

Involving patients



Ensuring patients are at the heart of everything we do is vital to the GOSc. Senior Research and Policy Officer, **Rachel Heatley**, interviewed David Gilbert, the NHS's first-ever Patient Director and patient engagement and leadership expert, to help inform our patient engagement work

Here at the GOSc, we are focused on how to better integrate the patient voice in our work. We have begun implementing a co-production model of patient engagement, based on the idea that engagement is a journey, not an ad hoc process (see p21 for more information).

To help ensure that our approach is successful, we talked to David Gilbert, the NHS's first Patient Director, who has more than three decades' experience in patient engagement and leadership. David's expertise is partly based on his own hard-won wisdom as a mental health service user.

What led you into the field of patient engagement?

In my early 20s I was an 'angry activist' based at Health Action International campaigning against big pharmaceutical companies in developing countries. I had a nervous breakdown at 25 and was in the psychiatric system for six years. My experience there exacerbated my anger and sense of injustice, seeing what bad care looked like first-hand.

However, it wasn't all bad! For example, towards the end of my time in the psychiatric ward I was invited by my consultant psychiatrist, Professor George Ikkos (who I am now friends with) to give a talk to his medical students about psychotropic medicines. The impact of being asked 'What matters to you?' and having someone listen and do



David Gilbert

David is the NHS's first-ever Patient Director and he has been based at the Sussex MSK Partnership (Central) since 2015. He is also the Director of InHealth Associates and the author of 'The Patient Revolution – How We Can Heal The Healthcare System'. David has 35 years' experience of working

with, and for patients, including as Head of Patients and the Public at the Commission for Health Improvement, and at NHS Croydon. He has also had posts at The King's Fund, a charity working to improve health and care in England, and the Consumers' Association, the charity that runs the Which? group.

something about it, helped me walk out of there as a professional and a human being. I have drawn on my experiences in the psychiatric unit throughout my subsequent career.

What are the challenges with traditional patient engagement?

Conceptually, the patient engagement industry doesn't work. There's often lots of action and minimal impact. It's predicated on two styles: patients provide feedback on retrospective data about the care that professionals have determined for patients; the other is that patients sit as 'representatives' on boards often with no support, training or clear terms of reference.

In my book 'The Patient Revolution – how we can heal the healthcare system', I share the stories of the many patient leaders I have met over the years. These are people who have been affected by life-changing illnesses and who have all changed the healthcare system in their own inspiring way. We didn't have support or training, we had to figure this out the hard way on our own.

This motivated me to set up the Centre for Patient Leadership (CPL) with my colleague Mark Doughty. We delivered skills training to enable patients to be change agents, but we didn't have the chance to scale up our offer and opportunities for significant influence were – and still are – few and far between.

Patient leaders need systematic opportunities, and some clout. That's what attracted me to my current role, with its commitment to shared decision-making, ensuring a focus on what matters and enabling people who use services to be in control of their own care and choices.

What is your current role?

I'm Patient Director, based at the Sussex MSK Partnership (Central), a unique not-for-profit partnership as a lead accountable provider across the musculoskeletal (MSK) pathway in Brighton and Hove, Mid-Sussex and Horsham and Crawley – receiving all GP referrals for MSK conditions, providing specialist musculoskeletal care in community-based clinics and overseeing secondary care referrals.

What makes the Sussex model of patient and carer partnership different?

We have developed a 'Patient Leadership Triangle' that ensures shared decision-

'Our partnership model means patients work with us as equals – to plan, design and help deliver our services'

making at executive, governance and improvement levels.

At one apex, is the role of Patient Director – I'm part of the senior leadership team alongside a clinical and managerial director. My role is to hard-wire the systems and processes that embed patient leadership, broker opportunities for dialogue - or co-production - between patients, carers and staff (in recruitment, training, research, improvement and governance). I'm also the corporate lead on patient and public engagement and patient experience, and oversee work that links to shared decision-making, self-management, information provision and inclusion.

The second apex of the triangle is a group of paid, supported and trained Patient Care Partners who have a portfolio of improvement projects and are more than just storytellers or patient representatives sharing their experiences.

The third apex is the Patient and Carer Forum – a mixed stakeholder group that oversees the patient-centred work and to whom I report. It is one of the four

key governance structures of the MSK Partnership (you can read more about the model here at: bit.ly/Patient-Leadership-Triangle).

We want to avoid tokenistic and 'tick-box' approaches to patient engagement that don't lead to real changes, and which can give engagement a bad name. Our partnership model means patients work with us as equals – to plan, design and help deliver our services. We want to set a helpful example to the rest of the NHS.

