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ppi pulse

Patient and Public Involvement Newsletter

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

Edition 10 – Autumn 2017

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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.

Sign up here: www.clahrc-oxford.nihr.ac.uk/ppi_signup

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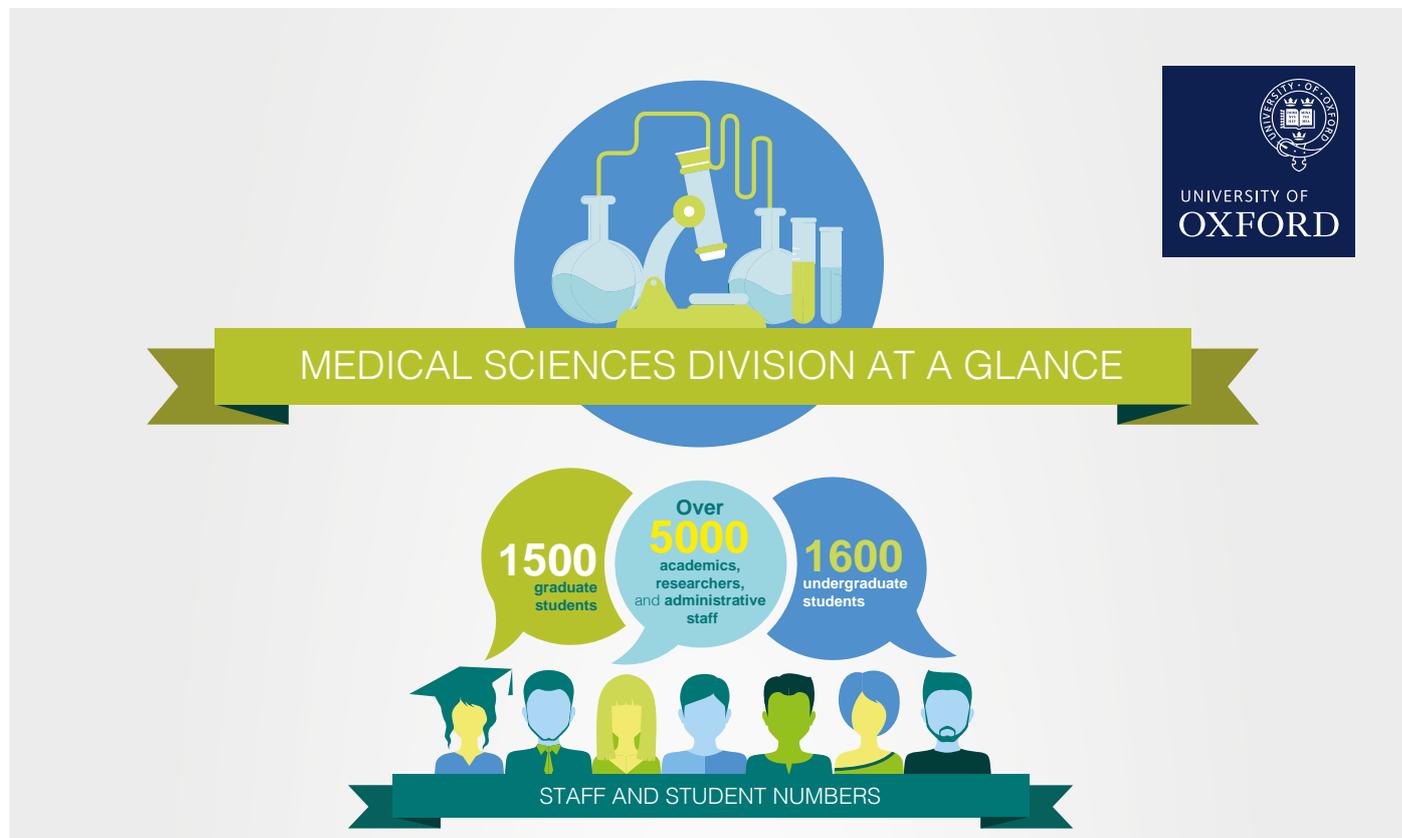
Nuffield Department of Primary Care Health Sciences

University of Oxford, Radcliffe Observatory Quarter, Woodstock
Road, Oxford, OX2 6GG

Tel: 01865 617198

Email: ppi@phc.ox.ac.uk

University of Oxford's Medical Sciences Division 'at a glance' infographic



The University of Oxford's Medical Sciences Division is an internationally recognised centre of excellence for biomedical and clinical research and teaching and is the largest of the four academic divisions within the University of Oxford.

A recently published infographic from the Medical Sciences Division illustrates key facts about the breadth, scale and diversity of the division.

Over 5,500 academics, researchers, NHS clinicians and GPs, and administrative staff, 1400 graduate and 1600 undergraduate students, together contribute to our extensive and exemplary research, teaching and clinical portfolios.

The history of the medical sciences at Oxford is closely entwined with the development of a medical school at the institution, but both clinical and pre-clinical departments have today made the University a world-leader in the medical sciences.

The Nuffield Department of Primary Care Health Sciences is a part of the Medical Sciences Division, and the CLAHRC works with researchers in seven of its departments.

You can view the infographic online and find out more about the history of the Medical Sciences Division at:

www.medsci.ox.ac.uk/about

Perceived barriers to public involvement questionnaire

The Nuffield Department of Primary Care Health Sciences is part of the NIHR School for Primary Care Research (SPCR).

The SPCR PPI Officer, Emma Palmer-Cooper, is currently working on a publication for an academic journal about perceived barriers to public

involvement from both researcher and public perspectives. As part of this, Emma is conducting a survey of views.

If you are or have been a public contributor for research involvement activities or events, she would be interested in collecting your views.

To find out more about the School for Primary Care Research visit:

www.spcr.nihr.ac.uk

To complete the survey visit:

bit.ly/SPCRppiSURVEY

local research news

Professor Gavin Screatton appointed Head of Oxford University's Medical Sciences Division



Professor Gavin Screatton took up his new role at Oxford University at the beginning October.

Professor Screatton was previously Chair of Medicine and Dean of the Faculty of Medicine at Imperial College London and has also served as Vice-Dean (Academic Development), and as Campus Dean for Hammersmith.

Gavin held a range of clinical academic appointments and fellowships in Oxford and at the John Radcliffe Hospital. He undertook his junior clinical training in Oxford and London. He was awarded a DPhil from Oxford in 1997 and his BA from Cambridge in 1984.

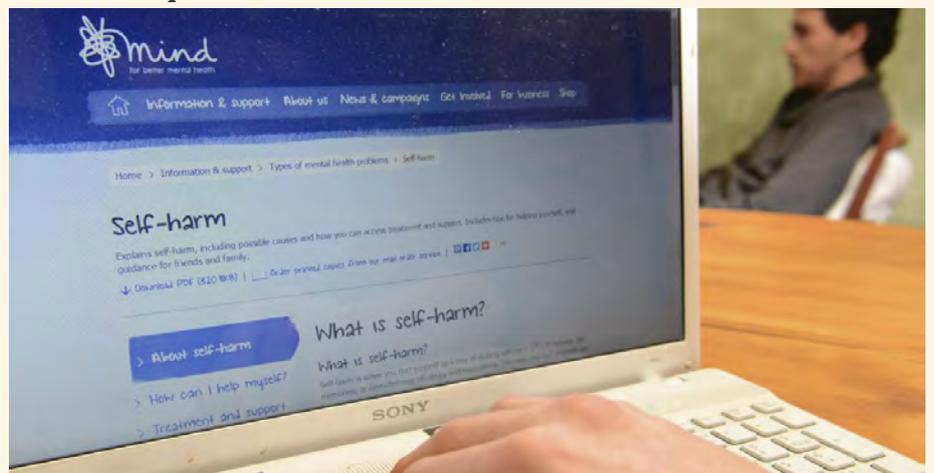
He said: "It is a great privilege to be appointed to lead the Division of Medical Sciences at Oxford. I spent nearly two decades at the University, first as a medical and then DPhil student, and during the formative years of my career in research."

