ppi pulse

Patient and Public Involvement Newsletter

From the NIHR CLAHRC Oxford and the Nuffield Department of Primary Care Health Sciences, University of Oxford.

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NUFFIELD DEPARTMENT OF
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HEALTH SCIENCES

UNIVERSITY OF OXFORD

NIHR | Collaboration for Leadership in Applied Health Research and Care Oxford

About PPI Pulse

PPI Pulse is produced by the Nuffield Department of Primary Care Health Sciences (NDPCHS), University of Oxford, and the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford.

We also produce, with other partners, the 'Involvement Matters' bulletin, filled with current training and other opportunities to get involved in research, health services and commissioning. Involvement Matters is sent out on a roughly monthly basis, depending on the available opportunities.

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Working groups: the local and the national

By Lynne Maddocks, PPI Co-ordinator, NIHR CLAHRC Oxford, on behalf of the Thames Valley Working Together Group

In all of our work involving the public in our research we are aware of the value of providing people with enough knowledge to enable them to carry out the tasks asked of them and enough skills to feel that they are confident to do so. Consequently, we have made learning and development opportunities a high priority for both staff and members of the public.

To make the best use of our resources we have also focused on providing these learning and development opportunities in partnership with other organisations in the locality who have similar aims.

So, in 2019 we are working with the two NIHR Biomedical Research Centres in Oxford to run a programme of workshops for the involved public based on the research cycle.

Each workshop will cover a different stage of the research cycle and discuss ways in which patients and members of the public can get involved. All PPI Contributors living in the Thames Valley who are interested in research are welcome to book for one or more of the remaining workshops. For the first time this year we are developing an exciting innovation for those who live further afield or who were not able to make the workshops, in that we will be putting the workshops online.

Running in parallel are another set of workshops that are not just about research and which are open to both the public and researchers. So doctors might find themselves sat next to a patient, a researcher might find they sit near a member of the public, a health commissioner might be learning from someone in health education. All of this mixing up helps to highligh the shared principles of professionals and public working together in health and care research. It also enables people to fully appreciate from each other the strengths that each 'side' bring to the party.

These workshops are arranged by the Working Together group, who also produce Involvement Matters, the monthly ebulletin that goes to all of our involved public. Full details of the learning and development programme for 2019 can be found here (bit.ly/2OZyEsR) with information on how to register.

In addition I, as the NIHR CLAHRC Oxford PPI Coordinator, have represented the organisation on a national steering group to develop a new website for learning and development in Patient and Public Involvement in research. This website is something that I knew was needed when I took up post four years ago. You can see the website at: http://learningforinvolvement. org.uk .

It is dedicated to learning and development for public involvement in health and social care research: what's it all about and how to do it well. It brings public involvement information and resources (such as guidance, websites, videos, articles and blogs) and training together in one place.

To add to the site, perhaps recommending an article or video clip, or to advertise a forthcoming course, click the ADD button. You will need to register or log in to do this. Resources or training opportunities will then be displayed and emailed to the site's followers.

The Learning for Involvement website is hosted by INVOLVE, and relies on your contributions, so next time you find a book, article or video that has been really useful, or are hosting an event or workshop on public involvement that you would like people to attend, please take the time to share it here.

local research news

Awards galore for medical-psychiatric multimorbidity researchers

Theme manger and senior Clinical Researcher Dr Jane Walker won the 'Don R. Lipsitt Award' for Achievement in Integrated and Collaborative Care by the Academy of Consultation-Liaison Psychiatry.

The award recognises an individual who has demonstrated excellence and innovation in the integration of mental health with other medical care through collaborative care.

Additionally, the Integrated Psychological Medicine Service team – who support a number of CLAHRC projects in the theme – won a prestigious 'Psychiatric Team of the Year' award at the Royal College of Psychiatrists Awards on 7 November 2018. The annual awards, which mark the highest level of achievement within the field of psychiatry, were presented by BBC TV presenter Victoria Derbyshire.

The Integrated Psychological Medicine Service team scooped the award in the non-age specific category, and was praised for delivering a novel way of providing psychiatric and psychological care to people who are physically ill. Speaking of the team and their work, the judges said: "It is valued by patients, carers and hospital colleagues, and has been highlighted as a beacon of excellence."

CLAHRC Director awarded CBE

Congratulations to Professor Richard Hobbs, Head of the Nuffield Department of Primary Care Health Sciences and Director of the National Institute for Health Research School for Primary Care Research and the NIHR CLAHRC Oxford, who was appointed CBE for services to medical research in the 2019 New Year's Honours list.

Richard's research interests focus on cardiovascular epidemiology and clinical trials, especially relating to vascular and stroke risk, and heart failure. His research has impacted on international health policies and clinical guidelines, with over 350 original papers in peer reviewed journals, 28 book chapters and 13 edited books.

Patient Forum: Oxford AHSN and CLAHRC mental health services spotlighted by NHS

The Improving Access to Psychological Therapies (IAPT) Network aims to continuously improve psychological therapies for adults suffering with common mental health disorders, such as anxiety and depression. The service was developed by Oxford Academic Health Science Network (AHSN) in 2014 and later received support from CLAHRC Oxford.

Recently, the NHS highlighted the work of the IAPT Network Patient Forum as part of a series of mental health case studies.

Including patients in the development and improvement of IAPT services has a been a key focus of the network. This was achieved through a patient forum.

The objectives of the patient forum included offering feedback and suggestions for improving IAPT services, consulting on proposed work programmes and projects, and prioritising, shaping and driving aspects of future projects.

The Patient Forum now provides input into all aspects of the IAPT Network's activity – shaping and informing its work with the aim of continuously improving patient outcomes across IAPT services.

Read more on the NHS website at: **https://bit.ly/2I7cwLP**

And find out more about the network at:

www.oxfordahsn.org/clinical-networks/depression-anxiety/about-the-network

One million bugs bashed by citizen scientists

An award-winning Oxford-based international project to tackle antibiotic resistance has achieved its one millionth classification.

