








Patient and Public Involvement Newsletter

Edition 5 - Summer 2016

The National Institute for Health Research celebrates its 10th anniversary



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2016 marks a decade since the National Institute for Health Research (NIHR) was established. Throughout the last ten years it has contributed significantly to the health and wealth of the nation and is now the most comprehensive research system in the world.

NIHR CLAHRC Oxford is proud to be

a part of this world-leading research institute.

The work of the NIHR has had a significant impact on the research landscape and has been growing year on year. In 2014/15:

- more than 260,000 people took part in NIHR research studies
- a record-breaking 21,499 people took part in dementia research supported by the NIHR
- £97.8 million was invested in training programmes, with more than 5,000 trainees receiving support in their career development
- £135 million has been invested in cancer research
- nearly £1 billion external research investment was attracted
- more than £41 million intellectual assets were generated
- 114 licensing deals were

conducted; and 111 patents were granted

- more than 250 NICE guidelines used NIHR-generated evidence.

The latest [annual report](#) highlights more activity undertaken by the NIHR.

The NIHR has developed a series of [information sheets](#) about its work and activities in key areas.

The Research Excellence Framework, a system for assessing the quality of research, has recognised the major role played by the NIHR.

In their report they said, “We consider that the overall increased NIHR funding seen since 2006 and decisions to maintain government science funding in times of economic hardship have had a positive influence in the increased quality of the outputs... and has put the UK in a very strong position worldwide in research.”

Have an input

Have your say on the [NHS extending the role of community pharmacy in urgent care via this survey](#).

This consultation is open until **November 2016**.

The quick guide explains how community pharmacy teams can reduce demand on other urgent care services. It includes examples of services that have already been delivered by community pharmacy teams. There are over 11,500 community pharmacies in England providing NHS services. In the areas of highest deprivation almost 100% of households live within walking distance of a pharmacy. Adults in England visit a pharmacy on average 16 times a year. Many pharmacies are open for extended hours in the evenings and weekends and nearly 900 of them

are open for 100 hours a week. Pharmacists train for five years, are experts in medicines and can be consulted without an appointment.

<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/quick-guid-comm-pharm-urgent-care.pdf>

Nominations for the [Kate Granger Compassionate Care Awards](#)

are now open. The awards are named after Kate Granger, the terminally ill doctor who has worked tirelessly to raise awareness around compassion in the NHS through her #hellomynameis social media campaign. The judges are looking for individuals, teams and organisations who have made a difference and demonstrated outstanding care for their patients. Anyone can nominate, using the [online nomination form](#) on the NHS England website.

Nominations close on 30 June 2016

Patient stories

The NIHR Clinical Research Network is seeking volunteers to tell their positive patient stories that can be put forward to top regional press contacts.

All you need to do is to tell them who you are and all about your experience in research. If taking part has benefited you in any way they want to know about it and want your story to be heard!

By increasing public understanding of how and why patients get involved in research the CRN hope to increase the number of people who take part.

[Sign up and tell us your patient story](#)



Nominate someone for the first Thames Valley Health Research Awards

The awards are for the special people who have gone out of their way to help make sure that health research is delivered in Berkshire, Buckinghamshire, Milton Keynes and Oxfordshire – whether in local hospitals, GP practices, or elsewhere.

Nominees could be patients who supported research studies, doctors, nurses, NHS support staff, or anybody else who has gone the extra mile in making research happen in the Thames Valley. Anybody can make a nomination.

As this is the first year that the awards are held, nominations can relate to any work that took place within the past 5 years.

The closing date for nominations is 30 June 2016 and the awards ceremony will take place in Oxford on 12 October 2016. The awards are an initiative by the NIHR Clinical Research Network Thames Valley and South Midlands. [Submit your nomination now](#)



Research update

We have moved!

Following a dramatic £14.1m renovation by the University of Oxford & the Nuffield Department of Primary Health Care Sciences, the former Radcliffe Infirmary's Outpatients' Building is now our office. The Grade II listed building, built originally in 1911, has been renamed the "Radcliffe Primary Care Building". In 1941, the building was the site of the country's first accident and emergency service. In the same year, the now demolished accident ward was also the site of the world's very first administration of penicillin to a patient.



The dedication to the advancement of healthcare in this historic building now continues with its reincarnation as the site of world-ranked primary care research.

