



Patient and Public Involvement Newsletter

Edition 7 - Winter 2016

CLAHRC Oxford funded study finds that early intervention services can save NHS millions.



In this issue:



A CLAHRC Oxford and Oxford AHSN study led by our Early Intervention theme lead and Deputy Director, Professor Belinda Lennox, has shown how early community intervention to tackle psychosis paves the way to shave £63 million off the societal costs of the illness.

Professor Lennox said, "Early Intervention Services are recommended in the NHS because of evidence gathered and analysed in a research setting that shows these services improve outcomes for patients and save money."

"We have now shown that each person treated in an early intervention service is twice as likely to become employed and 50% more likely to go into stable housing, compared to people with early psychosis who are treated in other services."

"People in early intervention services also spend less time in hospital, which is good news for them, and also saves the NHS money."

Read the whole story on the CLAHRC Oxford website <u>here</u>

Professor Richard Hobbs named one of the UK's most influential GPs

Richard Hobbs, Professor of Primary Care at the University of Oxford, Director of the Oxford

CLAHRC and National Director of the NIHR School for Primary Care

Research, made an appearance in Pulse magazine's 'Power 50' list, a list of the most influential GPs in the UK.

Readers of Pulse, a monthly news magazine for GPs, praised Professor Hobbs for being an 'inspirational academic, leading world class research'. They noted how his work has influenced national guidelines. For example, by demonstrating that NICE should reduce the threshold of an indicator of possible heart failure that GPS use to refer patients on for further testing.

His analysis of GP and nurse consultations, published in the *Lancet*, was praised by GP leaders as providing 'real evidence' of the current crisis in general practice after he showed that workload has increased by 16% from 2007 to 2014 and patients are seeing their GP 14% more than they did seven years ago.

Professor Hobbs is also chair of the European Primary Care Cardiovascular Society and hopes to continue to make an impact next year whilst ensuring he can still deliver clinical sessions at his Birmingham practice.

Results of our research

Out-of-hours GPs supporting home based end-of-life care.

<u>Clinical researchers</u> from the Nuffield Department of Primary Care Health Sciences and Oxford Health NHs Foundation Trust looked at how outof-hours GP services are being used to support patients dying at home.

The research, published in the British Journal of General Practice, examined the use of the Oxfordshire's GP outof-hours services over four years, finding that at least 1 in every 100 contacts was for palliative, or end-oflife, care.

Dr Gail Hayward, who worked on the study said, "We now know that lots of people are using out of hours GP services for end of life care. We need to carefully consider how we can best design services to meet the needs of this patient group."

Rapid blood test by GPs can rule out serious infections in children.

Using a simple decision rule and a finger prick to test blood, general practitioners could substantially reduce the number of ill children being referred to hospital, if the test is used on children identified as 'atrisk' of a serious infection.

The researchers claim that their findings are important for improving the accuracy of diagnosis of unwell children in primary care. Doing so could reduce the number of unnecessary hospital referrals, and ultimately, the strain on secondary health care services.

Dr Jan Verbakel, who led the study, said, "Our study showed that with this procedure, all serious infections were detected during the first visit to the general practitioner."

Full story

Full story

Do you, or someone you know, care for someone with Dementia?

Caring for someone with dementia can be stressful and sometimes carers can experience anxiety and depression. To help carers with coping strategies Oxford Health NHS FT and the Alzheimer's Society have developed and are evaluating an online therapy called 'Caring for Me and You'.

If you'd like more information, or to take part, visit <u>www.caringformeandyou.org.uk</u>

The project is being run by Oxford CLAHRC researcher, Dr Jane Fossey, but is not a CLAHRC project itself.

Urinary tract infection study scoops Royal College of General Practitioner's Research Paper of the Year award



Research highlighting an urgent need for improving how antibiotics are prescribed to pre-school children with urinary tract infections (UTI) has been recognised with a category prize at the recent RCGP Research Paper of the Year awards.

The observational study of over 7,000 acutely unwell children visiting their GP explores the notion that GPs may be underdiagnosing UTIs in children, and urges more suspicion of UTIs in the acutely unwell.

The study found that based on clinical grounds alone, GPs suspected a child had a UTI in less than one-third (31.7%) of cases that were later confirmed by laboratory tests of a urine sample.

The study, co-led by Professor Chris Butler in Oxford University's Nuffield Department of Primary Care Health Sciences, was carried out by researchers at the Universities of Cardiff, Southampton, Bristol (with co -lead Prof Alistair Hay) and in Public Health Wales' Specialist Antimicrobial Chemotherapy Unit, University Hospital of Wales and the Bristol Royal Hospital for Children. Full story

Results of our research

Brief intervention for weight loss trial

The BWeL trial wanted to find out if overweight patients would accept an offer of a referral to a commercial weight management programme and whether this would lead to weight loss.