BashTheBug is an initiative based in the University of Oxford's Modernising Medical Microbiology Group at the John Radcliffe Hospital and supported by the National Institute for Health Research (NIHR) Oxford Biomedical Research Centre (BRC).

It is a global citizen science project, rRun on the Zooniverse platform, the global citizen science project involves around 14,000 volunteers from all over the world. It aims to help researchers determine which antibiotics, and at which doses, can be used to treat different strains of tuberculosis.

TB is responsible for more deaths each year than any other infectious disease and recently strains that are resistant to the standard six-month treatment course have emerged.

Bash The Bug is part of the international CRyPTIC project, which is collecting samples of the organism that causes TB from up to 100,000 people globally over the next few years. Each sample of tuberculosis will have its whole genome sequenced and its susceptibility to a panel of 14 different antibiotics will be tested by volunteers who test the samples and report their findings.

Volunteers around the world test the samples and report their findings.

Dr Philip Fowler, Senior Researcher at the NIHR Oxford BRC who leads the project, said: "We've reached the millionth classification much quicker than I expected. It is a sign of how exciting it is to be involved in a citizen science project like this, with each person making a small contribution to a larger, more powerful whole.

"Having thousands of volunteers participating has resulted in pleasingly consistent results, and through our talk boards, they give us instant invaluable feedback."

You can help 'bash the bug' yourself, at: bashthebug.net

Recurring testicular tumours "missed" by current diagnostic tests

Of the seven in 100,000 men diagnosed with testicular cancer each year, most are under the age of 35. 98% live for more than ten years after surgery, but the number of relatively young survivors means that ongoing surveillance for relapse is particularly important.

Alongside clinical examination and imaging, blood tests which look for the presence of specific biological markers are often used by doctors to diagnose recurrent disease.

Now research from a team of Oxford University researchers has cast doubt on the use of these biomarkers due a lack of enough good quality evidence for their use.

The researchers systematically reviewed data from more than 1,200 patients collected by nine different research studies to assess the performance of these biomarkers in diagnostic tests for testicular tumours.

These studies assessed three biomarkers blood ⍺-fetoprotein (AFP), human chorionic gonadotropin (HCG) and lactate dehydrogenase (LDH) – all of which are currently cited in European guidelines for testicular cancer surveillance.

The results of the included studies were mixed. While two of the markers (AFP and HCG) showed some diagnostic potential, many recurrent tumours would be missed using these markers alone.

Lead author, Dr Brian Nicholson, a clinical researcher at the Nuffield Department of Primary Care Health Sciences, University of Oxford, said: "There's a lot of debate about how to make sure patients are followed up safely after a treatment for cancer to make sure that cancer is detected as soon as possible if it comes back. Important questions include what tests to do, how often they should be taken, and importantly for us whether they could safely be done in general practice?

What this review tells is that there is a great uncertainty over the current use of blood tests when following up patients who have survived testicular cancer, so it would be difficult to give GPs clear guidance."

The study received funding from the National Institute for Health Research (NIHR) Community Healthcare MedTech and In Vitro Diagnostics Co-operative and was published in the journal Cancer Epidemiology.

PPI news & resources

Advanced heart failure priority setting partnership update

Dr Clare Taylor, NIHR Academic Clinical Lecturer and GP, NDPCHS, University of Oxford
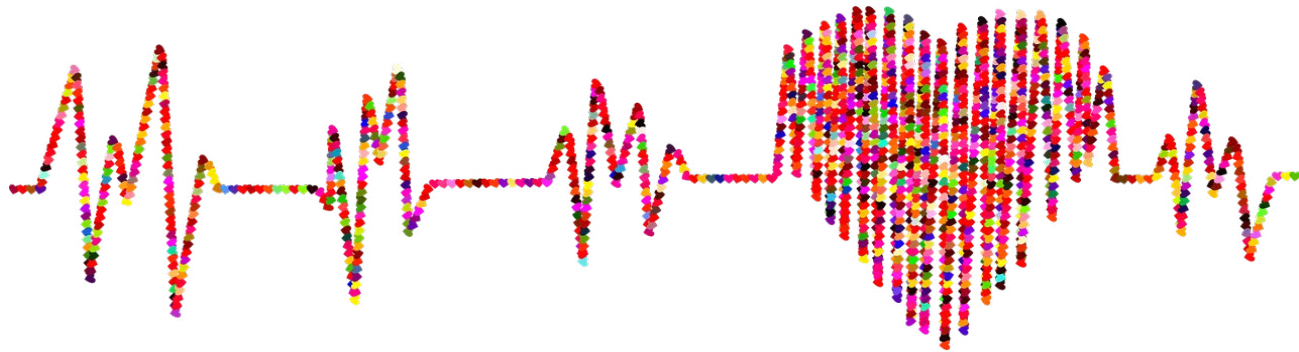
Heart failure is a condition which occurs when the heart can't pump efficiently enough to meet the needs of the rest of the body. People can experience breathlessness, fatigue and leg swelling. There are lots of treatments which can help people to feel better and live well with the condition for many years. However, in the advanced stages of the disease, people with heart failure can start to experience worsening symptoms, require extra medication and sometimes need to go into hospital.

Research priorities for most clinical conditions, including heart failure, are usually set by researchers, funders and the drug industry. We wanted to find out what matters most to people living with advanced heart failure to help us decide where research is needed in the future. To do this, we used the James Lind Alliance method to gather research priorities from the people most affected by the condition – patients, their carers and the doctors, nurses and other healthcare professionals who look after them.

We carried out two surveys. The first survey asked for ideas on what research questions were needed in the area of advanced heart failure. We had over 450 questions submitted. We then spent time merging the questions, taking out duplicates and checking the literature to see where questions had already been answered. Following this process, we had a list of 65 summary questions. Then we carried out a second survey asking people to choose their top 10 from the list of summary questions. This allowed a short list of 25 questions to be generated.