The Nuffield Department of Primary Care Health Sciences at Oxford has a strong reputation for postgraduate study. You can find out about the [breadth of different DPhil projects](#) currently undertaken by the department's students and their supervisors (outside Oxbridge DPhil is known as PhD).



Have you heard of the CLAHRC but wondered what it is?

The NIHR CLAHRC Oxford, along with the other 12 CLAHRCs across the UK, bridge the gap between the world-class research conducted by academics and its implementation on the NHS frontline, where it can impact on patient lives and the quality of service provided to them.

[A new brochure](#) is available explaining some of the highlights of the CLAHRC programme to

Training and support

Patients share their learning from MOOC in “highlights” video

The NIHR Clinical Research Network (CRN) released its first Massive Open Online Course (MOOC) in November 2015. Attracting over 8,000 people from all over the world, patients, the public and healthcare professionals were amongst the thousands who learnt about ‘Improving Healthcare through Clinical Research.’

On the back of the November course success, this free online course is running again in June 2016. To promote the course and evaluate the value and impact MOOC has had on the people who undertook it, a short highlights video has been produced.

The video features members of the public and patients who registered to undertake the MOOC, which is a four week online course. They each talk about their experience, and how the course has helped them to be more knowledgeable about research.

You can watch the video [here](#)
Sign up to register for the June MOOC by going to: www.futurelearn.com/courses/clinical-research

Help to assess media health stories

At the PPI Seminars we organised recently in Oxford some of the delegates said that they wanted to know **the truth behind the headlines in our media about**



science behind the headlines.

health issues. [This NHS resource](#), founded by Professor Sir Muir Gray, an honorary professor in the NDPCHS, gives the



[How to read health news](#)

Questions to ask from Dr Alicia White – follow the link above to get the details

Does the article support its claims with scientific research?

Is the article based on a conference abstract?

Was the research in humans?

How many people did the research study include?

Did the study have a control group?

Did the study actually assess what’s in the headline?

Who paid for and conducted the study?

Should you ‘shoot the messenger’?

How can I find out more?



The Benefits Advice Service for involvement continues.

INVOLVE, the national promoter of all PPI, has extended the funding for its Benefits Advice Service for the foreseeable future.

The Benefits Advice Service offers personal advice and support on payment of fees and expenses for public involvement that might affect people in receipt of state benefits. The service covers public involvement activities in health or social care research, service design or service delivery.

You can access this service if you are involved in any NIHR-funded research.

Contact INVOLVE on benefits@invo.org.uk or 023 8059 5628 and they will give you the necessary code to be in touch with the service, which is managed by a Citizens Advice Bureau.

General Practice



Parliamentary
and Health Service
Ombudsman

An opportunity to improve – General practice complaint handling across England: a thematic review

General practice forms 90% of all NHS interactions with the general public. While satisfaction with general practice services was recently rated higher than other NHS services, it's the lowest score since the survey started in 1983. Workforce issues, the growing need and rising expectations of an older population, with more complex healthcare needs, are creating demand pressures on general practice. Therefore, how will practices make sure that, amongst other things, pressures do not translate into a poorer patient experience?

Recommendations

1. Education and training: there is a need to support GPs through education before and after they qualify.
2. Sharing what has been learned: CCGs and local medical committees could share how practices have dealt with complaints with other practices in the area. Time should also be provided for staff in practices to review feedback from patients to improve the service provided.
3. Communication: an apology is not about accepting blame but an important part of providing closure; we believe the defence unions, such as the Medical Defence Union or the Medical Protection Society have an important role in encouraging apologies.

Read the full report here:

http://www.ombudsman.org.uk/_data/assets/pdf_file/0007/36547/GP_Complaint_handling_report.pdf

Is general practice in England nearing "saturation point?"

People in England are visiting their GP practices more often, and are having longer consultations than they were in 2007, resulting in a 16% rise in clinical workload, researchers led by the Nuffield Department of Primary Care Health Sciences have found.

Writing recently in the *Lancet*, the researchers suggest there are signs that the overall primary care system in England may be reaching "saturation point."

The study, supported by the [NIHR School for Primary Care Research](#), is the most comprehensive analysis of workload in primary care to date and involved an analysis of anonymised electronic health records from 100 million consultations with GPs and practice nurses in England. The data, obtained from 398 GP practices, was equivalent to 2.5 million patient years of observation recorded over seven years, between 2007 and 2014.