Read more at:

www.ox.ac.uk/news/2017-08-09-professor-gavin-screatton-appointed-head-oxfords-medical-sciences-division

New study emphasises need for self-harm services

CLAHRC Oxford supported study reveals the health service costs for hospital care of people who self-harm, emphasising the need for effective clinical services and prevention initiatives



Self-harm by intentional poisoning or self-injury is a very common reason for presentation to hospital, especially in young people. It is often repeated and carries a significant risk of future suicide. Self-harm was included as a key issue in England's National Suicide Prevention Strategy for the first time this year. Until now very little information has been available on the costs of hospital care for people who self-harm.

Now a new study, supported by CLAHRC Oxford, has linked information from a register of people presenting to a large general hospital following self-harm to financial records in order to estimate the economic costs of their medical and psychiatric care while in hospital.

In a report published in *The Lancet Psychiatry*, researchers from the University of Oxford and the London School of Economics showed that the average cost for each episode of self-harm was £809, with higher costs for adolescents than adults. They estimated that if such costs apply to all self-harm episodes presenting to hospitals in England the overall cost to the NHS amounts to £162 million each year.

Professor Keith Hawton, the senior author of the report and Director of the Centre for Suicide Research based at the University of Oxford's Department of Psychiatry, said: "The findings of this study highlight the need for high quality services for people who self-harm to provide effective medical care and to ensure that patients receive careful psychiatric assessment in order to plan suitable aftercare. The findings also underline the need for large-scale initiatives to prevent self-harm, such as school-based psychological well-being classes and other community programmes aimed at improving emotional health."

For more information on self-harm visit:

www.mind.org.uk/information-support/types-of-mental-health-problems/self-harm

89% of patients are positive about their GPs in Oxfordshire

Nearly a million NHS patients have given their views on healthcare in two national surveys.

The GP Patient Survey, run by NHS England together with Ipsos Mori, assesses patients' experience of healthcare services provided by GP surgeries, including their experiences accessing GP surgeries, making appointments, the quality of care received from GPs and practice nurses, satisfaction with opening hours and experience of out-of-hours NHS services.

Nationally, more than 800,000

people responded to the GP Patient Survey with almost 85 per cent rating their experience as good.

Of the 9,900 people who completed the survey for Oxfordshire 49% rated their 'Overall GP experience' in the region as very good and 40% as fairly good.

However, nationally satisfaction was lower across a number of areas, particularly in relation to making appointments.

This is a government priority area with a commitment to introduce evening and weekend appointments

across all practices by March 2019.

The second survey, the 'Cancer Patient Experience Survey', collected the views of more than 118,000 people treated for cancer and the results are expected to be published shortly.

Find more results, including for your own GP practice, or complete the survey yourself at:

www.gp-patient.co.uk

To search for specific CCG results, visit:

results.gp-patient.co.uk/report/13/result.aspx

Seeing the GP: Advice and tips for young people



A new guide aims to help young people who are thinking of visiting the GP, whether that's because of a minor problem, mental or sexual health, or to talk about a long-term condition.

The guide was developed by the ground-breaking Healthtalk.org, and funded by the NIHR Oxford Biomedical Research Centre, and led by CLAHRC Oxford researcher Professor Louise Locock.

The site is divided into four sections: minor short-term issues, mental health, sexual health and long-term conditions.

Each section makes use of text and video to give advice and tips from other young people that could be helpful before going to see the doctor. This includes advice about making an

appointment, confidentiality, and what the appointment might be like.

Visit www.seeingthegp.co.uk to find out more.

Healthcare staff who support NHS research honoured

Healthcare professionals who help run research trials in the NHS were honoured recently at an awards ceremony in Oxford.

Doctors, nurses and researchers were among those recognised at the Thames Valley Health Research Awards.

They contribute to research supported by the NIHR Clinical Research Network Thames Valley and South Midlands (LCRN), a Department of Health-funded body that helps get trials under way in the NHS.

A total of 30 awards were handed out to NHS staff from Berkshire, Buckinghamshire, Milton Keynes and Oxfordshire at St Hilda's College, Oxford on Tuesday, 26 September.

Staff were nominated by colleagues and winners were chosen by a judging panel at the LCRN, which provides staff to ensure patients are recruited to take part in research.

Find out who won at:

www.nihr.ac.uk/news/healthcare-staff-who-support-nhs-research-honoured/6986

Gene therapy shows promise for reversing blindness

Most causes of untreatable blindness occur due to loss of the millions of light sensitive photoreceptor cells that line the retina, similar to the pixels in a digital camera.

Now, researchers at Oxford University have shown how it might be possible to reverse blindness using gene therapy to reprogram cells at the back of the eye to become light sensitive.

Read more:

www.ox.ac.uk/news/2017-10-03-gene-therapy-shows-promise-reversing-blindness

PPI news & resources

What research is important to you?

The NIHR Dissemination Centre launches 'My Signals' collection.

NIHR Signals are summaries of the latest important health research, produced by the NIHR Dissemination Centre.

They explain why the study was needed, what the researchers did, what the study found, how this relates to current guidelines and what the implications are of the findings.

In My Signals, health and social care staff and service users reveal what research is important to them and why they feel others need to know about it.

The first My Signals collection has been collated by four members of the public with experience of health research. They explain which NIHR Signals have most interested them, or even prompted them to rethink their care, and explain why they feel the findings are worth sharing.

Read the first My Signals collection here:

www.dc.nihr.ac.uk/highlights/my-signals-patients.htm

You can find all the latest NIHR Signals here:

www.discover.dc.nihr.ac.uk/portal/home

Better reporting of public involvement

Despite the laudable increase in recognising the importance of patient and public involvement in recent times, and its increasing use in a range of

research and types of research, much of the published scientific literature arising from such research have scant details about how members of the public were involved and what form their involvement took.

This is a problem because it makes learning from these studies harder.

Now, new research has aimed to address this, resulting in the first international guidance for reporting patient and public involvement in health and social care. The authors included researchers from the University of Oxford and Simon Denegri, Chair of INVOLVE.

The guidance is in the form of a long or short-form reporting checklist called 'GRIPP2', which is freely available to researchers.

GRIPP2, developed alongside PPI contributors, builds upon and updates the original GRIPP (Guidance for Reporting Involvement of Patients and the Public).

View the checklists online at:

www.bmj.com/content/358/bmj.j3453

The Future of Health: The challenge of diversity

The RAND Corporation has recently published its report 'Future of Health - Findings from a survey of stakeholders on the future of health and healthcare in England'.

The report was commissioned by the NIHR and includes a section on Patient and Public Involvement on Page 51, "section 5.4. The changing nature of patient and public involvement in research".

This section focuses on the challenges around diversity and inclusion and the urgent need to develop approaches to public involvement and engagement as part of research design, delivery and dissemination so that NIHR research meets the needs of our diverse population going forward.