The final stage of the process was a workshop, held in Birmingham on Wednesday 13th March 2019. Thirty participants attended the day including patients, carers and a range of healthcare professionals such as nurses, a physiotherapist, a hospice manager, GPs and a cardiologist. We held the workshop at a spacious location, easy for people coming from all over the country to access and with lots of break out rooms. The day was facilitated by

three advisers form the James Lind Alliance, who guided participants through a complex process of prioritising and re-prioritising the list of 25 summary questions until we finally reached a 'Top Ten' of research priorities for advanced heart failure research.

We are now writing up the findings for publication and plan to launch the 'Top Ten' soon. This will be circulated to the wider advanced heart failure community including researchers and funders. We hope this project will put the key priorities of people with advanced heart failure, their carers and clinicians involved in their care at the centre of research for the coming decade and beyond. We are very grateful to the patients and carers who contributed to this project. Their generosity with their time and genuine enthusiasm for what we are working to achieve was very much appreciated by the study team.

The NHS Long Term Plan – what about PPI?

Lynne Maddocks, PPI Co-ordinator

You may well have heard in the national media about the launch of the NHS Long Term Plan at the start of 2019. It has three areas where it aspires to bring benefits to patients:

1. Making sure everyone gets the best start in life.
2. Delivering world-class care for major health problems.
3. Supporting people to age well.

It then describes in more detail the ways in which it intends to make this work happen:

- Doing things differently
- Preventing illness and tackling health inequalities
- Backing our workforce
- Making better use of data and digital technology
- Getting the most out of taxpayers' investment in the NHS

The work of embedding the new aspirations into the NHS has been allocated to the Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs), which are groups of local NHS organisations working together with each other, local councils and other partners. At the recent symposium meeting of the NIHR CLAHRC Oxford our expert panel focused on the work of these partnerships.

Between January and April this year the STPs supported by local Healthwatch groups and Age UK are tasked with ensuring that the views of patients and the public are heard in developing the local detailed plans. The national plan was consulted on and received 2,000 submissions from individuals and from groups representing the views of 3.5 million people.

As the plan promises more money to the NHS it might be assumed that it is universally

welcomed. However, that is not necessarily the case. For example, many have said it is not a plan but an aspirational statement.

Simon Denegri, the NIHR National Director for Patients, Carers and the Public, was disappointed that it did not give due regard to the role of research and innovation in driving forward a modern NHS which meets the priorities and needs of people. He also points out that research is relegated to a two page sub-section (the full document is 136 pages). More than that though is his view that that there is a "lack of a coherent vision of the partnership that NHS leaders and indeed Government Ministers want to have with patients, carers and the public in creating a healthy society and an innovative and efficient NHS at its centre. And they are in too much of a hurry to deliver their utilitarian view of life to find out. They are certainly not invested in the principles of public involvement as one of the ways we build a sustainable NHS."

He concludes, "It is certainly true that the noise and activity around public involvement, co-production has increased massively in the last few years with great work being done in many places. But it remains too variable and fragile an activity in the current environment for it not to be a deliberate and detectable act that is required of and open to scrutiny in every health and social care organisation. For the moment, it has gone missing in action."

Don Redding, Director of Policy and Partnerships of National Voices echoed this in his blog on the plan, stating "absent is any sense of proper engagement of communities in tackling the big health challenges[…] we will again see token, rushed 'engagement' in the next few weeks

as the ICSs (and STPs) nail their new five year plans in place. There are no apparent plans to subject the Plan as it now is to any further challenge or consultation; to consult on its implications for the NHS Constitution; or to involve the public in securing a new Mandate for NHS England. Mystery still surrounds the 'NHS Assembly' which will start in the spring. What is it for?"

Similarly, David Gilbert, a mental health service user with 30 years of experience as a patient and public engagement practitioner writes in The Future Patient Blog: "If you're looking for signs that the ten year forward plan will foster patient leadership, co-production or meaningful engagement with patients/users, carers, communities or citizens, then, er, don't. Gone is any pretence at 'harnessing the community's resources' or any remaining pledge to work with patients and the public as equal partners in decision making – whether in improvement work, governance at local level (for example in integrated care organisations) or at policy level, let alone in the workings of the (allegedly non-merging) NHS Improvement/NHS England.

Power in the system remains entrenched in the hands of the professional elite – clinical, managerial and policy makers."

Why not read the plan and decide for yourself?

www.longtermplan.nhs.uk

PPI in the Oxford medical school

By Ben Clyde, Co-ordinator for Patient Involvement in Medical Education, NDPCHS, Univeristy of Oxford

"It can't be that bad." "…exaggerated psychological response to pain." These are the comments, from two of her doctors, that propelled Rachael into medical education. Rachael is the first to acknowledge that the same doctors also provided good and empathetic care, but as she points out, "a few ill-chosen words, probably said on the spur of the moment, are the ones we remember."

Rachael works regularly as a Patient Tutor with medical students in Oxford, helping them to understand illness and treatment from a patient's perspective. This is a key aim of PPI in medical education, and to that end, patients and carers teach in several clinical specialities.

In Neurology, patients with conditions such as multiple sclerosis and Parkinson's disease show students how to spot signs (such as different kinds of muscle stiffness) that are important for diagnosing and distinguishing neurological problems. The students get to practise with real patients in a dedicated teaching environment rather than in a clinic where the focus is on patient care. And the patients can teach students exactly how, and how hard, to bend a wrist or yank a leg in order to elicit the sign without causing pain.

In Gynaecology, healthy non-clinicians use their own bodies to teach pelvic examinations (see the below article by Helen Salisbury and Elizabeth Swift). They teach technical skills and, just as importantly, they explain what a huge difference the doctor's demeanour and choice of words make. Finally, they examine the students' competence at the end of the module.

