

## Patient and Public Involvement Newsletter

Edition 6 - Autumn 2016

### Progress on 'Going the Extra Mile' one year on

that have been completed which will provide the building blocks upon which successful implementation of Going the Extra Mile depends. These include:

1) The award of the INVOLVE Co-ordinating Centre contract to the Wessex Institute for the next five years.

This contract began on 1 February 2016 and a new Director, Zoe Gray, started in April. The Co-ordinating Centre will shortly complete the recruitment of its senior team who will deliver a work programme very much aligned with the strategic direction set out in 'Going the Extra Mile.'

2) The establishment of an NIHR Patient and Public Involvement Senior Leadership Team.

The aim is to improve co-ordination and consistency in the delivery of activities across the system. The members of the Senior Leadership Team are: Simon Denegri, National Director; Jon Cole, [NETSCC](#); Zoe Gray, [INVOLVE](#); Zena Jones, [NIHR CRN](#); Caroline Magee, [Trainees Co-ordinating Centre](#); Phillipa Yeeles, [NIHR CCF](#); Una Rennard, public contributor; Judith Williamson, public contributor.

There has been progress too on specific recommendations



within the report.

- ⇒ Ongoing re-development of the [UK Clinical Trials Gateway \(UKCTG\)](#) means that is already much improved as a means of informing the public about all funded research. The next phase will enable patients and healthy volunteers to sign up and register their willingness to be **contacted** about taking part in research and **approved** researchers can register and access this pool of potential participants for their study.
- ⇒ NIHR standards for patient and public involvement: Exploring why and how to develop and use them can be found here: [http://www.nihr.ac.uk/CCF/PPI/PPIstandards\\_wshop2016\\_FI\\_NAL.pdf](http://www.nihr.ac.uk/CCF/PPI/PPIstandards_wshop2016_FI_NAL.pdf).
- ⇒ INVOLVE is taking the lead in developing PPI training <http://bit.ly/2c9Xnlp>

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On 29th June 2016 Simon Denegri, NIHR National Director for Patients and the Public in Research, (pictured) sent a letter to the whole of the NIHR network giving an update on the 'Going the Extra Mile' implementation a year since it was published. He says that there have been a number of major pieces of work

## Research updates

The findings of a recent study published in Family Practice could help to better understand **patient safety in primary care**, as current frameworks are largely based on health professionals' perspectives.

Dr Ignacio Ricci-Cabello from the University of Oxford's Nuffield Department of Primary Care Health Sciences led the study and said "So far most of the research in the area of patient safety has relied on information from health professionals, and very little attention has been paid to patients themselves. This study was very helpful to better understand how patients perceive and understand patient safety in primary care; which was crucial to successfully develop the Patient Reported Experiences and Outcomes of Safety in Primary Care (PREOS-PC) questionnaire - a new patient-centred tool to measure patient safety in general practices."

<http://www.ncbi.nlm.nih.gov/pubmed/27184996>

Read about the depth and impact of work carried out by the 15 **Academic Health Science Networks** across England via this [AHSN's Impact Report 2016](#)

In their fourth year the AHSNs have worked together to present this national impact report. It demonstrates the depth and breadth of their work – not just in their own areas, but also how they collaborate to address issues of national importance.

### New research aims to improve hypertension diagnosis during pregnancy

A new programme of research, led by the University of Oxford, will explore whether giving pregnant women the means to monitor their own blood pressure and urine safely from home can result in an earlier diagnosis of raised blood pressure (hypertension) and pre-eclampsia, for faster access to treatment.

Raised blood pressure during pregnancy affects around one in ten women worldwide, with around half developing pre-eclampsia.

*"We want to see if we can develop a simple and accurate way for pregnant women to measure their own blood pressure and urine from home."*

**Dr Kath Tucker, Nuffield Department of Primary Care Health Sciences, Oxford.**

**Michael Sharpe, Professor of Psychological Medicine**, has been presented with the Alison Creed Award by the European Association of Psychosomatic Medicine in recognition of his outstanding achievement in consultation liaison psychiatry research and service innovation.