What was your first success?

An early project involved an audit of calls for booking appointments. We were receiving lots of calls to cancel or change inconvenient appointments that we had booked for people.

Once we began to investigate, patients told us that our team phoned at inconvenient times to book appointments, for example when they were in Asda trying to shop. Once they got home and had a chance to look at their diary, they would realise the appointment didn't suit and had to spend ages on the phone to rebook.

Patients recommended we send opt-in appointment letters to enable them to book their appointments at a time that suited them in the first place. We tested the idea with hip and knee patients and it was successful both with patients and call centre staff. This sort of success has been replicated dozens of times – we have co-designed new pathways of care, self-management programmes, information provision and a new website, and worked with non-clinical staff to improve access, signposting, waiting room environment and communication.

Recently, Patient Partners observed clinics to assess the quality of shared decision-making alongside clinical peer-observers. This led to changes in the way shared decision-making was undertaken. Patient Partners are now looking to develop a 'patient-led' shared decision-making tool – if you are interested in finding out more please do contact me at: david.gilbert@inhealthassociates.co.uk

Ultimately, why are patient leaders so important?

Patient leaders bring 'jewels of wisdom and insight from the caves of suffering' alongside their experience of use of services. They check assumptions, ask questions, and they provide insights into reframing issues or identifying problems. The benefits are very real. ●

MORE INFORMATION

- To find out more about the impact patient leaders can have, you can read David's blogs at: inhealthassociates.co.uk/blog in particular the post, 'Seven Benefits of Patients and Carers as Partners for Change'. See: bit.ly/7-patients
- David's book, 'The Patient Revolution: How We Can Heal the Healthcare System' features real-life stories of ordinary people affected by life-changing illnesses, disabilities or conditions, who became 'patient leaders': bit.ly/patient-revolution

How has the pandemic impacted patient input?



While the focus shifted away from patient engagement during the COVID-19 crisis, Patient Director at the NHS, **David Gilbert**, is optimistic about some emerging trends

In many senses, the coronavirus pandemic is a societal macrocosm of the lived experience of being affected by life-changing illness, injury or disability. That is not to say that this virus has equalised humanity. It hits the poorest hardest and exacerbates inequality. But for those of us who have been vociferous about patient leadership or ‘lived experience’, or the importance of ‘experts by experience’, we know pain of suffering and loss of identity and purpose can ultimately lead to a deep knowledge of what matters in our lives, the primacy of relationships, and the vision of what good care and treatment looks like.

Across the NHS, patient and public engagement, like its close cousin, diversity and inequality work is seen as dispensable at times like these. Crisis-driven management changes mean that national, regional and local policy making in health and social care has been bereft of patient, user, carer and citizen input during the pandemic.

However, the optimist in me welcomes some countervailing trends:

- 1** Community connectedness has risen visibly to the fore.
- 2** Patient-professional interactions are changing. This is partly the result of the shift to virtual consultations in primary care and some parts of secondary care. I have spoken to several clinicians who report intriguing shifts in dynamics. One stated that the relationship: ‘has become more equal. They see me in my home, and may feel more comfortable. I have to change my way of using language and, in some ways, things have become more patient-centred, with us agreeing that who does what needs changing’. However, we need to be careful – access and inequality issues need exploring. Many who need,

‘Patient-professional interactions are changing – partly due to the shift to virtual consultations’

want or expect manual therapy might be disadvantaged.

- 3** There is a cadre of health professionals whose lived experiences are valuable and needed more than ever right now. Many staff have come out of the

COVID-19 period traumatised, and need support – I believe patients and patient partners can help this healing work.

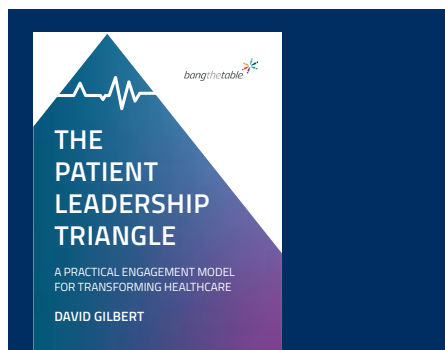
- 4** The activating of peer support networks in mental health trusts shows just how integral this emerging workforce is for the future.

Optimism is found in the ability to connect these trends to create a ladder of opportunities for people to lead – from leading their own care, to supporting others as peers, and in collaborative leadership roles in improvement and governance. This will help embed an infrastructure that is critical to a sustainable engagement model like The Patient Triangle (see more information below) and the well-being of healthcare systems.