In both cases, the non-clinical educator provides a vital subjective dimension that even the best clinical tutor cannot offer. The professor can't tell whether students are hurting you or whether you feel listened to and respected – only you can do that.

Medical students need to learn a huge amount of factual knowledge. In Oxford this is taught over three pre-clinical years of intensive scientific study. Partly for this reason, medical school graduates are in danger of adopting an overly mechanistic approach, which sees the body as a machine and medicine as a process of tracing and fixing faults, much as one would with a car. A new initiative in Psychiatry brings together a consultant and a patient to give a pre-clinical lecture on mood disorders. Once more, the patient's experience takes centre-stage.

Students come to appreciate that treatment is not just about identifying a chemical imbalance in the brain and correcting it with drugs: it is about understanding how the disease is affecting the patient, and working with the patient's concerns and priorities to formulate a suitable care plan.

Whilst this joint patient–doctor approach may seem obvious, it does require a change in mindset for some students and clinicians. That is why it is important for patients and the public to be involved in setting the culture of the whole course as well as in teaching individual sessions. How should we select medical students? What should be on the curriculum? What should we assess at the end of the course, and how? Non-clinicians have a role in thinking about all of these questions.

There are pockets of truly excellent PPI in the medical school. There is also plenty of room for growth. We are keen to expand our work – though it's important to note that, as yet, there are only limited opportunities for involvement.

Anyone with an interest in this area is invited to contact the PPI co-ordinator, Lynne Maddocks on

ppi@phc.ox.ac.uk.

Going one step further: a collaboration to teach and assess gynaecology skills

By Helen Salisbury, Honorary Senior Clinical Lecturer in COmmunication Skills, NDPCHS, and GP. Elizabeth Swift is a Clinical Teaching Associate in Oxford and a Lecturer in the Humanities.

Patients need their doctors to be able to perform sensitive and skilled clinical examinations, not least gynaecological examinations.

Traditionally, students have been taught at most medical schools using a plastic pelvic model and their skills

are further developed in outpatient clinics. The clinic is not, however, an ideal learning environment. Many patients are apprehensive, students are nervous, and supervising clinicians are focused primarily on diagnosis, and treatment.

In 2007 our medical school established a gynaecology teaching programme, which trains lay people to become Clinical Teaching Associates (CTAs) who teach students how to conduct a sensitive and effective pelvic examination using

their own bodies.

The CTAs, are trained to teach the technical, practical, and communication skills needed to perform a cervical smear, a bimanual pelvic examination, and a related consultation. In a dedicated 2-hour session for two students at a time the CTAs first demonstrate a consultation about cervical screening followed by a speculum and bimanual examination with one CTA taking the role of the doctor and one of the patient. The students then each replicate the consultation and examination, taking the doctor role.

Thus, every student learns to conduct a consultation and a pelvic examination while receiving expert feedback.

The teaching has been well received by students, but we wondered whether the assessment, an Objective Structured Clinical Examination (OSCE), which still used the plastic pelvic model, could also be improved. There was a lack of alignment between teaching and assessment and, more importantly, we thought that information from the person being examined was crucial to any judgement about a student's skills and competence. We did not doubt that the CTAs would assess students' skills at least as consistently and accurately as consultants but we felt that it was unfair to ask the small team of CTAs to assess, as it would involve 28-30 students performing a pelvic examination in one afternoon.

Clinical teaching associate's perspective

When the possibility of leading the OSCE was raised with the Oxford CTA team, it seemed like a logical step and we were surprised that it had taken so long for us to become involved. How could the students' skills in communicating with and examining

people be assessed properly when they were being observed carrying out examinations on a plastic model? More specifically, how could the consultant-examiner know whether the student had conducted a "comfortable" speculum examination?

As CTAs, we were sure that we wanted to go ahead with this, we just had to work out the details. The main uncertainty that we needed to address was at what point it would be acceptable to "step in" if a student were making a mistake that would be likely to cause the patient pain, while still maintaining exam conditions and parity. In conversation with clinicians we established guidelines on where to draw this line, and we ensured that such a decision could come from both the patient-CTA and the observing, chaperone-CTA.

Where we are now

In the current OSCE station, one CTA acts as the patient throughout, while another CTA observes the consultation and acts as the chaperone during the physical examination. Each CTA grades the student independently; the chaperone-CTA's mark sheet is very detailed, covering hygiene, appropriate language, information-giving, and technical skill during the physical examination.
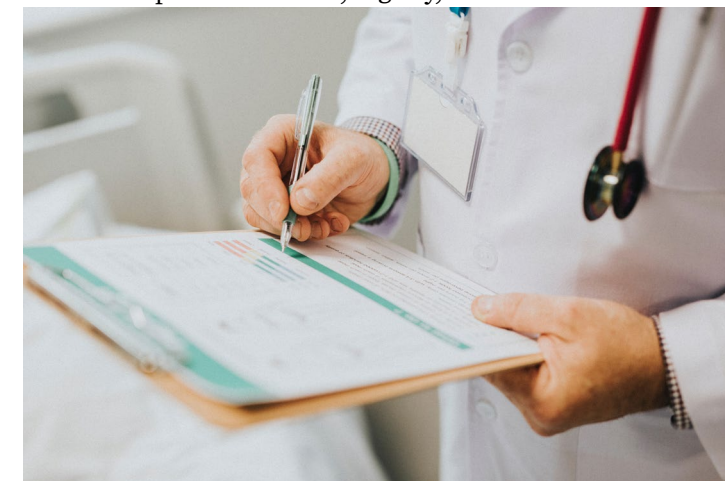
The patient-CTA's mark sheet is simpler, with broad areas covering patient comfort, dignity, and communication.

CTAs swap roles and maximum

number of physical examinations for each CTA in an afternoon would usually be six (although in practice it is often fewer).