### Preventing falls and fragility fractures

This is a new project from NIHR CLAHRC Oxford.

UK hospitals see over 300,000 patients with fragility fractures per year. Health and social care services have all set targets to reduce falls, prevent fractures and improve the health & wellbeing of older people.

New services and innovations are regularly introduced to help prevent falls and fractures. Yet, these innovations are often poorly evaluated and we can't be sure how effective they are. By developing and applying novel statistical techniques to this routinely collected data NIHR CLAHRC Oxford hopes to be able to tell how effective different interventions have been at reducing falls and fractures. We are also working with the Oxford AHSN Best Practice Falls Network to evaluate up to three new interventions as they are introduced.

## Research updates

### **A project to develop assisted-living technologies for older people with complex needs wins an award in the first year of the Vice-Chancellor's Awards for Public Engagement with Research.**

The study, which included 40 older people with complex needs, focused on those under-represented in previous co-design studies, such as diverse ethnic groups, non-English speakers, and those with dementia.

*"We gained many insights from working with 'housebound' elderly, who are generally hidden from society, and researchers in particular ...and we also had to develop new ways of engaging people with cognitive impairments in the co-design process."*

Professor Trish Greenhalgh, Nuffield Department of Primary Care Health Sciences.

The 12 winners of the inaugural Vice-Chancellor's Awards for Public Engagement with Research were announced by the Vice-Chancellor, Professor Louise Richardson, in a ceremony at Merton College.

The Vice-Chancellor said: "We want to create a climate in which we can embed public engagement even more deeply into our research practices...Our aim is to ensure that Oxford acquires a reputation for engaging the public that equals our reputation for research. I encourage you to take inspiration from the inaugural winners of the University's Public Engagement Awards and reflect on opportunities to engage the public with your own research."

Trish Greenhalgh, Professor of Primary Care Health Sciences, and her team in the Interdisciplinary Research in the Health Sciences (IRIHS) group have been recognised for their project Using co-design principles to inform the design of assisted living technologies for older people with complex needs.

The project team included researchers from Nuffield Primary Care Health Sciences; Sara Shaw, Joseph

Wherton and Christine A'Court pictured left, led by Trish Greenhalgh pictured right.



### **Is it worth it? Patient and public views on the impact of their involvement in health research and its assessment.**

38 PPI contributors involved in health research across the UK were interviewed for [this qualitative study](#).

While there appears to be widespread support for PPI impact assessment among PPI contributors, their views on what to assess and how are diverse. PPI contributors should be involved as equal partners in debates and decisions about these issues. Individual feedback on impact may increase PPI contributors' potential impact and their motivation to stay involved.

# 10 impacts of



The NIHR (National Institute for Health Research), created “to improve the health and wealth of the nation through research”, is 10 this year. To read the full report on their impact in this time; <http://www.rand.org/randeurope/research/projects/nihr-ten-years.html>

## 10 ways in which NIHR funded research has impacted on patient health & wellbeing

### Bringing breakthroughs to patients

Risk adapted radiotherapy for breast cancer is a less toxic form of radiotherapy shown to be as effective as conventional whole breast radiotherapy in preventing recurrence of cancer, while requiring far fewer hospital visits.

### Supporting the nation to deliver world leading research with global impact

More than 1 million people worldwide who would otherwise die each year from traumatic injury stand to benefit from NIHR funded research into the novel, off-label use of a drug, tranexamic acid, that has been shown to significantly reduce the risk of bleeding to death if administered within the first 3 hours of trauma.

### Making the nation's health and care system the best it can be

Research into methods of expediting treatment for patients suspected of having a transient ischaemic attack (mini stroke) has provided a route to preventing 10,000 strokes per year.