Patient leadership has become even more important

This virus might serve to amplify our common vulnerability, fallibility and suffering, which is why, now more than ever, we need to re-inject patient leadership into policy and practice. Valuing the ‘jewels of wisdom and insight gleaned from the caves of suffering’ is the key to decision-making. Without that, we will lurch from one crisis to another.

Like many other services, our co-design work fell behind during the COVID-19 crisis. But we have swiftly resurrected it – patient partners have been in all five recovery plan workstreams – from changing the way we undertake triage, to redesigning referral routes, and in our website, communications and virtual technology implementation work. I believe the only reason this resurrection happened so efficiently was due to our model of engagement – one that truly sees patients as partners in decision-making at all levels. ●



MORE INFORMATION

You can download the free eBook *The Patient Leadership Triangle* by David Gilbert. It looks at the work done within the Sussex MSK Partnership to embed a different approach to patient and public engagement or co-production, to support people with MSK conditions to be partners in decision-making at all levels: delivery, improvement, governance and leadership. Go to: bit.ly/Patient-Leadership-Triangle

Putting patients at the heart of our work

Patient engagement can bring benefits for all involved

A major priority for the GOsC is to listen and learn from osteopathic patients to help us learn more about the patient perspective on: osteopathic education, standards, practice and regulation; and about what we do as the regulator and how we do it. We want to work in partnership with patients and osteopaths to make sure that we put patients at the heart of what we do, and to do everything we can to maximise the opportunities patients have to share their views with us and with the profession.

As a first step to increasing our patient engagement, we plan to hold more focus groups to understand the patient perspective on osteopathic care specifically as a result of the coronavirus pandemic, and how best we can include the patient voice more generally in policy and decision-making in the future. We want to know from patients about the barriers and enablers to osteopathic treatment as a result of the current situation; potential gaps in our infection control guidance; what more GOsC needs to do during and post-pandemic from a patient perspective.

Once we establish and begin to roll out more focus groups, we plan to share the findings – watch out for further updates in due course.

It can be challenging for patients to get involved in areas such as osteopathic education, standards and regulation, as they can sometimes seem remote to their own experience of osteopaths and osteopathic treatment. However, the only experience we require is for patients to have seen an osteopath in the past 12 months.

If your patients are interested and willing to support good quality osteopathic care, we can provide training and the support necessary for them to participate fully to help inform our work and enhance skills that may be transferable to other contexts. For example, training could be provided in the following areas:



Sharing views and patient insight

If you or your patients would like to know more, or if you are interested in some free posters and/or flyers for your practice, you can download them at: osteopathy.org.uk/patient-voice

If you have an example of where you have learned from a patient feedback exercise (an objective activity), or if you have any ideas on how we can enhance our patient engagement activities, then do please let us know.

You can email us at: goscmail@osteopathy.org.uk

- In the work of the GOsC – what we do, how we do it and why we do it.
- In the wider context of the allied health professional in the NHS.
- In broad areas including confidentiality, equality and diversity, and influencing.
- And particularly for both face-to-face and online meetings and events, training about: how to ask questions; probe assumptions; build on points; avoid bias; draw on evidence to enhance influencing skills; so that our patients build on broader skills that may be useful in other contexts.

What are the benefits of patient engagement?

Patient engagement brings benefits for patients, for osteopaths, and for us

here at the GOsC. We set some of these benefits out here:

Patients can:

- Use their unique insights and experience to help others learn and to enhance patient safety and patient care.
- Gain additional knowledge and skills in relation to communicating with health professionals, participating in working groups, and in influencing and communicating.
- Receive feedback on how their participation has informed change or the development of a particular initiative.

Osteopaths can:

- Show patients that osteopaths are committed to involving patients' views in their practice and to being regulated effectively.
- Be assured that their education, standards and the way they are regulated are informed by patients' perspectives.
- Gain new insights and consider different perspectives by hearing from patients.

For the GOsC:

Feedback from patients can provide different insights and perspectives, which can help the GOsC to:

- Ensure we are meeting our core objectives of public protection; promoting and maintaining public confidence in the profession of osteopathy; and promoting and maintaining proper professional standards and conduct for members of that profession.
- Improve our guidance for patients and the public so they get the information they need about osteopathic practice.
- Enhance our guidance for osteopaths to support working in partnership with patients.
- Inform training about patient involvement within osteopathic education. ●