What we have learnt

More things are possible than you may initially imagine. The clinicians in the team assumed that it would be inappropriate to ask the CTAs to take part in the formal assessment of students' skills. Although they were aware of the deficits of the old examination, they underestimated how strongly the CTAs felt about the importance of an appropriate, patient-centred assessment of students' examination skills. The success of the teaching and assessment programmes has depended on developing mutual trust and respect, between the CTAs who work closely together and between clinicians and CTAs. The CTAs are empowered to make decisions about what will and will not work for them and set limits on what is acceptable. The clinicians trust the CTAs to let them know if arrangements are not working for them, without feeling any pressure to undergo more examinations than is comfortable. The students are now taught and tested on their gynaecological examination skills by experts in the performance and experience of this procedure. A skilled observer, however expert, can by definition only comment on the technical, observable proficiency of the student and not on the experience of the patient. Our current teaching and assessment takes account of both perspectives and we believe this prepares students well for their careers as doctors, in gynaecology, and in wider clinical practice.

contributor/ Interview

Georgina McMasters was born in Maidenhead, and while she spent some time away for work, including studying for her law degree at Nottingham University, she always found herself back in the Thames Valley sooner or later.

By training, Georgina is a qualified solicitor with 23 years spent working full time in the Magistrates' Court's Service. Most of this time was spent in criminal law, especially youth crime, as well as some family and road traffic work.

After developing rheumatoid arthritis (RA), Georgina worked part time for 10 years. Eventually the RA progressed enough that she had to take early retirement.

How did you find taking early retirement?

Very difficult. I think when you work for a long time, and you've liked your job, you value yourself by having something worthwhile to do, so that was difficult.

But the doctor who did my first hip replacement turned out to be the Medical Director at my local hospital. He asked me if I'd join their patient panel. I had been critical of the hospital and the patient panel had been, in his words, 'packed with people who are grateful, I want somebody who isn't.'

And that's how you first got involved in PPI?

Yes, I joined the patient panel at probably the tail end of 2007. And I am involved in quite a lot of things there now, including environment inspections, quality rounds and service feedback.

And then one of the people I was working with mentioned the Clinical Commissioning Group Authorisation Project was looking for public volunteers, so I volunteered. It was fascinating and gave me an insight into the changes that were going on in the health services.

Things snowballed from there, because once your name's in the hat, it gets passed on!

What types of things are you doing now?

A mixture of primary and secondary care involvement.

I took part in some CQC inspections when they were trying to improve the image of CQC. I was involved in five hospital inspections with CQC. It was probably the most useful education you can have for having anything to do with health services afterwards.

I am involved with Quality Assurance for Specialised Commissioning in the region. I also contribute 'patient stories' to Health Education England's management courses.

Somewhere along the line I was roped in for a project on medical revalidation and did some assurance work on that. I was also a member of the patient panel for a HERG (Health Experiences Research Group) project (part of NDPCHS), which was researching the use of data by frontline hospital staff.

I've also contributed to quite a few of the plain English checks on the 500 words submissions for funding and I'm doing some work on a research project which is reviewing the use of allied health professionals in GP practices.

I just do bits and pieces of work that appeal to me.

I enjoy doing the plain English summaries, because I spent a lot of my life in youth court, and you've got to be able to very clear and simple.

What do you feel is the real value of PPI in research?

I think it grounds it.

The fact that researchers know that they're going to be involving patients helps to ensure that what's going on is patient focused and not just research for the sake of it.

Also, I'm probably old enough to be a lot of researcher's granny. I think the different generation adds a different perspective. Different backgrounds and experiences add a different perspective, which is why a lot of the health organisations are increasingly open to PPI.

How do you think PPI could be more inclusive, reach 'hard to reach' groups?

Everybody I know who's involved is either a patient or caregiver. And I think you tend to attract older, possibly retired, possibly middle-class people.

Partly, because of the hours usually offered – everything is day time, when a lot of people aren't available. They're available at weekends or after six o'clock, tacked onto a working day. And not everybody is mobile: you need to go out to other places more.

The issue about hard to reach groups is that they're always going to be hard to reach. But I think you can reach out to the people who work with them and use them as an intermediary: the charities, local authority or NHS workers, that work with the harder to reach groups.

If you can't link to a group of people, at least link to somebody who knows them well. And I think that is better than just saying the hard to reach are hard to reach.

A lot of people don't lead conventional lives, they don't necessarily live organised lives, or even own a watch. That's one thing I learnt from working in the criminal courts: you've got to think about other people's realties and not your own if you want to be inclusive.

Do you think there are any problems with PPI or how it's been done, in your experience?

Certainly, some see it as a threat, and for no good reason. I don't want their job. I've had my career – I've retired – I just want to do something useful and interesting.

I've found there are some hospitals that don't really want to engage in PPI because, I think, they believe it's going to be negative.

Also, you are not always told the end of the story, how you've helped or what changes have been made from what you've said, and I think that's terribly important.

It can be very irritating when someone doesn't tell you what they've used – and they might have even taken credit, if they thought it was a good idea!

However, I know that Lynne does a lot to encourage the researchers to keep people in the loop, even if it's to say, 'sorry, I didn't get the funding'.

What do you think PPI might look like in the future?

I think patient voices will be listened to more. I think there is now an acceptance that the professionals haven't always got it right.

There's an awful lot of things going on that are wasteful, bad care, not the best use of resources, or are just old fashioned. PPI can be the elephant in the room – I can say the thing that nobody else dares to mention. And then they all join in.

I think with a lot of NHS things there can be a bit of a feeling that "we've got to be a little gentle rocking the boat, because we've got to work together afterwards." If somebody from outside comes in and says the thing that everybody knows and nobody likes to mention, it makes it much easier to discuss it and do something about it.

The floodgates open, and people start taking a totally different perspective.

What would you say to someone who's bit unsure about getting involved in PPI?

I would say start off by going to one of Lynne's training events, because if you meet and talk to other people who're doing it, it will help make up your mind. You'll meet researchers and you'll see that they actually speak the same language as you.

