, with a particular emphasis on:

- reducing health inequalities across the life course,
- urban and rural living,
- the experiences of ethnic minority groups and populations living in situations of particular disadvantage e.g. homelessness, refugees etc.

The Commission invites short [written responses](#). Evidence should be submitted to cscsu.talkinghealth@nhs.net by the deadlines given below. Please note the dates for the meetings in your diaries.

If you are asked to give verbal feedback, you will be contacted to confirm your availability at least one week prior to the event:

Two sessions will have taken place by the time this newsletter is printed, on 'beginning well' and 'living well'. Two further sessions remain;

11 April, 9.30 to 12.30pm at the Rose Hill Centre in Oxford.

'Ageing well'; submissions are invited on older people's health including living with dementia. Deadline for submissions is 29 March.

23 May, 9.30 to 12.30pm in the Council Chamber at Oxford Town Hall in Oxford.

Major cross cutting themes and challenges: submissions are invited on major cross cutting themes, including housing, education, rural living, and poverty. Deadline for submissions is 6 May.

For queries about how to submit evidence call 07919 346547 or send an email to cscsu.talkinghealth@nhs.net

NHS England appoints Anu Singh as Director of Patient and Public Participation and Insight in December 2015.

Anu Singh joined NHS England from Staffordshire County Council where, as Head of Business Improvement, she was responsible for the commissioning of mental health, social care, community safety and education.

She is also a Non-Executive Director of the Whittington Integrated Care NHS Trust in north London.

Anu has already begun her work developing a partnership with the

people who use NHS services, and helping the NHS to interpret what they think and feel of the services provided.

NHS England and public and patient participation policy

NHS England has strengthened its commitment to public and patient participation with the publication of a new Patient and Public Participation Policy and Statement of Arrangements.

The policy sets out their ambition to put people at the heart of everything the NHS does. They would like to hear your experiences of how well they

• are working in practice and will be gathering feedback until the end of December 2016.

• You can find the policy at: www.england.nhs.uk/ourwork/patients/ppp-policy

• And give your feedback at: www.engage.england.nhs.uk/survey/strengthening-ppp

Bits and bobs

Care Quality Commission (CQC) inspections of GP practices.



These inspections have highlighted common features of inadequate practice. How is your practice doing?

The CQC are sharing these short case studies to encourage improvement in patient care.

In each example, a common case of inadequate practice is highlighted with an explanation of the negative impact this has on the practice and on people receiving care.

Read more here: www.cqc.org.uk/content/what-does-inadequate-practice-look-examples-our-gp-inspections

Access to GP records

A new video from NHS England highlights the patient benefits of access to GP online records.

By 31 March 2016, everyone can request access to their GP online records, including medication, allergies, immunisations, illnesses and test results.

All GP practices across England are getting ready for this change.

- You can view the video on YouTube at: youtu.be/un4rd_3ZomY
- For more information email england.patient-online@nhs.net.



Sign up for the NIHR CLAHRC Oxford Newsletter!

- The quarterly newsletter gives an overview of the CLAHRC's work, highlighting key projects and their impact in Oxford and the Thames Valley.

• Visit eepurl.com/bQHrD5 to see the last newsletter, and sign up for future newsletters

• To stop receiving PPI Pulse, please email [Lynne Maddocks](mailto:Lynne.Maddocks@phc.ox.ac.uk) to be removed from the mailing list.

Patient Experience Tweetchat

A Tweetchat – a pre-arranged chat on Twitter – hosted by [@OxPrimaryCare](https://twitter.com/OxPrimaryCare) and [@OxfordHEXI](https://twitter.com/OxfordHEXI) discussing how patient experience is used by healthcare organisations, commissioners and academics can be viewed at: bit.ly/1Szoo83

The tweetchat brought a range of social media active researchers and patient experience experts together in the discussion.

Past issues of PPI Pulse can be found on our website:

You can find them at: www.clahrc-oxford.nihr.ac.uk/get-involved/ppi/information-for-patients-and-public

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www.phc.ox.ac.uk | [@OxPrimaryCare](https://twitter.com/OxPrimaryCare)

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