GPs were asked to deal with a visiting patient's problems as normal, and then, at the end of the consultation, offer to refer them to a weight management programme and make the appointment while in the surgery.

12 months after people first saw their doctor, they were invited back to be weighed. About three quarters of them returned.

Overall, the group who were offered a referral to the weight loss group lost 2.4kg, about 5 pounds. Those in this group who went on to actually attended the weight loss programme lost 4.7kg, about 10 pounds.

The group who were only advised to lose weight had lost 1.0kg, about 2 pounds.

This is a bit more than we would have expected, suggesting that even if the doctor does something as simple advising weight loss, this could motivate people to try.

The results tell doctors that it really is OK to bring up weight out of the blue and that patients will think it appropriate and helpful if they do.

They tell doctors that doing more than that, offering and then making a referral while in the practice will help their patients lose weight and that will

"While you're here, I just wanted to talk about your weight " said the doctor to their patient.

The BWEL (Testing a Brief intervention for WEight Loss in primary care) trial tested the effect of GPs advising people who are overweight about losing weight. At the end of a consultation about another health problem, GPs spent just 30 seconds advising their patient that the best way to lose weight was to attend a weight loss programme and offered an NHS referral to a weight-loss group in their local community.



a parallel, two-arm randomised trial. Aveyard P et al. Lancet 2016: DOI: 10.1016/S0140-6736(16)31893-1

lead to health benefits.

For patients, the results tell us yet again that asking for a referral to a weight loss programme is a good idea if you want to lose weight.

HEALTH SCIENCES

Professor Paul Aveyard who led the study said, "On average, people consult their doctor five times a year meaning there is huge opportunity to deliver this low cost intervention on a large scale."

Congratulations to the BWeL study team whose Lancet paper describing this research achieved international media attention and an Altmetric score of 1,331, making it one of the most talked about research studies of the year. Full story

Local news

Oxford to get new Mental Health focussed Biomedical Research Centre

People affected by mental illness will benefit from a new Biomedical Research Centre (BRC) based at research hubs across the Warneford Hospital site.

The new BRC, awarded £12.8 million by the Department of Health, is a partnership between the University of Oxford and Oxford Health NHS Foundation Trust and will focus on three main research themes: precision psychological treatments, adult mental health and ageing, and dementia

The news comes after an announcement that the existing Oxford Biomedical Research Centre (BRC) will receive funding for a further five years.

Read more here.



Oxfordshire's Commission on Health Inequalities publishes recommendations.

The recommendations aim to narrow the health and wellbeing gaps which divide some communities in the county.

The Commission was set up earlier this year by the Oxfordshire Health and Wellbeing Board to tackle inequalities which have a significant impact on people living in poverty and those who are more vulnerable.

Read more here.

Oxfordshire's healthcare transformation programme.

Please check out a new website which carries the latest information and updates about the programme.

The website includes opportunities to get involved and have your say in shaping the way high quality services are delivered in Oxfordshire in the years to come. It includes information on the partners involved in the programme and a summary of the six 'Big Conversation' roadshows held in July and August which were well attended.

Click here to view the website.

The University of Oxford has topped the *Times Higher Education* World University Rankings

This is the first time in the 13-year history of the rankings that a UK institution has secured the top spot.

The rankings judge research-intensive universities across five areas: teaching, research, citations, international outlook and knowledge transfer.

In total, UK institutions took 91 of the 980 places, with the University of Cambridge (fourth) and Imperial College London (eighth) also making the top ten.

NIHR Clinical Research Network delivers Thames Valley Health Research Awards

Patient Leadership: The Diabetes Reference Panel.

The Diabetes Reference Panel is a voluntary group of members of the public who have given their time to advise researchers on patient access to diabetes research.

Patient Leadership: Bernard Gudgin, Gordon Moultrie and Jean Simmonds.

Bernard, Gordon and Jean have freely given their time to make sure the patient and public voice is heard and influences the work of the NIHR Clinical Research Network Thames Valley and South Midlands.

Innovation in Patient and Public Involvement: Quality Time Study Team.

Quality Time is a research study based in the Emergency Department (ED) at the Royal Berkshire NHS Foundation Trust. It uses a qualitative methodology called Experience-based Co Design (EBCD) which gathers the experiences of the Emergency Department from a patient, carer and staff perspective and they work together as equals to co-design improvements in the delivery of healthcare

Training topics



New health research 'explainer' tool

A new interactive '<u>Understanding Health Research</u>' <u>website</u> has just been launched.

The site is designed to more easily explain complex health research.

Despite advances in open access publishing making scientific health research easier to access, the style and language of published research papers can prove inaccessible to non-specialist or non-scientific audiences.