Start with something simple like a plain English summary review or something else that you're interested in. And just take little steps and build up your confidence.

I believe you do a lot of work with the Oxford Academic Health Science Network (AHSN)?

I've just been appointed to the clinical innovation adoption committee, but we haven't had a meeting yet.

I'm involved in another project, which is the cognitive behavioural therapy app for poor sleepers called Sleepio. We are doing some patient and public involvement work for that.

I was also involved with their Arthritis project – "The angry hand".

So, what was your input with the Angry Hand?

There was a small working group of rheumatoid patients and a facilitator. We discussed what mattered to patients with RA and what would get through to people. We then went to a marketing media firm that pitched three ideas of what might be good for promotion, which we discussed.

One of them was a bit obscure. We chose the one that would talk to most people.

Do you know how that project has gone?

It achieved quite a lot of its aims. It certainly raised awareness.

But there were all sorts of other strands going on, like a training package for GPs, to raise their awareness and to get home the message of how early intervention is incredibly important. There's this little window of opportunity, which is probably about six months, between your first symptoms and getting on the right medication. If you miss that window of opportunity, you are likely to have a lot of additional health problems.

It's one of the things that came up in the working group. I remember that several of us has had to find our way into the system because our GP hadn't recognised RA. In my case, he just said 'it's your age take some aspirin'. But I was only 42 - I wasn't that old! I'd gone in with bright red hand joints, which is textbook RA.

What else fills your time?

I love theatre, ballet, films, all sorts of things. I probably end up in London about once a month to see something. And museums. An old school friend and I have just been to the Dickens Museum in London, which is fabulous. I time visits very carefully though, because I'm a bit wobbly standing on the underground.

I also enjoy spending time with family and friends and am a new member of the WI.

After receiving his PhD in developmental neuroscience, Dr Stuart Faulkner went on to follow a mostly typical start to his career as a post-doctoral researcher. That work included translational science at the interface of research, clinical trials and medical devices. It wasn't until he moved to Toronto Canada, working on regenerative medicine, that he became more involved in the wider landscape of projects and research initiatives working with partners across many disciplines and countries.

This led to increasing involvement in the research of how treatments and new therapies are translated into real world care; how they actually get to the patient.

Following a move to Oxford in 2016, Stuart was the programme and operations manager of the Centre for the Advancement of Sustainable Medical Innovation (CASMI), whose aim is to address some of the challenges currently facing medical innovation getting to the patient.

His work continues in the Nuffiled Department of Primary Care Health Sciences where he works on a number of large national and international collaborative projects on improving healthcare innovation.

How did you find the switch from working in a lab-based environment to a policy focussed role?

It's been a lot of learning – lots of very quick learning! But also, a lot of problem solving, which I quite like.

Lots of my time in the lab was problem solving, you're presented with an issue and must quickly find the right information, propose a solution and workout how to implement it.

So, I think that really translated well over to these larger projects. They tend to be multi-layered and multi-faceted as well. And so, problem solving, exploring various solutions and trying to come to the consensus as to what the best solution is.

Where on that journey did you first came across PPI as a concept?

It was gradual. I thoroughly enjoyed my early research, but I quickly came to the realisation that a lot of what I was doing perhaps might never reach the patient.

So that's whan I started to move across into more pre-clinical translational work, where you were working much more with the end users, both the patients and the clinicians, to get their expertise, input and voice into what you were doing.

I began to experience the power and value of patients and the patient voice with a large European project, called ADAPTSMART (https://www.infographic. adaptsmart.eu/). It sought to develop new models to foster access to beneficial treatments for the right patient groups with high unmet medical needs at the earliest appropriate time in the product life-span of medicines in a sustainable fashion

A key component of that was collaboration with all stakeholders to co-create solutions. That's where working with patients and patient organisations really came into my work – they were integral in the co-creation of our consensus building and our outputs.

Could you explain a bit more about your current project and how PPI is important to it?

It's a 30 month, 34-member consortium project called PARADIGM (Patients Active in Research and Dialogues for and Improved Generation of Medicines). It aims to enhance sustainable, ethical and meaningful patient engagement in medicine development at the European level through co-creation. In this context patient engagement (PE) is effectively the same as PPI in the UK.

PPI/PE really is the crux of the whole project.

These projects, under the Innovative Medicines Initiative (IMI) are set up as a public-private partnerships; with 'public' meaning academia, patients, patient organisations, and the 'private' being largely the pharmaceutical industry.

That partnership is important on two levels.

One is that the public and private partners are all on an equal level, in an entirely open and transparent process, which is key – trying to move away from a model of work being done largely by one stakeholder group which can hinder the uptake of outputs.

Secondly, having all stakeholders actively involved in the co-creation of outputs helps to ensure that outputs better account for all stakeholder needs, including patients and that can in turn help embed patient engagement across medicine development and improve or enhance the end product.

Have you come across any sort of friction in those partnerships?

The short answer is yes, lots. But for me, that's part of the fun – if fun is the right word.

When you talk about all the major players in medicines development, you're talking about the patient and patient organisations, academics, industry, regulators, health technology assessment bodies, and healthcare professionals.

They all have their own goals, remits and views as to what should be done and how. Person A's idea of how something should be done often doesn't match with Person B, which is why we're doing this project. Once you unpick some of that, you can then start to work a way forward to build a consensus.

What's the end goal of this project?

Our ultimate goal is the development of new tools, templates, and frameworks that can enhance and sustain patient engagement in medicine development because they were co-created with them. This will help to embed patient engagement in the everyday life of the other stakeholder groups, to make it 'business as usual'.

We are also trying to better address the needs of more vulnerable populations often neglected when incorporating the standard patient voice, specifically the elderly and their carers, and young people.

What's it been like bringing all those groups together?