### Working with charities and the third sector on common agendas

NIHR's network of Experimental Cancer Medicine Centres is jointly funded with Cancer Research UK and is increasing the number of patients taking part in trials so innovative new cancer treatments, such as those for refractory myeloma can be tested.

### Supporting public health delivery

Studies of low hazard nicotine products reduce the harm from smoking by providing the evidence to underpin smoking prevention strategies.

### Putting patients and the public at the heart of all stages of research

Devices for Dignity (D4D) initiative has provided a platform for patients and the public to submit their ideas and become part of the healthcare innovation process. D4D focuses primarily on renal technologies, assistive and rehabilitative technologies and urinary continence, thinking about the development of interventions and devices.

**Creating opportunities of economic and social returns**  
‘Smart specs’ help the visually impaired by augmenting users’ vision. Funding from NIHR’s Invention for Innovation programme enabled researchers at the University of Oxford to produce an advanced prototype tailored to patients’ needs.

### Enabling clinical research excellence

A School for Primary Care Research-funded study found that a mobile device that measured patients’ blood pressure while they were mobile was more accurate and cost effective than either clinical or home monitoring. NICE has since updated its hypertension guidelines to recommend ‘ambulatory’ monitoring.

### Supporting, training and developing a diverse workforce in the NHS and academia

Between 2006 and 2015 NIHR funded 165 Doctoral Research and Clinical Doctoral Research Fellows in England. These fellowships have had a demonstrable impact on individuals’ careers and have created a skilled research and clinical academic workforce in both medical and non-medical professions.

### Investing across the nation

A project involving the East Midlands CLAHRC led to the development of the ‘Leicester Self-Assessment Tool’ to aid early identification of diabetes risk in ethnic minority communities, who form a large proportion of the region’s population and are among those most likely to suffer from diabetes.

## Improving PPI



## National Voices

People shaping health and social care

### 6 principles for engaging people and communities

This [document](#) is about creating person-centred, community-focussed approaches to health, wellbeing and care. It is aimed at NHS Leaders.

1. Care and support is person-centred: Personalised, coordinated, and empowering
2. Services are created in partnership with citizens and communities
3. Focus is on equality and narrowing inequality
4. Carers are identified, supported and involved
5. Voluntary community and social enterprise, and housing sectors are involved as key partners and enablers
6. Volunteering and social action are key enablers.

### Research hospital vision

[This opinion piece](#) from Simon Denegri, NIHR National Director for Patients and the Public in Research sets out a vision of a 'research hospital' from a patient and public perspective. It argues that patients will increasingly value those hospitals that: visibly focus on research to improve quality of care and treatment; actively enable their patients to contribute to this endeavour; and help to make the results of this research more accessible to its public.

### Informed consent

Here's a paper about [The New Era of Informed Consent – Getting to a Reasonable Patient Standard through Shared Decision Making](#).

It comments on 2015 UK Supreme Court case (*Montgomery v Lanarkshire Health Board*). In its final decision, the UK Supreme Court ruled that the standard for what physicians should inform patients about the risks, benefits, and alternatives of treatment will no longer be determined by what a responsible body of physicians deems important but rather by **what a reasonable patient deems important**.

In rendering this decision, the court swept away decades of medical paternalism in the United Kingdom to embrace a new patient-centred standard. Perhaps more compelling, the head of the Royal College of Surgeons urged that the only way to operationalize such a substantial and needed change is through shared decision making, a collaborative communication process between clinicians and patients that integrates the best evidence available with the patients' values and preferences, to promote high-quality health care decisions.

## Research & GPs

### Survey finds that patients are increasingly positive about their GP surgery

As the NHS treats more patients than ever before, [new data shows the majority of people are increasingly positive about their GP care](#), with more than 85 per cent rating their overall experience of their GP surgery as good. The GP Patient Survey 2016 compiled responses from more than 800,000 people across the country on their experience of healthcare services provided by GP surgeries. The survey found almost four in five patients would recommend their GP surgery to someone who has just moved to the local area and more than 73 per cent of patients rated their overall experience of making an appointment as good.