The report will be considered at the next NIHR Strategy Board later this year where we will find out how the NIHR's future plans might reflect the findings of the report.

You can download the report online at:

www.rand.org/pubs/research-reports/RR2147.html

INVOLVE appoints new chair of advisory group

INVOLVE – the NIHR Co-ordinating Centre for the promotion and advancement of public involvement in health research – recently announced the appointment of Tina Coldham as the new Chair of its Advisory Group.

Tina is a mental health service user, research reviewer and survivor researcher. She has served for five years on the INVOLVE Advisory Group including two years on the INVOLVE Executive Group.

Tina said, "I am delighted and very honoured to be appointed as the new INVOLVE Advisory Group Chair. INVOLVE encouraged me when I started out many years ago as a lay person in research, so I am excited to continue our journey together in this leadership role. Having a Chair who comes from a service user perspective significantly reinforces public involvement in, and user-led research. There is plenty to do and I look forward to working with everyone in our endeavours."

Tina Coldham will take over from the current Chair, Simon Denegri, on 1st December 2017.

Read more here:

www.invo.org.uk/posttypenews/involve-appoints-new-chair-of-advisory-group

Prioritising research for patients



8 priority themes for tobacco control research

The Cochrane Tobacco Addiction Group's research prioritisation exercise involving over 300 people identified a total of 183 unanswered questions in tobacco control through two online surveys and an Oxford-based workshop, narrowed down to

24 priority questions across eight research themes:

- ☆ Addressing inequalities in tobacco use
- ☆ Delivery of smoking cessation treatments
- ☆ Electronic cigarettes
- ☆ Quit attempt triggers
- ☆ Preventing tobacco use in young people
- ☆ Tobacco use in people with mental health problems and/or substance abuse issues
- ☆ Interventions targeting whole populations rather than individuals
- ☆ Quitting during pregnancy



Read the full report: tobacco.cochrane.org/ctag-taps-project



NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

This project was funded by the NIHR
School for Primary Care Research.



Making sure research ideas are relevant to patient need, focused on answering a particular question and are achievable given the available funding can often be a challenge for researchers. The availability of research priorities, developed with patients, clinicians and other stakeholders, that identify the most important unanswered questions, can address the mismatch between what researchers want to research and the needs of patients and the health community.

Researchers in the Nuffield Department of Primary Care Health Sciences have recently undertaken their own prioritisation exercise to identify the top eight priority themes for research into tobacco control.

Funded by the NIHR School for Primary Care Research, the Cochrane Tobacco Addiction Group involved over 300 people who identified a total of 183 unanswered questions in tobacco control. The group consulted with doctors, stop smoking advisors, smokers and ex-smokers, health service commissioners, researchers, funders and policymakers through two online surveys and an Oxford-based workshop, where the questions were discussed and narrowed down.

One of the common themes during

the workshop discussion was the “moral issue” of addressing tobacco use in deprived areas and some of the least well-off in society, as well as the perceived safety of electronic cigarettes and their long-term side-effects.

Dr Jamie Hartmann-Boyce, Senior Researcher and Managing Editor in the Cochrane Tobacco Addiction Group, and a NIHR CLAHRC Oxford DPhil Student alumus, said “The range, appearance and accessibility of tobacco products has changed significantly in recent years and technology has given rise to new ways of delivering nicotine that can help reduce the harms associated with traditional cigarettes. To ensure our research continues to address the contemporary issues in tobacco control, we aimed to develop a set of research priorities that represent the views of the widest group possible.”

Published in the journal *Addiction*, the new priorities will help to make sure that research designed to evaluate new methods of controlling tobacco use is aimed at the people who need it most, and investigates the latest products and services.

Read more here:

tobacco.cochrane.org/whatwefound

More priority setting projects from CLAHRC Oxford partners

Top 10 Depression Research Priorities

Department of Psychiatry, University of Oxford.

The Depression: ARQ project has identified the most important research priorities according to people affected by depression, their friends and family, and health care professionals.

www.psych.ox.ac.uk/news/top-10-depression-research-priorities

Broken Bones in Older People Priority Setting Partnership

Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford

This Priority Setting Partnership brought together all those involved and affected by broken bones in the leg, anywhere from the pelvis to the feet, to prioritise the top 10 research uncertainties.

www.ndorms.ox.ac.uk/research-groups/oxford-trauma/broken-bones-in-older-people/main-page

Infertility Priority Setting Partnership

Nuffield Department of Primary Care Health Sciences, University of Oxford

Infertility is a heart-wrenching reality for one in seven couples.

This partnership would like to bring together people with infertility and healthcare professionals in a James Lind Alliance Priority Setting Partnership, aiming to ensure that those who fund and undertake research answer the questions which really matter to people with infertility and healthcare professionals.

This partnership is actively recruiting now.

www.phc.ox.ac.uk/research/hypertension/pregnancy/jla-infertility

At last, young people's voices are being heard about the future of the NHS



“For me, [being part of the NHS forum] was like being introduced to a whole new world. I wasn’t aware that young people could be offered opportunities like that, to actually talk to key decision makers and get people from really important organisations wanting to come and talk to us ... It’s helped me with my communication skills ... it’s taught me how to speak properly and confidently.”

This was Georgia talking about her involvement in the NHS England Youth Forum (NHSEYF) in 2016. It aims to improve health services for young people and to give them a voice on health issues that matter most to them.

A team from the University of Hertfordshire carried out an examination of the work of this forum. We found that the young people were highly motivated and committed to being involved in decision-making about NHS services. They found contributing to society through this forum a valuable opportunity and welcomed having their voices heard.

What emerged from our interviews was how much commitment there is among young people about the future of the NHS. Here’s Josh:

“It’s a major concern for me about the NHS ... and I want to improve it, I want to give back ... After being elected as young mayor in our local area ... we get lots of opportunities about how we can contribute back to society

and one of them was the NHS Youth Forum ... I saw it and I thought what a brilliant opportunity that would be to kind of get my voice heard, obviously as a service user but also as someone who represents young people locally. It was a brilliant opportunity.”

Georgia, who we have heard from before, had another more personal reason for being committed to having a say in the running of the NHS:

“The reasons behind why I wanted to join were more personal ... I was quite passionate about mental health because my [relative] suffers from schizophrenia.”

It is important to listen to young people about services that directly affect them. In the UK, the idea of youth forums is now well recognised. There are more than 620 youth councils and forums in existence aiming to give young people the opportunity to be involved in decision-making in their local communities. One example is the High Trees Community Development Trust which focuses on social issues that affect young people and provides training and support so that they can feel confident to participate in the decision-making process.

What is the NHS England Youth Forum?

The NHSEYF was established in 2014 to allow young people to participate in decision-making about the NHS. The aim

was to give young people the opportunity to have a voice and “to contribute to improving and developing services for young people”.

There are 25 members of the NHSEYF ranging between the ages of 11 and 25. Publicity snowballed with the introduction of their own website, Facebook page and Twitter feed. Following the establishment of the NHSEYF, a number of other local forums for children and young people have developed within local hospitals and other areas across the UK including England, Scotland, Wales and Northern Ireland.

Getting involved

We found that NHSEYF members were involved in an extensive range of activities and commitments at local level – including hospital committee membership, local youth forum events and seminars as well as high-profile national events such as the National Children’s Inpatient Survey, national conferences and attendance at the NHS Citizen’s Assembly.