NHS England publishes plan to transform general practice

The [General Practice Forward View](#) is a plan to support the transformation of general practice over the next five years and improve services for patients. By 2020/21 there will be an extra £2.4 billion a year going into general practice. In addition, there will be a one off, five-year £500 million investment to support GP practices. The General Practice Forward View includes plans to grow the workforce, increase use of technology, develop better premises and improve the way services are provided so patients have better access to the right service at the right time.



Meet a Researcher



Phil Turner—Researcher and Industry Liaison Officer

Tell us about the research you are currently working on?

Two research projects, both of which are collaborative with partners from industry.

- a diagnostic test for people with chronic obstructive pulmonary disease to test if patients could use a device at home to provide an early warning of when their condition is starting to worsen,
- a diagnostic test for the prevention of heart failure identifying people who are at higher risk of developing heart failure and offering these people a blood test, the results of which would be used to guide subsequent treatment.

What was your childhood ambition?

To climb the north faces of the Eiger, Grandes Jorasses and the Matterhorn in the European Alps before my 18th birthday. I didn't quite manage to do that, but I have climbed other beautiful mountains and had enormous amounts of fun along the way.

What do you like most about working at Oxford University?

The people are fantastic, the environment is stimulating and I have a 20-minute cycle commute.

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

Part of my job is to co-ordinate the diagnostics group's PPI meetings. The interactions with our PPI representatives always raise the unexpected (as they should) and send us away with much to contemplate about our work. It is all too easy to become entrenched in our own project world, and our PPI Contributors help us to take a few steps back and to consider what we do from the perspectives of others.

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

This would probably be an extended holiday travelling through game reserves in Zambia and Uganda with my wife and three boys.

Meet a PPI Contributor



Marion Judd

Tell us about the projects you are currently involved with:

The project I am currently involved in seeks to find out whether current methods and frequency of monitoring patients with chronic kidney disease are effective in terms of testing and how often patients are tested and monitored in practice by hospital departments and GPs.

Why did you first get involved in medical research?

I first developed an interest in medical research through working as a physiotherapist in the NHS for a number of years. In the early 90s I was lucky enough to be seconded to a physiotherapy research programme at Kings College London and subsequently had the opportunity to complete a small research project of my own for a Master's degree. After retirement I had a further opportunity to undertake a research project, this time in the field of medical sociology.

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

As a lay person and patient, I am glad to be able to contribute to ongoing medical research work and to know that the results of this research will eventually result in more effective treatments for patients. Also, I very much appreciate the opportunity to flex my ageing brain while it retains enough capacity to be of some use to others!

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:

A spell as a lay member on a university ethics committee was, perhaps, when I made the most worthwhile contribution towards medical and other areas of research, through bringing a lay perspective to the critique of methodological and ethical aspects of student's research proposals.

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

My dream holiday would be a trip to India with a friend or relative, to see and learn more about some of the wonders of its rich heritage, its people, and, of course, to enjoy local cuisine. I shall have to win the lottery!

PPI information

Two new faces are bringing valuable insights to shape the work of the Thames Valley Patient Experience Operational Group.



Douglas Findlay is a learning and development specialist with a background in the pharmaceutical industry. He works with the NHS and industry. He also campaigns as a patient/carer advocate, is a patient leader at the Royal Berkshire NHS Foundation Trust and is on the board of Healthwatch Reading.



Martin Sykes is a

senior commercial executive with international experience. He is a fellow of the Institute of Directors. Martin has been a patient representative with the North and West Reading Clinical Commissioning Group and at his GP surgery.

One of the key outputs from the Thames Valley Patient Experience Operational Group is the **Leading Together Programme**. There are still places for patient and public contributors to sign up for this course run by an internationally acclaimed company The Performance Coach. [Follow the link to learn how to apply.](#)



What is co-production and how does it work?

This is an extract from an article written by **Hildegard Dumper** of **People in Health West of England**. For the full [article](#):

You might have noticed there are a number of buzz words currently flying around, the most common starting with the letters 'co-'; co-produce, co-design and co-create. I thought I would share with you my understanding about these 'co' words, and what they mean for us.

The first thing we need to understand is that all these 'co' words describe an approach to working with the public which regards each individual, regardless of their role, as having a valuable contribution to make. Central to this approach are principles of reciprocity and equality. NHS England's Citizen's Assembly describes co-production as 'service users, or the public in general, working in partnership with service providers or commissioners to jointly make decisions'.