However, it also suggests areas for improvement, with less patients reporting that they can usually see their preferred GP,

and a reduction in the number of patients with one or more long-standing health conditions saying they had enough support from local services or organisations.

### A tool to deliver person centred care is being rolled out.

The [Patient Activation Measure \(PAM\) tool](#) captures the extent to which people feel engaged and confident in taking care of their health and wellbeing, helping professionals tailor support to better meet their needs. Evidence shows that when people are supported to become more activated, they benefit from better health outcomes, improved experiences of care and fewer unplanned care admissions.

### Genetics of type 2 diabetes revealed in unprecedented detail

The largest study of its kind into type 2 diabetes has produced the most detailed picture to date of the genetics underlying the condition.

Andrew Farmer, Professor of General Practice in the Nuffield Department of Primary Care Health Sciences is one of more than 300 scientists from 22 countries who collaborated on the study, which analysed the genomes of more than 120,000 people with ancestral origins in Europe, South and East Asia, the Americas and Africa.

The findings, published in Nature, identify several potential targets for new diabetes treatments, but also reveal the complexity of the disease that needs more personalised strategies for treatment and prevention.

### Did you know?

If you receive State Benefits and are offered payment for your PPI Contribution then you can get personalised advice that is free and confidential.

Contact INVOLVE on [benefits@invo.org.uk](mailto:benefits@invo.org.uk) or 023 8059 5628. You will then be given an email address to contact the Benefits advice service directly, together with a unique code that will need to be quoted.

### Fab Change Day: 19th October 2016

A countrywide event in England: NHS Change Day.

The idea is to create a mass movement of NHS staff demonstrating the difference they can make by one simple act, proving that large-scale improvement is possible.

<http://fabnhsstuff.net/fabchangeday/>

## Research & GPs



### Improving the discharge process

Following the publication of [Healthwatch Oxfordshire's report on the discharge process](#), in September 2015, there was agreement from the county's hospitals on a number of changes to the way in which patients are discharged from their care.

Oxford University Hospitals NHS Foundation Trust, which runs the John Radcliffe, Churchill, Horton General and Nuffield Orthopaedic hospitals, and Oxford Health NHS Foundation Trust, which runs the county's community hospitals, set out a number of improvements to the discharge processes. These include:

- Reviewing the way in which the current discharge liaison team functions to prove greater support across the trust or very complex discharges;
- Identifying a named nurse to patients as a point of contact for discharge queries;
- A re-designed patient discharge summary with input from clinical staff, including GPs and pharmacists;

- A review of all current discharge posters and leaflets for patients, with the aim of producing a comprehensive leaflet, which will include standard useful information, but will also include a section with personalised discharge information for that patient. Healthwatch Oxfordshire approved the wording on the current poster and the same language would be adopted on the leaflet.
- A discharge plan to be adopted for each patient which will include the named nurse and provide contact numbers in the event of queries.

Oxfordshire over four years, finding that at least 1 in every 100 contacts was for palliative – end-of-life – care.

Dr Rebecca Fisher said: "Out-of-hours services cover more than two-thirds of the hours in a year (from 6.30pm to 8am daily and 24/7 at weekends and bank holidays). Despite this, until now, no one had looked at how patients with palliative care needs use out-of-hours services."

Dr Dan Lasserson said: "We found that of nearly half-a-million patient contacts over four years, just over 6,000 were for end-of-life care, which equates to almost 70,000 out-of-hours contacts each year in England as a whole. "

Patients with palliative care needs were most likely to contact the out of hours service in the daytime at weekends, coinciding with the busiest period for the service."

The team say that their research raises many questions, and that more research is urgently needed. Dr Gail Hayward said: "Since the majority of contacts were in weekend daytime hours, the possibility of a dedicated palliative service covering this time period should be explored".