Attending these events raised the profile of children and young people’s needs and allowed the NHSEYF’s members to be active in consultancy-type roles. Our interviews with participants provided clear evidence that the young people were highly motivated and committed to the giving of their own time to ensure the youth voice was heard and represented.

The young people play a pivotal role within NHS England and their knowledge of their home community enabled them to network with professionals and peers within local and national government arenas in order to influence and get involved in decisions about children and young people’s care needs. Evidence from the data collected suggests that the personal growth and development of the young people involved is also likely to have influenced the success of the NHSEYF.

Measuring impact

Our evaluation of the NHSEYF clearly demonstrates the impact of the voice of young people. The Youth Forum Wheel (right) was developed to highlight key areas of importance, as a model that can be applied elsewhere.

The YFW is offered as a model that has the potential to underpin the development of other youth forums, both within and outside of a health context.

It’s important that central and local government measures improvement outcomes for people’s health and/or lifestyles by listening to their views directly rather than focusing on statistics or figures. There is also a recent growing emphasis on services actively involving children, young people and parents and/or carers in the commissioning, development and evaluation of services.

There is a need for ongoing research and funding to ensure that this youth forum model is widely recognised and extended. At the heart of this is recognising the commitment,

motivation and enthusiasm shown by these young people in positively influencing service provision for children and young people. As one of our interview subjects concluded:

“I think the most key point is showing adults that young people want to have their voices heard ... yes the NHS England Youth Forum has done its job because health professionals were coming to speak to us and saying: ‘Oh, how do we engage with people?’”

It is about time we listened to the young people who will determine the future health of the country and take their views seriously. The NHS England Youth Forum aims to do just that.

(Youth Forum members’ names have been changed in line with the ethics requirements of the project.)



The Youth Forum Wheel (YFW)

Written by:

Lisa Whiting
Principal Lecturer and Professional Lead, Children's Nursing, University of Hertfordshire

Gary Meager
Lecturer in Children's Nursing, University of Hertfordshire & Children's Community Rapid Response Nurse Practitioner, University of Hertfordshire

Julia Petty
Senior Lecturer in Children's Nursing, University of Hertfordshire

Sheila Roberts
Senior lecturer, Children's Nursing, University of Hertfordshire, University of Hertfordshire

This article was originally published on The Conversation. Read the original online at: theconversation.com/at-last-young-peoples-voices-are-being-heard-about-the-future-of-the-nhs-77333

The views expressed are those of the author(s) and not necessarily those of the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care Oxford, the NHS, the NIHR or the Department of Health.

meet a PPI contributor / Interview



Alison Langton

Alison Langton comes from a family with a strong medical background and an unspoken expectation, from both family and herself, that she might follow suit. However, she says, that at the age of 20, the thought of facing long years of training to be a medic was too much.

Instead, she took up a career that still allowed her to build on her interest and enthusiasm for science and medicine: publishing.

Alison worked in medical publishing for her entire career, working first for Oxford University Press, then Blackwell Science/John Wiley, culminating in

the position of Vice President and Publishing Director, Health Science Books for John Wiley and Sons.

Alison retired five years ago and now makes use of the skills from her publishing background in the arena of PPI and patient groups.

Alison has lived in Oxfordshire for most of this time, noting the concentration of scientific publishers in and around Oxford.

How did you first hear of PPI?

I had to ask Lynne (CLAHRC PPI Coordinator) how I first started in it as I couldn't remember, and even when she told me I couldn't quite remember the details!

She thinks I first got in touch after seeing an advert somewhere, in early 2016.

I also work for a GP patient participation group and sit on the GPs' locality executive as a patient representative. I'm interested in the whole area of trying to help the NHS, and medical research.

How long have you been doing that?

I've been doing that for a bit longer, though not much, as I've only been retired, I think – I can't remember that either! – coming up to four years. Maybe even five.

How're you finding retirement and what do you do for fun or hobbies?

I was very worried about retiring and I held off for some time. It's a sort of one-way valve; once you've done it you can't go back. So, it's a frightening decision for that reason.

When I first retired I was thinking, 'what on earth can I do?' I was worried that there would be blank days really. And of course, there are some, but you can actually enjoy that, the whole pace changes a bit. But the days soon get filled up, there's no problem about that! I have three grandchildren, and I love spending time with them

I seem to have started playing a bit of bridge and playing golf – very, very badly! – which are both fun and sociable.

I also sing. I'm in two choirs, and a small singing group in Oxford. So, music, concerts and opera are the sort of things I like. Apart from that, the usual: walking, European travel, reading – I'm in a book group – and I love film.

So, PPI is something you got into after you retired?

Yes, when I was looking for new things to do. I knew it had to be something that I really wanted to do and was interested in. Lots of possible voluntary areas didn't interest me enough. And I gradually got more and more interested and involved in PPI.

What attracted you to PPI?

I believe passionately in the NHS and the importance of properly run research and evidence-based medicine so, I want to be able to contribute something and I'm pleased to be able to do that. So, I do feel as though I've homed in on something that I'm really interested in and quite good at, so it's a good fit for me.

I think it probably was a desire to give something back to the NHS and research. And I quite like presenting the other point of view – the patients' point of view. I'm quite interested in that.

In the past I've published books about epidemiology [the study of how diseases affect the health and illness of populations], clinical trials, and evidence-based medicine. So, there's something about the thought of being a little bit involved in the research myself, rather than just publishing it, that's quite appealing.

Have you been involved in any projects you're able to mention?

The one I got most involved with recently is about eating less meat. I was invited to a day when they had. . . let's call them 'enthusiastic meat eaters', semi-vegetarians, and total vegetarians. We were asked to comment on a quite detailed idea for research, and I found that very interesting.

After that I offered to edit the questionnaire and all the patient leaflets.

I've also done quite a lot of reviewing people's research proposals. They're intended for the public, and so I often do quite a heavy edit on them.

One or two, I think, have said that they find it helpful, but sometimes I don't really know. Some people appreciate editing, and others don't. I've found the same in publishing, but my aim is to make the text clearer: simple and clear.

What sort of things have these proposals covered?

Recently there was one about GPs talking to patients who should lose weight for their health, and how you might best be able to influence their behaviour to aid that. There was also one about chaperones in primary care.

And I'm often asked to comment on the importance of the research as well as the proposal itself: whether I think it's a key area for research.

How have you found your interactions with the researchers?

I've worked a lot with researchers, and in fact my son's a biomedical researcher. So, in some ways perhaps I'm not a typical patient representative. Maybe I've gone native a bit in all my years of publishing with doctors and researchers. But on the other hand, perhaps I can give a more informed opinion than some people.

So, I guess I have pluses and minuses as a patient representative.

Have you found that has brought you into any kind of conflict?

I don't think so, no. I haven't really found a conflict within my PPI activities, it's perhaps more with the patient group.

I realise that sometimes with the GP group I tend to automatically believe that they are right about something, whereas other members of the patient group might not. So, I had to try very hard to represent the patient point of view, or help to inform them about the prevailing medical opinion on something as much as possible.

Did or do you have any anxieties or concerns about being a PPI contributor?

No, not really.

Though I suppose one was that I didn't want to spend too much time doing it when I agreed. But in fact, the tasks come relatively infrequently and they usually have a relatively generous deadline. And I'm aware that I can say if I haven't got time.