It has been shown that where genuine co-production has taken place, it can deliver better outcomes, support better use of scarce resources and improve the well-being of those involved – clearly a win/win situation for patients and the public, as well as health service providers.

Read [NHS England's Business Plan 2016/17](#).

The new NHS Business Plan talks about patients & the public being at the centre (p49-50). There is a commitment to launch a Patient Supported Self-Management Programme, a NHS Citizen Active Communities Alliance, enhance feedback from the Family and Friends test, recruit 2,000 members to the NHS Citizen Peoples Bank and develop a NHS Citizen Participation Academy to improve skills in participation for NHS England staff and the public.

You and your genome

Genomics
england



Genomics research in Oxford and Patient & Public Involvement

A genome is essentially all the genetic information that is needed to make a person. We inherit this information from our parents, and pass some of it on to our children. Each of our genomes is unique and its complexity is clear in the observation that there are likely to be more than three million differences between your genome and anyone else's, yet our genomes are all 99.9% the same. The last decade has seen an explosion of interest in understanding the genome; this field, and associated techniques, is called 'genomics'.

Reading the first human genome, a technique called sequencing, took 13 years and cost £2billion. It can now take a day, costs £1,000, and has already been fundamental to changing healthcare. In diabetes, for example, it is now possible to identify patients, using genomics, who can switch from injecting insulin to taking a cheaper but equally effective pill. In some areas of cancer medicine it's possible to identify who will benefit from expensive drugs, allowing them to be used only for those most likely to respond well, or identify who will do well with fewer radiotherapy sessions than normal.

Genomics can also help to control unwanted organisms – for example, genome sequencing of bugs like MRSA that cause such terrible problems when they run rife in hospitals can allow targeting of antibiotics.

In 2012, recognising the potential of genomic medicine to revolutionise healthcare, the 100,000 Genomes Project was launched, aimed at using genome sequencing to understand genetic contributions to rare diseases, and cancer.

There is a lot of genomic research underway in Oxford, underpinned by organisations such as the NIHR Oxford Biomedical Research Centre (BRC) and, in 2014, Oxford University Hospitals NHS Foundation Trust was designated one of 11 national Genomic Medicine Centres (GMCs) to deliver the NHS 100,000 Genomes Project.

In March 2016 Oxford's genomics work received a boost from patients and the public when they gathered to see how they could be meaningfully involved in all this work. A PPI group has now been set up, spearheaded by Liz Ormondroyd and Jude Craft, which will meet a couple of times a year and also work "remotely". Issues they will tackle include development of the GMC website and helping researchers better understand why so many patients don't attend appointments they have booked to explore participation in the 100,000 Genomes Project. If you are interested in the PPI group, please contact liz.ormondroyd@cardiov.ox.ac.uk. She is especially keen to hear from potential members who are participants in the 100,000 Genomes Project.

Thanks to Sophie Petit-Zeman for this article; Director of Patient Involvement NIHR Oxford BRC & PPI lead, Oxford GMC. sophie.petit-zeman@ouh.nhs.uk

Follow this link to see more about how the Genomics work is influenced by patients and the public nationally; <http://www.genomicsengland.co.uk/about-genomics-england/how-we-work/patient-and-public-involvement/>

PPI makes a difference



Learn how a patient challenged a hospital to work differently

Thanks to Sarah Rae, Co-founder of PROMISE Global, for this article.

I have experienced mental health challenges since my teenage years but it was spending six months as an inpatient at the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) in 2005 that gave me the impetus to try and influence the design and delivery of services. At that time I felt there were many opportunities for improvement. I frequently observed the lack of meaningful interactions between staff and patients and the use of coercion reinforced the 'them and us' culture.

Staff have to deal with distress on a daily basis, which can result in desensitisation and affect their ability to deliver compassionate care. Delays in accessing care meant that some service users had become very

unwell and were thus at the receiving end of coercive strategies.

In 2013 I took a two-day Patient Leadership course and became an 'Expert by Experience with teeth'. Thus when The Mind report on restraint in mental health services came out in 2013, I felt empowered to try and find out more. The report highlighted the extensive variation in the use of physical interventions (PI) and in particular the use of prone (face-down) restraint which can cause injury to patients and occasionally results in death.