With health research in the news every day, and with patients being more involved in decision-making, it is important that patients and the public have the support and ability to find and understand health research.

The Understanding Health Research tool is designed to help anyone interested in understanding a specific piece of published health research.

The website asks the user to answer a series of questions about a piece of research and provides guidance on what these questions mean.

The questions aim to encourage critical thinking about the type and quality of the research, such as funding sources, peer review and ethics, and guide the user towards forming an evidence-based opinion about the research.

Succinct, plain English introductions of complex scientific concepts are also provided, as well as links to resources promoting health literacy.

Dr David Ogilvie, from the University of Cambridge, said, "More and more scientific papers are out there on the internet, freely available for anyone to read. But providing access to papers is not the same thing as making research accessible to people.

Tools like Understanding Health Research can help make science more democratic and more useful by making it easier for people to engage with it, whether they work with health evidence in their jobs or are just interested citizens."

The team of academics who created this website includes our own Prof. Susan Jebb.

Read more here.

NHS National Institute for Health Research

How well do you #KnowYourResearch?

The NIHR have launched a quick quiz to test their knowledge of health research findings.

While it's mainly aimed at health researchers, anyone can have a go and test their knowledge – the results might surprise you!

Take the quiz here.

Patient Voice in Primary Care Web Seminar

The Patient Voice in Primary Care web seminar was so popular that all fifty places were booked.

Paul Devlin, Chief Executive of the National Association for Patient Participation (NAPP) shared ideas and resources and you can see these on the <u>Patient Voice South website</u>, as well as a recording of the event where you can 'listen-again'.

NHS PPI Courses

If you do any PPI work in the NHS then you can make use of courses specifically designed courses by the NHS to help you make more impact..

You can find them at:

https://www.england.nhs.uk/ participation/learning/

Meet a researcher

Dr Geoff Wong.

Geoff is a GP in Swiss Cottage, north London and a Clinical Research Fellow in the Nuffield Department of Primary Care Health Sciences.

His research centres on making sense of complex health and social interventions in which human agency is key.

Tell us about the research you are currently working on?

I'm currently working on a project to develop reporting standards, methodological quality standards and training materials for realist evaluations.

Realist evaluation is an approach to research that seeks to answer questions such as why interventions work, for whom, in what circumstances, how and to what extent.

What was your childhood ambition?

I was curious about most things and can't remember being that focused on any one ambition. Perhaps that is why I'm a GP – you can have an interest in anything as in the NHS pretty much everything is a GP's problem.

What do you like most about working at Oxford University?

This will sound cheesy, but it is the wonderful people you get to work with. I love the helpful and can-do attitude we have in our department. It is a great place to work.

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 on a number of projects where the insights that have been shared by PPI members have been so invaluable. Sometimes these are completely unexpected insights.

I'm not going to focus on specific projects, but instead want to say that the greatest successes have come from the approaches the research team have brought to such meetings.

The research team needs to set the stage right – that we are all equals and are here to learn from each other.

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

What's a 'holiday'?

DPhil Student Jack reaches the FameLab final

Surfer Jack explains why he moved from sunny Australia to freezing England, and puts some of the issues surrounding over diagnosis of cancer into perspective.

<u>FameLab</u> is an international competition, designed to engage and entertain by breaking down science, technology and engineering concepts into three minute presentations.

Click here to see Jack in action at FameLab.

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Meet a PPI Contributor

Martin Wood

Tell us about the projects you are currently involved with:

For the last few years I have been involved with the Oxford Renal Cohort Study, which is looking at the incidence and development of kidney disease in a target group of over 60 year olds. It is with studies like this that we will help the NHS prepare itself for the needs of our growing and changing population.

I am also Vice Chair of the Six Counties Kidney Patients Association supporting

patients in Oxfordshire, Bucks, Berks, Wilts and parts of Northants and Gloucs and I help keep our members informed of research in the renal area and the opportunities for them to get involved.

Why did you first get involved in medical research?

I have seen the amazing developments that research has brought to the treatment of kidney patients over the last fifty years. My mother was one of the lucky ones to be treated on an "artificial kidney machine" in the mid 60s. I myself had the incredible good fortune to receive a successful kidney transplant at the excellent Churchill Hospital in 2011. Having seen how research has changed the lives and the life expectancy of kidney patients, I want to see more and even better changes carried forward for the next generation.

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

It gives me a chance to show my appreciation and give something back for the superb care and life-changing treatment I have received.