I told Lynne that it is lovely to know if my input was helpful. And since I mentioned this, people have always written to say thank you.

If researchers take the time just to write a two-line email and be a little specific about anything that was helpful, then that would help guide you for next time. If I'm spending hours on stuff people frankly don't find helpful or useful, then what's the point for anybody?

“I believe passionately in the NHS and the importance of properly run research and evidence-based medicine so, I want to be able to contribute something and I'm pleased to be able to do that.”



James Sheppard

Dr James Sheppard is a Senior Research Fellow at the University of Oxford's Nuffield Department Of Primary Care Health Sciences, and leads the OPTiMISE project as part of the 'Patient self-management of chronic disease' research theme of CLAHRC Oxford.

James is a Population Health Scientist whose main interests are in blood pressure management and cardiovascular disease prevention in Primary Care.

In particular, his research focusses on how high blood pressure treatments can be better targeted risk prediction models with routinely collected

clinical data from Primary Care.

Outside of work, who are you? Have you any hobbies or that kind of thing?

I don't think anyone's asked me what my hobbies are for years, so I've not really thought about it!

At the moment, I'm predominantly a Dad – we've just had another kid! But I'm quite a keen cyclist, so I try to get out on my bike when I can. Though I can't really do that so much at the moment.

I really like my food, actually. I'm a bit of a foodie. I love eating good food, and cooking good food as well. I've realised the best way of eating nice food is learning how to cook it, then you can eat it whenever you want.

And I'm absolutely mad about sport. Anything sport related, either on TV or in real life I'm quite happy to go and watch.

In fact, I originally studied sport and exercise science as my undergraduate degree.

How did that progress to what you do now?

Well, as part of that I had to do a research project for my dissertation, which to my surprise I really enjoyed doing. More than I was expecting to.

After that I had the opportunity to do a PhD in the same department, which focussed more on lab-based research, rather than the more applied research I do now.

After my PhD there was an opportunity to go and work in the primary care research department. This was much more applied research, but linked to what I'd done before around blood pressure and cardiovascular disease.

That was eight years ago now, and I haven't looked back since.

Where along your research career did you first become aware of PPI?

Definitely since I started working in primary care research – I wouldn't have said it was something I was familiar with before that.

The first time I really got involved with PPI was with a previous CLAHRC – I was involved in one of the original CLAHRCs in Birmingham – and we did some work around stroke and how stroke patients are managed across the care pathway.

That project had a very patient-focused aspect to it and we had stroke survivors on our steering group who were really helpful in guiding the project and helping us to focus on specific areas that were relevant to them.

Can you tell me a bit about a project you're currently doing that has some PPI element?

The obvious one is the project I'm leading with Professor Richard McManus, which is partly funded by the CLAHRC, the OPTiMISE trial.

This project is looking at if we can safely reduce anti-hypertensive (high blood pressure) medications in older patients who may have other conditions and may be taking lots of tablets to control lots of things.

We know that people who take lots of tablets have more adverse events – more side effects and more problems. So, our trial is looking at whether you can safely reduce the number of drugs that patients are taking without it causing dangerous changes in blood pressure.

And how has PPI been brought into that?

PPI has been present right through the process of putting

“... I feel very blessed to have fallen into research really, because, to be honest, I can't imagine doing anything else....”

this trial together, from application stage to the recruiting patients, which we're doing now. We have regular team and steering group meetings that include PPI contributors, and it's been very useful.

It was especially helpful when we were developing the protocol for the study. We had some really useful discussion with patients at that stage.

We also wanted to talk to some people who could potentially be participants in the trial about how they would feel if we offered them the opportunity.

Initially, I found it quite challenging to engage with this particular group of patients. These are people over the age of 80 who might be quite frail, might not leave the house much, and so it's not necessarily an obvious where to go to meet them.

We tried to go to some nursing homes, but even if you just want to have a quick chat about some fairly generic things it's not always straight forward.

I believe there's a story about how you went and spoke to friends of your gran?

Yes, that was actually during the protocol writing stage.

My granny, who was 85 at the time, was attending an Age UK day-group each week. Through her I asked if they wouldn't mind if I came along and had a chat to the people there.

The way I pitched it was that I would give the group a talk about stroke – a very light hearted educational talk – and tack on some discussions at the end about our specific trial and some of the issues that I was interested in.

It was actually the Queen's birthday that week, so they were having a tea party to celebrate. Which was good because I got lots of free sandwiches and sausage rolls!

How did you find that?

It was really useful. Finding out what simple things were important to them.

For example, they didn't really want to read a 15 page information booklet, because many of them had poor eyesight and the idea of sitting and trying to read those was really off putting to them.

And so, we did change our recruitment procedures to try and tackle those issues.

What sort of things did you change?

We did two main things that were different to what you would normally do in a trial.

You usually have to put a lot of very detailed information about the trial in a patient information booklet. We still included this, but we also had two pages at the beginning which summarised the key aspects of the trial and signposted to more detail further into the booklet.

We also commissioned a two and a half minute video, a kind of cartoon, which explained very succinctly exactly what the trial was about, what it involved and what it would entail for people.

We scripted that in a way that would be ideal for GPs to show potential participants at the beginning of their visit.

And did you find that made much of a difference?

We've just been reviewing our consent process in the trial – we've got about 80 patients recruited so far. It's been really interesting.

All of the GPs have used the video bar one, who didn't use it at all. It seems to really affect how the rest of the consultation goes and how the patients interact with the patient information sheet having seen the video.

Particularly, contrasting that to the GP who didn't use the video, where it seems there's a lot more explaining needed to get patients to a point where they feel informed enough to say if they want to get involved.

Any problems in producing that for these kinds of patients?

When we were designing the video the first version produced for us was this all signing, all dancing flashing lights thing. It just whipped through the information. I think it lasted less than a minute and a half. I was exhausted watching it, and I wrote the script!

We ended up having an older person narrate it, who spoke at a much slower rate, and everything was slowed down.

It was an interesting process, and was another point at which we used PPI contributors to get feedback on it.

A lot of people mention that it can be a problem that the majority of PPI contributors are older than the general population, retirees usually, but I guess that wasn't a problem for you?

Yeah, for me that works perfectly!

That is one good thing, we've not had to schedule meetings at difficult times to engage with the right people, because most of the time they're quite happy to come along and get involved – if they're mobile enough.

Anything I've not asked you with regards to PPI that you'd like to mention?

I think it can be easy for researchers to just 'do the PPI', because that's what a funder wants you to do, so it can sometimes be a bit tokenistic. I think that, if you take that attitude towards it, you really won't get a great deal out of it.

Whereas, if you think well about it, ask 'what am I not able to understand about this project and what is it a patient can add to it?', I think you're much more likely to have a fruitful relationship with PPI contributors and the process in general.

What is it that gets you up in the morning? What motivates you?

It's my little two year old charging through the door at half six!

I actually do love being a researcher to be honest. It's a bit cheesy but I really like doing something that I perceive to be genuinely meaningful and purposeful, and one day I hope to do a piece of research that changes people's lives. But, I have learnt over the years that you don't do those kinds of things overnight – it tends to be a lifetime of work that really makes an impact.

I feel very blessed to have fallen into research really, because, to be honest, I can't imagine doing anything else.