### Researchers call for more focus on ways to improve end of life care at home

In a service evaluation published in the British Journal of General Practice, Rebecca Fisher and Gail Hayward from the Nuffield Department of Primary Care Health Sciences and Dan Lasserson from NIHR CLAHRC Oxford looked at the use of the GP out-of-hours service for

# Developments in PPI



## PPI Guides

### Healthcare Quality Improvement Partnership

(HQIP) has formally published [three new and updated patient and public involvement \(PPI\) guides](#), with a special YouTube launch video created and presented by its Service User Network (SUN) members.

The resources, which are available to download, include updated versions of HQIP's PPI guidance, a guide to patient-led panels and a new e-learning toolkit suitable for newly qualified clinicians, patients and the general public.

Each resource is equipped with practical examples, case studies, tests and the most up to date PPI theory.

To download click on the links below:

- [PPI in quality improvement: the benefits of PPI and how to do it](#)
- [Developing a Patient panel: a step-by-step guide](#)
- [Introduction to QI for patients and public: eLearning](#)

**Check out the [Patients Know Best Patient Portal website](#).**

Claiming to be the world's first **patient-controlled medical record**, it is set up by a social enterprise.

The NHS Confederation is the authentic voice of NHS leadership.

The NHS Employers organisation, part of the NHS Confederation, is the voice of employers in the NHS, supporting them to put patients first.

Read their report published in June 2016 **Public and patient partnerships: How they can address the inequality and finance gap in health and care** <http://www.nhsconfed.org/resources/2016/06/public-and-patient-partnerships>

Both values-based and evidence-based considerations increasingly point to patient and public involvement as being key factors in achieving better patient outcomes. The UK would appear to have a very promising foundation for extending and promoting the wider adoption of patient leadership and communities as co-designers of services.

Nevertheless, research also suggests that few people really know what effective public or patient involvement means or how to implement it effectively. It argues that while it's a positive idea to involve the patient, it is important to be both practical and specific about what this actually means in practice.

<http://www.nhsconfed.org/supporting-members/involving-patients-and-communities>

## Effective PPG groups

The National Association for Patient Participation (N.A.P.P.) has launched a new [resource guide](#) to help all GP practice Patient Participation Groups (PPGs) work effectively.

NHS England commissioned N.A.P.P. – the national voice for patient participation in primary care – to develop *Building better participation*. It has sections on;

- Building better participation
- Getting PPGs in place
- Helping PPGs work well
- Knowing and working with patients
- Influencing beyond the GP practice
- Self-assessment sheet.

# Patient innovators & PPI impact

**Devices for Dignity Healthcare Technology Co-operative** (D4D) is a national initiative funded by the National Institute for Health Research (NIHR), the research arm of the NHS since 2008. Their core aim is to maintain or improve people's dignity and independence through the development of technology solutions. Each project is different, and they work closely with patients and carers, clinicians, academics, engineers, designers, charity and industry partners to build bespoke project teams of experts to collaborate in recognising unmet needs, developing solutions, generating evidence, and evaluating patient outcomes and clinical effectiveness.

They focus on four areas that are commonly associated with poor patient experience through loss of dignity and independence:

Assistive and Rehabilitative Technologies  
 Paediatric Technologies  
 Renal Technologies  
 Urinary Continence Management

Members of the public are encouraged to register their unmet needs on their website and inventors can apply to work with D4D to develop their ideas through to a marketable product.



## **Nightscout**

Developed by parents of children with Type 1 Diabetes and has continued to be developed, maintained, and supported by volunteers.

<http://www.nightscout.info>

## **Patient Innovation**

A platform created for patients and those who care about them to share and access useful solutions to cope with their diseases.

<https://patient-innovation.com>

## **PPI Impact**

A report on the impact of public involvement on the ethical aspects of research evidences how public involvement can help to make research more ethical and produce better outcomes.