In short, phenomenal. The depth and breadth of experience from the various stakeholder groups, including patients and public, is impressive. It's been very eye opening.

Some stakeholders, like regulators, can be a bit of a black box – you don't really understand what they do. They're seen as a gate to get through and that's all you know about. Again, understanding the constraints and frameworks that they work in and the work they do is really important.

Will Brexit be an issue for this project?

Thankfully, for this current Innovative Medicines Initiative, our funding is secure to the end of the project. But of course, beyond that it's uncertain.

I think the future funding for these projects is very important – keeping a broader take on medicines development and healthcare in general is vital. So much mutual learning and trust is gained. So how the UK can be involved in these in the future is a big concern for me.

What does a typical day look like for you -- what gets you out of bed to the morning?

A typical day's very busy!

There is a lot of coordination, meetings and teleconferences to assess, build consensus, and implement actions to undertake the various work streams and produce the outputs.

And then, at a broader level, I'm also part of the committee that looks at how well the whole programme of work is progressing.

What do you get up to outside of work?

"I began to experience the power and value of patients and the patient voice with a large European project, called ADAPTSMART..."

I'm a very active person. I love my sports and anything outdoors like running, cycling, swimming, or hiking.

I enjoy travelling, which is also quite nice for this work – many of my colleagues are Europe-based so I regularly travel to Brussels or Paris for meetings. I can't complain about that.

Do you come from a scientific or medical family at all?

No, not really. I'm the first for the proper science background. Most of my family have been involved in academia in some level, but certainly not science. I'm the first, so it often makes for interesting conversation.

Anything, I've not asked you the perhaps you'd like to say?

Our project is roughly halfway through its 30 months. We've already produced a number of deliverables that are on the website (https://imi-paradigm.eu/) What we produce has an EU focus with a global application, so I look forward to sharing my experiences and learning with UK colleagues as this project progresses.

So, it's really exciting times.

Links for further information on Stuarts projects:

PARADIGM: https://imi-paradigm.eu
DAPTSMART: https://www.infographic. adaptsmart.eu

Love them or hate them? Bringing emotions into the study of assisted living technologies

Professor Trisha Greenhalgh and Gemma Hughes reflect on their recent public engagement programme at the Pitt Rivers Museum.

The public engagement programme brought together researchers from the Nuffield Department of Primary Care Health Sciences with community members, design students and colleagues from the Pitt Rivers Museum to consider the emerging findings from the SCALS (Studies in Co-creating Assistive Living Solutions) research programme. The research team had found that there was often a mismatch between the way people actually use assisted living technologies to help them live at home and their intended use. The public engagement programme offered a novel way of considering the complexity of human and societal connections with technology.

This is a picture of Trish's bicycle. It's heavy, slow and only has three gears, but of all her bicycles it's the one she likes best. She got it from the charity Elephant Bike, who recondition old Post Office bikes; they send one to Africa for every one they sell in the UK. It's old-fashioned and sturdy and embodies a sense of history (50 years ago, someone delivered letters on it). It fits well with the surrounding landscape as Trish commutes between Oxford's ancient buildings. Somewhere in Africa, her bicycle's twin is helping a person set up a small business and pull a family out of poverty. Trish says; 'I love my bicycle because it is functional and aesthetically pleasing and because it connects me with things that matter to me across both time and space.'

In 2002, Marianne de Laet and Annemarie Mol published a study of the Zimbabwean Bush Pump (a low-technology hydraulic pump which, implemented adaptively in different settings, had brought affordable clean water to remote communities). In their opening paragraph, they announced that "[We] happen to like, no, even better, to love, the Zimbabwean bush pump in all its many variants. But even if affection moves our writing, this is not an exercise in praise. Rather, we want to analyse the specific quality that attracts us to the Zimbabwean Bush Pump. This turns out to be its fluidity."

De Laet and Mol's emotionally-driven approach to researching technologies defiantly challenges the expectation that scientists should act as detached observers. These authors love the Zimbabwean Bush pump because it is solid and mechanical and cobalt blue and built from locally-sourced components and owned, installed and tended by communities whose children dance around it—and because it still works even if a few of its bolts are missing. Most of all, they love it because different communities adapt, repair and extend it in different ways to meet their varied and changing needs. Like Trish's bicycle, the Zimbabwean Bush Pump has practical value, cultural meaning and moral worth in the contexts where it is used.

De Laet and Mol are [post-] actor-network theorists who draw on insights from Bruno Latour. The technological is never separate (or separable) from the social. Rather, technologies are deeply embedded with, and shaped by, their human and societal connections (indeed, it is often helpful to think of a technology as part of a dynamic socio-technical "assemblage"). Technologies have a history and a provenance, as well as aesthetic and moral dimensions. They mean different things to different people and in different contexts. And as the Zimbabwean Bush Pump story illustrates, technologies are made to "work" (or not) through complex infrastructures (networks) of people-and-technologies who take adaptive actions over time to embed and maintain them in a changing society.

SCALS: Studies in Co-creating Assistive Living Solutions

For several years, Trish's team has been conducting interdisciplinary research on assisted living technologies—that is, technologies designed to help people live independently in their own homes despite chronic—and often progressive—illness and frailty.

In both our previous ATHENE project, funded by the Technology Strategy Board, and the ongoing SCALS project, funded by the Wellcome Trust, we have been struck by the mismatch between policy ideals of "assisted living solutions" and the reality of how individuals and their families actually use technologies to support independent living. This mismatch explains why people often choose not to use particular technologies (or find they are unable to do so).

Policymakers' dreams and visions for assisted living are inspired by apps and gadgets produced and sold by commercial suppliers, which will—they anticipate—empower users, radically transform the way care is delivered and generate efficiency savings for the health and care system (a set of linked assumptions that sociologists call "technological determinism"). Almost without exception, the assisted living technologies in policymakers' minds are novel, futuristic and manufactured at scale as generic (though perhaps not universal) solutions to particular target conditions such as dementia, social isolation or risk of falls. When developing such technologies, the emphasis is usually on technical performance in an isolated laboratory-style setting rather than on the technology's cultural symbolism or how it actually performs in the messy reality of the home.