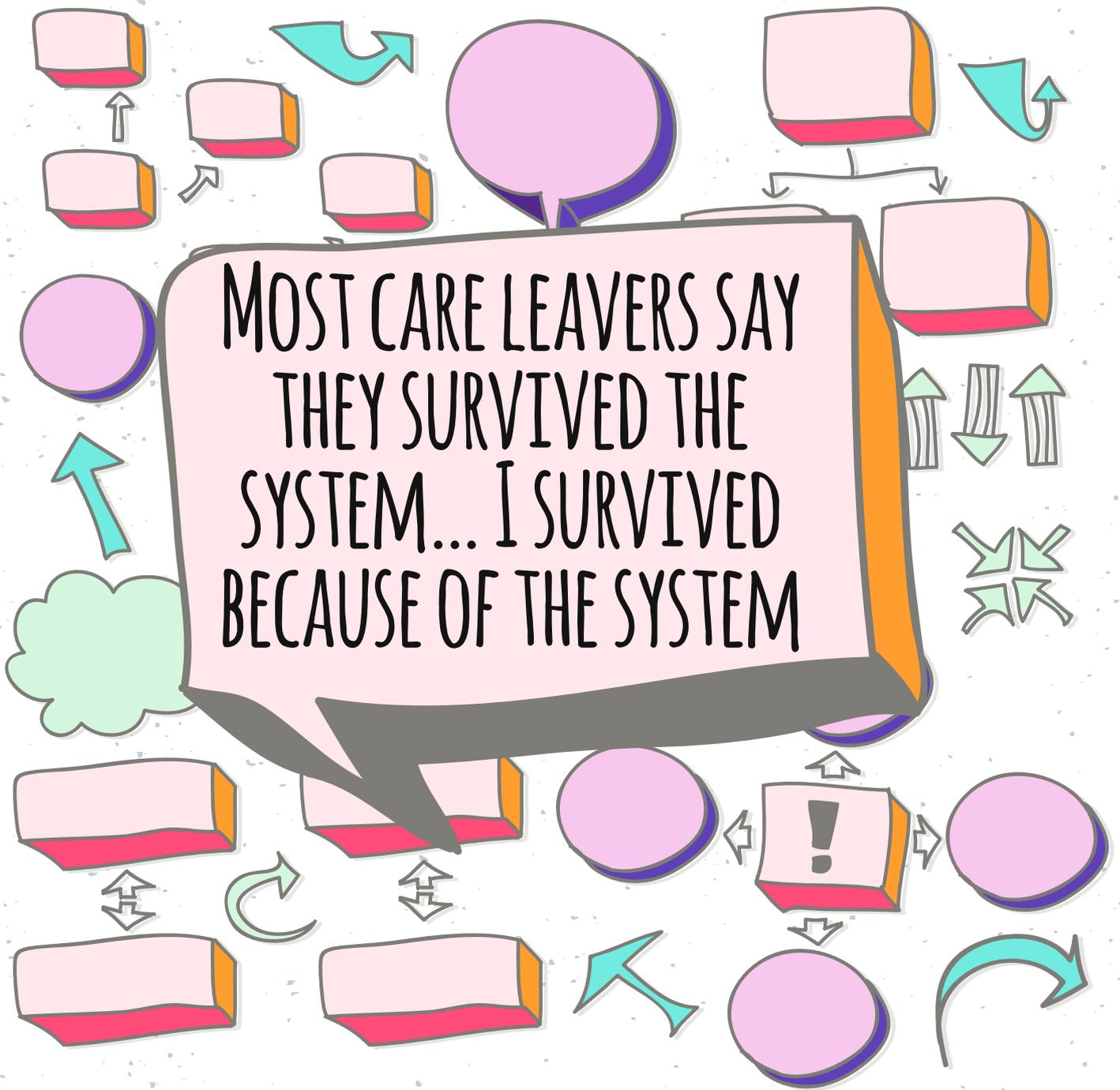
It also helps working in such a great department, working with really good people makes it all a lot easier to get up in the morning and come in to work.

You can view the OPTiMISE video at:

www.youtube.com/watch?v=bIU-Ko9I7A

And find out more about the OPTiMISE study at:

bit.ly/OPTiMISE



Researcher Áine Kelly is using her experience of growing up in care to help others in the system. What role does first-hand experience have in expertise, and how important is it in making health and social care better? Michael Regnier explores a new kind of expert.

At a conference in September 2016, Áine Kelly was telling a group of academics about her work. She is studying for a PhD at the University of Oxford, where she focuses on the health experiences of children and young people in care. But when she happened to mention that her interest had started because she herself had grown up in care, the tone of the conversation changed.

The respect given to a fellow academic instantly evaporated and she found herself being talked down to. One of them asked her if she thought extra allowances had been made for her to get into Oxford. She laughs now, but this exchange still rankles. Why should anyone think that experience of the care system makes a person any less able to study it? And, more importantly, to change it for the better?

Yet, historically, the very people who know most about the system from the inside have been denied a voice when it comes to making sure it is as good as it can be. Instead, other experts – medical, legal, political – have been given much more power. Things are changing, though, as service providers are realising that they just don't have the full range of expertise unless they genuinely involve people with direct experience of using their services. This is not just in social care, either. Members of the public, including carers and patients, are being included in research and reform in all kinds of health areas, right from the start.

In many ways, Áine Kelly is a living example of this combination of expertise and experience. But as she has discovered, some people still struggle to acknowledge the benefit it brings.

Áine was seven years old when the police arrived at her house, suspecting she was being abused by her parents. They escorted her and her mum to a children's hospital, where she was examined. As she has described on her blog, every bruise, burn and cut on her body was counted, measured and photographed. Various adults were asking how she had got these injuries. With her mother standing right there, she was too scared to say. But the evidence was stark. She was taken into emergency foster care straight away.

Many people who have grown up in care in the UK will say that they "survived the system". Áine says she survived because of the system. Until she was six, she hadn't known that her life of neglect and abuse was not normal. She lived in a three-bedroom house in the south of England with her mum, stepdad and two younger sisters. The youngest was still a baby, but Áine took care of her other sister, who had severe epilepsy and complex medical needs.

"I would give her her medicine, give her a bath, put her to bed," she says. "And I was always very protective over her, so if I could see my mum and stepdad were going to argue, I would make sure she was out of the way and I would take the punishment.

"We were quite badly neglected, and I was badly physically abused and emotionally abused. If I was caught getting a drink of water, I'd be beaten for it. I wasn't allowed to sleep at night – they would make me stand in a corner with my legs apart and my hands on my head, and if you're found to be asleep in the morning, you'd be beaten or locked in the shed."

Áine was even caught stealing food from school to take home, because she was scared that she and her sister would have died of hunger otherwise.

Then, one Christmas, Áine's parents asked the local authority to take her into respite care for a short time. They told her it was a punishment for her bad behaviour, but it turned out to be an unintended gift. She spent two weeks with a foster family who showed her that she was not the naughty child her parents always said she was. For a few precious days, she was able to play with the family, joining in their games and festivities. It gave her an idea of what life could – should – be like for her and her sister. "Having days out, having proper family meals and sitting down, asking each other how the day's gone. Simple things."

Back with her parents, Áine had a psychological assessment. She remembers thinking that this would be an opportunity to tell someone what was going on. But her mum had told her that she would be able to hear everything Áine said, even if she wasn't in the same room. So Áine played at happy families for the psychologist's sake.