<http://www.hra.nhs.uk/resources/public-involvement-research>

**Health Research Authority published a report stating that the involvement of the public in research may lead to the following benefits:**

1. Making research more relevant
2. Helping to define what is acceptable to research participants
3. Improving the process of informed consent
4. Improving the communication of findings to research participants and the wider public

To read the full report: <http://www.hra.nhs.uk/resources/public-involvement-research/>

## Meet a PPI Contributor

### Richard Mandunya

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

I am currently involved in a project to establish how patients' online comments can be tapped to improve quality in health delivery in primary care.

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

Having used research to find answers to questions in business,

I realised the same is true in medical research. However, unlike customer experience outside the health sector, this was not something that researchers may have had first hand experience with. So it turned out little tweaks to how tasks are done had a huge impact on patient cooperation and willingness to help researchers.

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

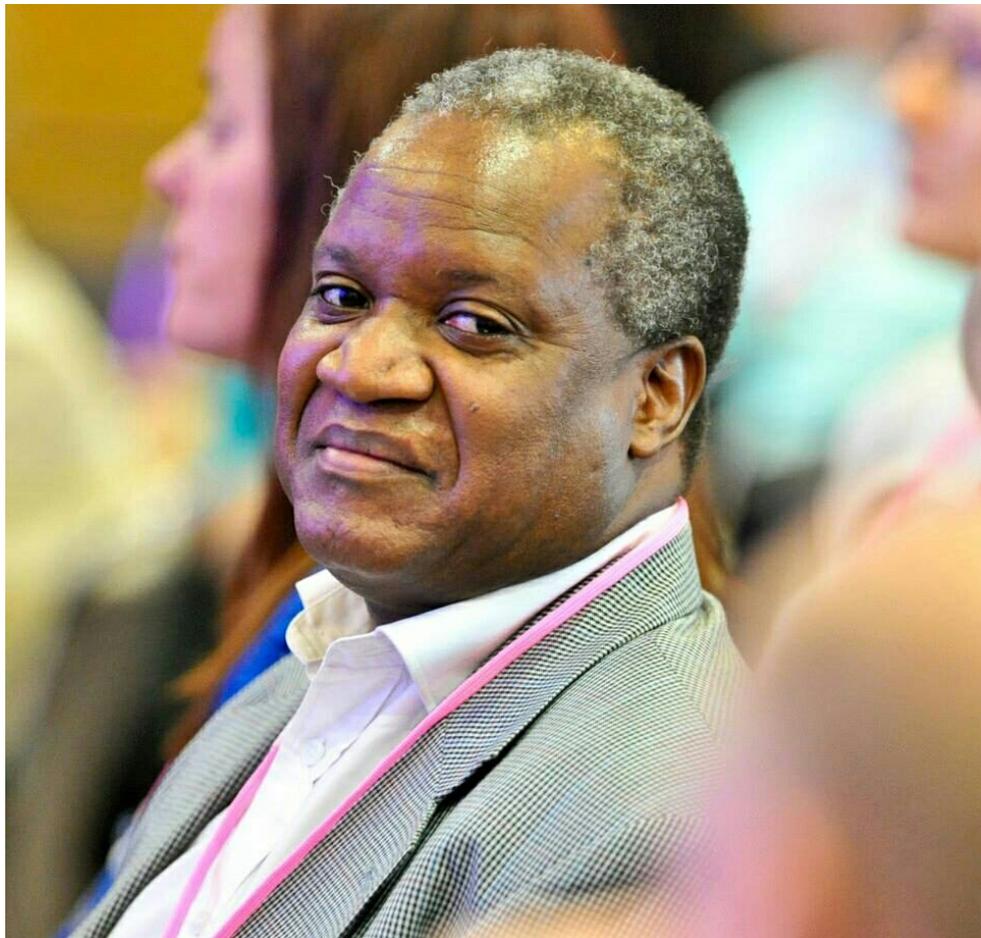
I like to see the results and outcomes in medical approaches, as well as helping contribute to the body of knowledge about difficult conditions.