I was curious to discover what CPFT was doing to address this issue, which led me approach the Clinical Director of adult services. Fortunately, he is a keen proponent of recovery and it was this meeting that sparked the inception of a

project known as PROMISE (Proactive Management of Integrated Services and Environments). We set up a multidisciplinary steering group and successfully obtained funding to support staff and service users at CPFT on a journey towards eliminating PI.

PROMISE is already having an impact with a 40-50% decline in incidence in the use of PI. Assaults on staff have fallen by over 50 per cent (210 in 14/15 compared with 451 in 13/14.) It was recognised recently that the initiative has made a real difference to frontline care delivery when PROMISE won a national patient experience (PEN) award. The active involvement of people with lived experience is central to the PROMISE ethos.

PROMISE has been funded and supported by the National Institute of Health Research Collaboration for Leadership in Applied Health Research & Care East of England

PPI makes a difference



Patient Involvement Film

The Support and Treatment After joint Replacement (STAR) research project team shows how patient involvement (not only participation) has been embedded into a research project and how it made a difference.

https://www.youtube.com/watch?v=k4Udm_q74tl

INVOLVE has long been interested in gathering evidence about the impact of public involvement on research.

[Follow the link to learn more about the examples that they have gathered.](#)



Get involved - make a difference

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

An NHS Patient Champion has an impact

“Every now and again I experience something that has a profound effect on me and I want to share with you the impact that listening to Ashley Brooks, NHS Patient Champion at our 2015 Leadership Summit had on me.

Ashley is the NHS Patient Champion, sponsored by the Department of Health. He was appointed following the recognition of his campaign to reduce MRSA and other infectious diseases within hospital settings and improve hygiene in general across the NHS. Ashley’s involvement followed treatment for leukaemia at St Bartholomew’s Hospital, London in 2001.

As a patient he is open about the highs and lows of his patient experience and talks about how love, professionalism, compassion and dignity surrounded every aspect of his care. However experiences of care in different hospitals showed him that there are sometimes huge variations in the quality-of-care provision within the NHS, between different hospitals and sometimes between different wards within a hospital. The inequality in the system puzzled and frustrated him but importantly for all of us, whether we work for or receive healthcare services is that Ashley wanted to make a difference, to change things.”

These are reflections from Merrill Bate, Head of Leadership at Thames Valley and Wessex Leadership Academy.

Read the full article here;

<http://www.tvwleadershipacademy.nhs.uk/engage-with-us/keeping-patients-centre-everything-we-do-reflection-patients-perspective>

‘Is it worth doing?’ Measuring the impact of patient and public involvement in research

A study by Kristina Staley

In recent years, there has been considerable interest in finding out what difference patient and public involvement makes to research projects. The evidence published so far has been criticised for being weak and anecdotal. I conclude that the statistical evidence is weak, if the studies do not consider the context in which involvement takes place and the way that it is done. This means that detailed accounts of involvement from researchers already provide valuable learning to others, in the same way that patients’ insights help shape research.

Follow this link to read the [full study](#) and others that focus on PPI.

Bits and bobs



Carers – a date for your diary

A carers event is being organised by NHS England South (South Central) on Wednesday 12th October 2016 at Swindon Steam Railway Museum.

The key note speaker is Paul Mayhew-Archer who recently spoke at a national NHS E carers event. <http://www.bbc.co.uk/iplayer/episode/b072xkcz/inside-out-south-07032016>

If you would like to attend contact Kath Rooksby 0113 8251561 k.rooksby@nhs.net



Researchers at the Nuffield Department of Primary Care Health Sciences and the Oxford Biomedical Research Centre reflect on the process of adhering to the principle of **publishing all trial results** which they promote as part of the [All Trials Campaign](#). You can read their publication in the [British Medical Journal](#).

Twenty reports to make you think

The Patient Experience Library is founded on a key recommendation from the Francis Inquiry: that results and analyses of patient feedback must be shared. They have nearly 17,000 reports for last year, but in this report they highlight 20 that give real insight.

[Download your free copy here.](#)

The National Association for Patient Participation (N.A.P.P.) will hold its annual

[conference](#) on 11 June 2016 in Stretton, Cheshire.

NAPP supports Patient Participation Groups in GP surgeries.

The theme of this event is 'Transforming services together: transformation, integration and federation - what do they mean for patients?'

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