The only means she had to communicate the truth was through dolls. Áine's recollections of her childhood are supported by her case files, which she requested a few years ago. The psychologist's report from that day notes:

"[Áine] was given some unstructured free play time with the dolls house in which she, first of all, depicted a scene where the father and a child went shopping whilst mother and the other two siblings stayed at home. Father brought a lot of shopping back home which pleased the family. But then the eldest sibling pinched the baby and was subsequently beaten up by every member of the family and thrown down the stairs. Following this, she was sent to her bed as an additional punishment. The beating up of the eldest sibling was repeated before she was forgiven and could re-join the family..."



The fact that [Áine] did not wish to discuss the meaning of her play with me reinforces the earlier interpretation that these negative feelings are too threatening to acknowledge on a conscious level.

Áine doesn't blame the professional for misinterpreting her unwillingness to speak as being psychological rather than the direct result of her mother's threats. But today she puts her efforts into making sure that children in care can always have their say in her research, and beyond. "When you're in care, you don't really have a voice over anything that happens to you."

§

There are around 70,000 children living in care in England today. Statutory guidelines say that a child in care should have a health assessment every six months if they are under five, and every 12 months if they are older. From the young person's perspective, this can be an unwanted and unnecessary intrusion into their lives. Áine remembers the "weird things you don't want to do", such as stripping down to her underwear and standing on one leg. She stopped going for them when she was 11 (young people are within their rights not to consent to an assessment, but not many of them know that).

"[It] all builds up to the point where you don't trust any health professionals," she says. "I just wanted to be normal."

I think what people don't realise is how many professionals are involved. You have to see hundreds of them."

Health assessments can feel particularly pointless to some young people in care, because they feel healthy enough. A recent survey by Coram Voice, a charity that supports children receiving social care services, found that 83 per cent of children in care would say they are better off than when they were at home. Aine thinks that having a routine, regular meals and a set bedtime, be that in residential or foster care, gives children a structure that makes them feel physically healthier, too.

Except there is evidence that children in care have worse physical and mental health than those who are not. A small study in Surrey, in south-east England, published in 2004, found that the healthcare needs of children in care were not only higher, but also often unmet or poorly managed. As a group, the children in care seemed in particular to have a lot of asthma, developmental delays and emotional and behavioural problems.

But for all the efforts, there is a lack of data. In the Surrey sample, one-third of children had not had a health assessment in the past 12 months, while the information that's gathered during assessments that do happen is rather limited, according to Aine. "What is the actual health status of children in care and care leavers? We don't know."

Statutory guidelines for promoting the health and wellbeing of children in care are framed in terms of 'corporate parenting' – the duties and responsibilities of the state to the child – and acknowledge the greater significance of health issues, particularly mental health, for children in care. The stated aim is to put the child at the centre of the process, getting their consent and making sure they understand what is going on in terms of their healthcare. In practice, there are still challenges in linking up local authorities' services with the NHS.

In her research, therefore, Aine is collating what data there is from health assessments and doing as much to understand it as possible. She's exploring which factors make a young person more or less likely to consent to a health assessment. She's also looking at whether the forms that are used could be tailored to the children more, and what their experience of healthcare is actually like. It's vital work, because these experiences influence what happens to people's health after they leave care as well.

A three-year project on the healthcare needs of older adolescents in care and care leavers of all ages is due to report this summer. Jakeb Braden, a health development worker at the Care Leavers' Association, which has led the work, says its results will show that not enough is being done in terms of care support, and suggests it may be necessary to make care leavers a higher priority within the healthcare system.

"There needs to be support for everyone to do what they want with their lives. And underpinning all that is mental health. If you're depressed, anxious and isolated, that's not going to happen."

It's understandable that mental health is a priority anyone who experiences trauma from an early age is likely to need support as they grow up, although a lack of resources means

not everyone does receive help. But the focus on mental health may mean that physical health needs have been inadvertently underestimated or overlooked.

Jakeb says people are usually at their most vulnerable when they transition from care to independent living. Unless you stay in foster care or education, state care ends when you reach 18. But if the state is acting as a parent to young people in care, is it right that it just stops at a certain point?

Not having a go-to person to talk to often leads to problems with eye care and dentistry, he explains. "People can't afford to go, or don't know how to get a dentist appointment." A lot of younger care leavers end up at A&E for minor problems like flu, he adds, because they don't know when to go to their GP for help, or even how to register with one.

"There's growing recognition that the state is a corporate parent and these parenting duties should last a lifetime," he says. "Parenting never stops."

§

When she is interviewing young people in care for her research, Aine says she won't tell them about her own experiences. But, she says if they want to ask her any questions at the end, she will be happy to answer them.

“There needs to be support for everyone to do what they want with their lives. And underpinning that is mental health. If you're depressed anxious and isolated, that's not going to happen.”

"How many of them have questions?" I ask.

"All of them," she replies.

They ask her about dealing with negative stereotypes, and whether people think she is stupid because she grew up in care. "One of them asked if I thought she was clever enough to go to university."

The same question was in Aine's mind at every stage of her route to university, a Master's and a PhD: 'Am I clever enough?' Having struggled at school, she was convinced the answer was no. But if she learned nothing else from a childhood of constantly moving from place to place (she says she has lost count of how many people she lived with after leaving her parents, but reckons it was at least 30), she learned to rely on herself and not give up.

When she finally got to university to study applied psychology and sociology, her academic skills started to bloom, and she discovered that she was good at things that other people struggled with. But it was still far from easy.

She had to work long hours to support herself financially, and found the academic work challenging, too, although less so once she had been diagnosed with dyslexia (after submitting an essay on naturism instead of nativism). But it was all worth it. She would find herself listening to lectures thinking, "Oh, that sits with my experience, actually", and then she would go away and read more on the topic later. "I read one paper that said because I was abused, I'm gonna die ten years earlier," she says, chuckling drily.

Learning about psychology enabled Aine to reflect on her past, and to understand some of the behaviour she experienced – not least her own. For example, there had been a point where Aine had run away from foster care and gone back home. She later realised that this happened because she had been so desperate to have a normal parent-child relationship.

After a couple of weeks, the abuse had started again, but

her mum and stepdad wouldn't let her leave. It was another year before she got the chance to run away again, during which time she was self-harming and thinking about suicide. What stopped her was the thought of her sister.

Her sister's complex medical needs had meant they were separated when they went into care. Unlike Áine, her sister maintained contact with their mum and actually idolised her, which was hard for Áine, "but you have to promote that relationship". Áine still had that vision of a happy life for the two of them, and she worried about who would look out for her sister if she wasn't around. But keeping in touch with her sister and going to her hospital appointments meant that she couldn't sever all contact with the rest of her family.

On more than one occasion, Áine's birth mum tried to track down where she was living. In 2012, she turned up at the university and assaulted Áine. Having been warned not to come back onto the campus, she later managed to find Áine's phone number and would leave threatening messages and texts. Áine went to the police, but all they could advise was that she think about changing her name. She resented the idea of giving up the only constant in her life because of her mother's actions.

At around the same time, Áine's own health had been deteriorating. Her sister had been put on life support, and Áine was travelling up and down the country to visit her every day. It took a toll: "I couldn't laugh, couldn't be happy, couldn't cry. I was falling asleep all the time. And I just didn't understand how the health system worked." Every time she went to see a GP, they would suggest she was depressed, or that growing up in care was catching up with her.

At last she found a doctor who listened more closely to what she was saying. "And she said, 'Ooh, I think you've got something quite rare called narcolepsy.'" The diagnosis was confirmed in 2011, and with the help of this GP, the local designated looked-after children's nurse and her old social worker, she was eventually able to get treatment and bring it under control.