Messy realities

Our research has shown that when real people address the challenges of living with chronic illness, disability and isolation, the solutions they produce are very different from the prototypes offered in commercial exhibitions of what is sometimes called "senior living". For one thing, such solutions may not involve technologies at all. If technologies are involved, they are typically repurposed from materials already present in the individual's home, perhaps with adaptations or extensions provided by relatives. Almost always, workable solutions are bespoke and developed with or for the individual by someone who knows and cares about them. The technology "works" because it aligns with what matters to the person (often because it has particular historical and cultural connections for them) and because it fits into a wider assemblage of people-and-technologies that can be strengthened and stabilised through adaptive human action.

The mismatch between vision (new shiny things)

Amulet (Pitt Rivers Museum collection) and pendant alarm (on loan from Philips) (picture by Gemma Hughes)

and reality (pragmatic repurposing and adaptation of old things) in assisted living prompted us to develop a series of public workshops culminating in an exhibition in collaboration with Oxford's Pitt Rivers Museum, entitled Messy realities: the secret life of technologies. We used the word "secret" because the ways people actually use technologies to help them live in the home are typically hidden from public view. We thought it was time to surface these messy realities.

From pendant alarms to amulets

Take pendant alarms, for example. Designed primarily for older people living alone, a pendant alarm is typically offered to a person who is considered to be "at risk" (especially of falling). The device is intended to be worn constantly around the neck and activated in an emergency (for example, if the person falls and cannot get up), alerting a staff member in a call centre who can initiate a response. Once it has been supplied, everyone (the person, their relatives and care staff) tend to feel reassured. But research by our own team and others has shown that many people don't wear their pendant alarm (because they don't like the look or feel of it, or because they are anxious about setting it off accidentally) and that many people don't use their alarm as directed. For example, they might keep wearing the pendant when they go out of the house even though it only actually works when used within the home, because holding onto it makes them feel safer.

The dictionary definition of a pendant is "a piece of jewellery that hangs from a chain worn round the neck". In many cultures throughout history, amulets (defined as "anything worn about the person as a charm preventative against evil, mischief, disease, witchcraft, etc.") have been worn as pendants. Thinking about our research data within the museum gave us an insight into the way that, for some people, the pendant alarm has acquired amulet-like qualities (which explains why they take it with them even when they leave the house when it no longer "works" in the way intended by the designer or supplier). For others, the pendant alarm has no cultural meaning but symbolises ill-health and dependency. Small wonder that such individuals "forget" to wear their device.

The Pitt Rivers museum includes over 6000 amulets, both ancient and modern, sourced from around the world. The picture above shows one such amulet

alongside a pendant alarm typically found in our ethnographic research with people living in the UK 2015–2018. The pendant amulet on the left originates from Myanmar. The necklace is made of woven plant material, and the centre of the amulet contains a seed pod. On close examination the seed pod can be seen to have two protuberances that resemble snake fangs. The amulet recruits sympathetic magic to protect the bearer from snake bites. The visual comparison between the amulet and pendant alarm starkly illustrates the gap between cultural objects which belong to their context and institutional objects that are culturally sterile and functional. One idea for personalising pendant alarms, and therefore making them fit better into (some) people's homes and lives, that came up from discussions with visitors to the Museum and the Yarnfulness project was to crochet a cover and chain (shown below).

Crocheted pendant alarm cover (picture by Gemma Hughes)

Trish, of course, tweeted about our work at the Museum and made connections with others interested in these ideas. We heard about the body of academic work that examines, and seeks to extend the design of technologies in relation to human connections including, for example, that of Professor Jayne Wallace. Professor Wallace has studied the relationships between jewellery, the body and human relationships and is currently investigating the potential of digital media in enabling ongoing connections between people. Combining the functions of an alarm with the aesthetics of jewellery has inspired the creation of an onyx pendant alarm that doubles as jewellery made by a commercial supplier (shown below). This kind of approach acknowledges the need for assistive living technologies to have aesthetic appeal to the people who will be using them, as well as serving a functional purpose.

Onyx pendant alarm by Cair. Available at https://we-cair.com/bringing-onyx-pendant-life

Rethinking how technologies 'work'

Our exploration of amulets and other technologies in the Pitt Rivers Museum illustrated that whilst assuring safety for vulnerable people at home is often presented as a modern, technological challenge, it is also an issue that has been addressed through cultural artefacts over the centuries. For a pendant alarm to "work", it needs to have appropriate technical connections (to the call centre)—but also appropriate material properties (not too heavy or clunky to use) and symbolic connections (to the cultural meaning of things worn around the neck). For amulets to "work" they need to come from, and be accepted as connecting to, a protective network of beliefs.

This article was originally posted online on the University of Oxford's Medium.com page:

medium.com/oxford-university/love-them-or-hate-them-bringing-emotions-into-the-study-of-assisted-living-technologies-88c8b0dffe99

PATIENT AND PUBLIC INVOLVEMENT IN RESEARCH WORKSHOPS: 2019

The NIHR CLAHRC Oxford, Oxford Biomedical Research Centre and Oxford Health Biomedical Research Centre are running a series of workshops in 2019 for patients and members of the public.

Each workshop will cover a different stage of the research cycle and discuss ways in which patients and members of the public can get involved.

• Carrying out a research study: 18th April

• Analysing research outcomes: 14th May

• Publicising research outcomes:14th June

• Influencing clinical practice: 18th July

• Monitoring and evaluation: 14th August.

Find out more about each workshop and book your place visit:

www.clahrc-oxford.nihr.ac.uk/ppi_workshops_2019

All are in Oxford and open to interested members of the public living in Oxfordshire, Buckinghamshire, Milton Keynes and Berkshire