#### 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:

I was involved in a project to review a blood transfusion trial on acutely ill patients. I was pleased to help the researchers change the approach so participants were not pressurised in any way to respond at a critical juncture of their health journey. I really felt valued because the contribution was accepted, and of course, it made a huge difference to patients' consent

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

My dream holiday would be a visit to Hawaii! I would of course take my wife, hoping she can survive the heat!



## Meet a researcher

### Cynthia S Srikesavan

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

Amongst other things, implementation of SARAH (Strengthening And Stretching for Rheumatoid Arthritis of the Hand), an evidence-based hand exercise programme as a web-based training course for NHS physiotherapists and occupational therapists and as a web-based home exercise programme for patients through NHS Choices, <http://www.nhs.uk>

#### What was your childhood ambition?

I was very passionate about becoming a professional singer! Though I didn't make it, I am happy that I got the opportunity to sing in my school choir all my school years.

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

Plenty of opportunities and resources for learning, supportive colleagues and a motivating work environment.

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

My previous experience with patient partners has been in Canada where we successfully collaborated to develop a new computer-game based hand function measurement tool. They helped us shape the research questions of our proposal, and provided us their perspectives of



day-to-day functioning with arthritis affected hands, and functioning of the tool. At Oxford patient partners will help to develop the patient version of SARAH as a web-based home exercise programme, as part of the Oxford CLAHRC.

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

My dream destination is Paris. I hope I will make a visit with my family next summer.

### Request for input from another CLAHRC

"As part of PhD research carried out, we'd like to learn more about healthcare professional-patient/public collaboration across a variety of quality improvement initiatives, and will feed back anonymised results to participants, providing useful learning about such working across various Quality Improvement contexts.

**We will be conducting semi-structured interviews, over the phone, Skype or in person (where feasible), which will last no longer than one hour.** If you would like to share your experiences, or would like further information/have questions, please do get in touch with Meerat Kaur, Associate Lead for Patient and Public Engagement and Involvement at NIHR CLAHRC Northwest London" [m.kaur@imperial.ac.uk](mailto:m.kaur@imperial.ac.uk).

## Bits and bobs

### Community grants available to highlight patient and public participation in the voluntary sector

NHS England's 'celebrating participation in healthcare' community grants scheme is open for applications. Grants of up to £1,000 are available to voluntary organisations that want to showcase how they have been involving patients, service-users and the public in improving health services. The deadline for applications is 21st September 2016. [Apply online](#)

### COACH

A one stop 24/7 health and care resource COACH was developed by the Oxfordshire GP Federations with NHS funding. Easily accessed trusted information needed to understand and manage health conditions and find local health and care support services. <http://dev.my-coach.org.uk/>

### Patient Experience Network National Awards

Recognises best practice in the experience of care and particularly keen to hear examples from primary care. The awards are now open for entries – the **closing date is 28 Nov 2016**. Contact [awards@patientexperience.network.org](mailto:awards@patientexperience.network.org).

The [ECRAN Project](#) (European Communication on Research Awareness Needs) aims to make understanding clinical trials easy, and tells you all about taking part in them.

### Date for your diary:

**Saturday 10 September from 1pm to 4pm 2016 the University is holding an event during [Open Doors](#) weekend for the first time.**

It will take place in the Blackwell Hall of the Weston Library, which is itself a recently opened space which enables the public to see exhibitions of some of the Bodleian Libraries' greatest treasures. Stallholders from across the collegiate University will be on hand to provide information about how members of the community can benefit or get involved in activities led by the University.

At the fair, the Pitt Rivers Museum will show off some of its collections and the Department for Continuing Education will tell people about the courses it offers. Oxford Sparks will demonstrate some of its science outreach activities, and there will be information about visiting the University Parks and Wytham Woods, which are maintained by the University and kept open to the public for free.



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