Áine now has two doctors who she trusts – her current GP and her neurologist. She jokes that they are never allowed to retire because she is able to ask them questions that no one else ever answered for her. Simple things, like what constitutes a healthy diet.

"It was only because I was confident enough to go to the GP and ask a question like that that she sent me to a dietician, who actually sat me down and explained what everything does and the different foods you need to eat."

Again, this is part of the challenge around helping young people transition to independence and care for themselves as young adults. How well people manage with issues like eating healthily and using adult healthcare services was something Áine wanted to explore further as she embarked on a fully fledged research career.

First, though, she reluctantly decided to change her name. She deliberately chose something unusual, and, to her surprise, when she filled out the forms and got her new name, it had a huge positive effect. "I felt like I got rid of the child-in-care version of me – someone who felt worthless, unloved and unwanted. I saw my new name as my professional name – someone who could use their experiences in a positive

way."

Her increasingly expert understanding of psychology, and attachment theory in particular, helped Áine move on. She began to view her parents' actions in terms of the neglect and abuse they each suffered growing up. But perhaps the biggest help was that she was finally able to articulate her experiences.

"At seven, I wouldn't have been able to say, 'My mum threw me down the stairs,' or, 'My mum gives me my sister's medication,'" she says. "If you haven't got the words to describe what's happened and you can't tell someone and you can't write it down, how do you then get it out of your head?"

Although she admits there are still some things she hasn't told anyone, Áine is able to enjoy her life. She's not haunted by the abuse or the years of ever-changing foster families. She has been able to reflect and deal with it all, at least in part because of her education. "I don't know where I'd be if I hadn't gone to university," she says.

In the office that she shares as a PhD student at the Rees Centre for Research in Fostering and Education at the University of Oxford, Áine takes off her shoes and puts on a pair of slippers. Around the walls hang life-size paper figures, decorated by young people during her research interviews.

For this part of her research, she gives each young person a camera and sends them off for a couple of weeks to collect material for a collage about their experience of health. Then they make the collage while Áine talks to them about what it means to be healthy and whether they think they're healthy or not. Remembering her own annoyance if professionals cried when she spoke about her experiences as a child, she trained herself not to cry in these interviews by watching lots of sad films first.

She points out one collage, which has twigs stuck to the feet, "Be safe" written on one hand and "Be happy" near the left knee. "This girl, her interview was four and a half hours and she spent a lot of time just doodling and just talking. I barely had to ask questions.

"I find it really helps, because obviously given their past experiences they're not always that trusting," she says. It also takes away the pressure of a standard interview where there's someone in power and someone not, and removes the need for eye contact. "Also," she adds, "they say it's fun."

Generally, the young people feel they are pretty healthy. Áine thinks they genuinely believe that, even though it often later comes out that they are living with certain conditions, such as chronic pain or eating issues or asthma. If a condition is under control, the young people don't count it as a health issue. It's possible, then, that such issues don't get discussed during the regular health assessments either – so we may have a very poor understanding of these children's health.

Ultimately, Áine is gathering information so that she can make informed recommendations to policy makers about how to improve the care system. She's not the only person doing this, nor the only care leaver working in this area. At the Care Leavers' Association, for example, every member of staff has to have experience of being in care. "You can't truly understand what it's like growing up in the care system unless you lived it yourself," says Jakeb Braden.

Áine certainly finds her own experience has advantages



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when it comes to doing research, but not because the experience of care is the same for everyone. She tells the young people she works with that they are “experts by experience”, yet she hesitates to call herself an expert precisely because everyone’s experiences are different, “no matter what the similarities are”.

Rather than relying only on her experiences, she has an advisory panel of 15 or so young people in care. She is keen that they become “mini-researchers”, whether that’s by helping to analyse data or using other skills to support the project. “I think if they feel valued and that they’re actually contributing to something, then most young people from care will want to help improve the service in some way.”

Involving service users in research and reform has been on the increase over the past couple of decades. Martin Lodemore, a senior adviser at INVOLVE, which is funded by the UK’s National Institute of Health Research to promote involvement in health and social care research, says that this trend has been driven by the desire to improve services. In some cases, the level to which the public are involved has reached such depth that it has become ‘co-production’.

“Social care led on co-production, embedding it in research,” he explains. And what exactly is co-production? “The simplest way I can describe it is: working with members of the public to actively involve them in research from the very start. Then they are involved at every stage.” This includes working out what research questions to ask, identifying and prioritising topics, designing research, analysing results, and disseminating and implementing the findings. It can be challenging, especially when involving people before a research project has funding, but it is worth it.

“There is real value in bringing different types of expertise together,” says Lodemore. It keeps researchers from losing sight of the big picture – helping the people using a particular service, such as the care system – as well as making it easier to recruit and retain participants, and often keeps the language used to describe the research more user-friendly.

Áine has experience of being involved like this herself. She sits on the BMJ’s patient panel, which promotes co-production in the research it publishes and invites patients, their carers and advocates to comment on articles alongside peer review. Áine draws on her experiences with her sister, who died in 2016, as well as her own health.

Her perspective is also coloured by an earlier experience as a ‘lay member’ on a committee intended to create guidelines relevant to children in care. She felt the ‘experts’ were treated very differently to the lay members – the former met to decide the remit of the committee before the others were allowed to join. When she was the only person to have grown up in care to be present in a meeting, Áine was frustrated by the tendency to take her experience as a fact, rather than just one experience.

If people work together as a team – acknowledging that each member brings their own expertise – improvements could be achieved more quickly than by ‘experts’ working alone. “When you apply someone’s experience of something to their body of knowledge about something,” explains Áine, “then it is so much more valuable, because they are able to think about all the ‘minor’ details that other people might not even recognise as important. That’s why it is so important for people to work with those who have experience of whatever it is they have knowledge about.

“It is definitely something that is starting to be recognised in the world of health and healthcare. But I think there is quite a way to go before professionals truly recognise the importance of experience and stop seeing it as a tick-box exercise.”

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At 3.30pm on Tuesday 28 March 2017, a group of peers, at least one Member of Parliament and assorted experts file into a committee room in the UK’s House of Lords.

They have come for the inaugural meeting of the All-Party Parliamentary Group on Young People’s Health. Áine Kelly is there. Whether she’s there as a care leaver, an adviser to the Association for Young People’s Health, or a young academic working in this area doesn’t really matter – she brings with her all these different types of expertise.

At the end of the meeting, she goes straight up to the MP, Kelly Tolhurst, who has mentioned her work with looked-after children in her constituency in Kent. Áine secures an invitation to set up a meeting, and leaves, pleased to have extended her network yet again.

Áine, of course, can never separate her lived experience from her academic expertise. But would she want to? She does think it has advantages, especially when dealing directly with young people currently in care. She jokes that we need a new category for her and others like her who are both service users and academic researchers. I don’t think she really worries about labels, however, just the work – and her motivation to help make the care system better looks set to last a lifetime.

“What could be more rewarding than improving the experiences of people who’ve had a bad start in life?” she says.

This article was originally published on the Mosaic Science website, an online publication from the Wellcome Trust.

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Written by:

[Michael Reginer](#)

Edited by:

[Chrissie Giles](#)

Copyedited by:

[Rob Reddick](#)

Fact checked by:

[Lowri Daniels](#)

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