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:

While investigating the incidence of kidney disease within the Oxford Renal Cohort Study, some members of the target group will be diagnosed as having the disease from the routine tests they undertake from time to time. They may have had kidney disease for many years without knowing it. This is valuable information for giving a better understanding of the incidence of the disease within the wider population, but it may also have major implications for the individual concerned. I clearly remember how I felt when I received my diagnosis many years ago. I trust that from my personal experience of this and as a result of my input on this point there is better appreciation of the impact of this diagnosis and the sensitivity with which it is handled.

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

My dream holiday would be somewhere out of the reach of WiFi and with no internet connectivity. I would take the family for a totally relaxing break where nobody felt the need for reading their emails or checking their Facebook updates or Twitter feeds every few minutes. Oh.... the good old days!



Get involved nationally

National Specialties PPI Toolkit launched by the Clinical Research Network

<u>Read here</u> about good examples and how PPI has made a difference to studies.

Open Up About Medicines

Do you take all the medicines you are prescribed?

Click on <u>this link to watch a YouTube</u> video about this campaign to make sure patients get the most from their medicines.

It involves GPs, pharmacists and patients having conversations that lead to them taking home only the medicines they need.

The Healthcare Value Partnership

The <u>Healthcare Values Partnership</u> engages in research projects weave together academic expertise and healthcare practice to pursue the conceptual questions and practical concerns which inform healthcare.

They particularly pursue partnerships which unite humanities, social sciences and healthcare in practical service of the common good.

The Healthcare Values Partnership is led by Professor Joshua Hordern of the University of Oxford who collaborates with a range of colleagues_in Oxford and elsewhere.

The ethos of the partnership is to develop working relationships

The Cicely Saunders Institute has launches Public Involvement forum

This Public Involvement Forum is for research in palliative care and rehabilitation.

This is an online <u>Forum</u>, in collaboration with King's College London's existing patient and public involvement members. It is the first of its kind in palliative care and rehabilitation research.

Find out more here

Visit the forum here



between patients, researchers, healthcare practitioners, managers and policy makers to explore questions of value in healthcare today. They welcome new conversations and partners who share this focus.

For those who enjoyed the ethics seminar with Dr Andrew Papanikas that we ran for our PPI Contributors you may be interested to know that Dr Papanikas is part of the Healthcare Values Partnership.

@NHS Twitter account gives patients the chance to tell their stories

The **@NHS** Twitter

account has launched to lift the lid on the NHS through the voices of the people on its frontline.



@NHS will see a different NHS patient or member of its 1.3 million staff become curator each week over a <u>three month pilot</u> and report first hand their experiences of the health service. Jane Cummings, Chief Nursing Officer for England, said: "This is a fantastic opportunity for our much valued patients and NHS staff to hold a magnifying glass up to the system"

Have your say on the sale of sugary drinks in hospitals

NHS England is asking patients and the public to share their views on the sale of sugary drinks in hospitals by responding to <u>its consultation on the subject</u>. You can give your views on the consultation up until 18 January 2017.

A new involvement hub helps patients and the public get involved in NHS England's work

NHS England has launched an Involvement Hub where patients and the public can find out about opportunities to get involved in NHS England's work, and other parts of the NHS.

The hub also provides information about how people are already getting involved and training that is available for patient representatives.

Follow the link to the hub

Bits and bobs

Heart in hand...

This is a 13 minute talk from Tal Golesworthy, who is a boiler engineer.

When he needed surgery to repair a life-threatening problem with his aorta, he mixed his engineering skills with his doctors' medical knowledge to design a better repair job.

Video here.

GP online services help patients to manage their health

NHS patient, Graeme Johnston, has rheumatoid arthritis and needs regular blood tests and a broad range of medication to manage his condition. His surgery offers online record access and he can monitor and review his progress wherever he is.

He finds this particularly helpful when visiting his specialist as they do not have access to his medical history. Graeme says in <u>a recently published video blog</u> "Online test results, current and past, are the most important tool in my self-management." To sign up for <u>GP online services</u>, please visit your surgery's website or talk to your GP receptionist. If you would like further information, please email <u>england.patient-online@nhs.net</u>

The history of NHS reform

This interactive timeline brings 70 years of reform to the National Health Service to life, charting the evolution of this public institution from its inception in the post-war years through to the present day.

<u>nhstimeline.nuffieldtrust.org.uk</u>

Patient Experience of Participating in Research

In early 2016 the central PPIE team and colleagues across the CRN ran a national pilot patient satisfaction survey about patient experience of participating in clinical research

The report demonstrates what can be achieved in terms of collecting, presenting and using data of this kind

This Report, prepared by the NIHR Clinical Research Network, is now available from the Clinical Research Network - <u>click here.</u>

Research Involvement and Engagement Journal

This is interdisciplinary, health and social care journal may be of interest to some. It focusses on patient and wider involvement and engagement in research, at all stages.

Visit the journal here

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