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THE PATIENT LEADERSHIP TRIANGLE

A PRACTICAL ENGAGEMENT MODEL FOR TRANSFORMING HEALTHCARE

DAVID GILBERT

The Patient Leadership Triangle: A Practical Engagement Model for Transforming Healthcare

Edited by Sally Hussey

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Introduction

Traditional Patient and Public Engagement (PPE) is, seemingly, committed to a top-down method of engaging patients, a narrow focus on service user experience, and, ultimately, distances patients and carers from decision-making. Throughout the decades-long patient engagement industry, energies have been overwhelmingly directed towards data gathering and capturing views of 'representative' groups – where patients are invited to complete questionnaires, participate in focus groups, or lend their story for board meetings – and away from valuing the wider expertise and wisdom of patients and carers. This cloistered vision has led to an inauthentic engagement in the extreme.

The Patient Leadership Triangle confronts this dramatic underemphasis on valuing patients and carers. Providing a practical engagement model, David Gilbert moves beyond the tick-the-box, patient feedback and representational approaches that serve to maintain status quo and preserve institutional authority. For Gilbert, the demarcation of an 'us and them' mode is not only unwise, but, in the failure of shared decision-making, perpetuates an immature engagement dynamic – that is, either a condescending paternalism, ("structured dependency") or combative adolescent-parent style engagement. This shiftless model requires an overhaul. As Gilbert writes, "If we are serious about partnership, then we need to overhaul the engagement industry."

In its three-part structure, this accessible ebook traces the rise of patient leadership over the last decade, introduces a new engagement model – the 'Patient Leadership Triangle' – and reflects on its usefulness in transforming healthcare. Echoing Gilbert's powerful examination of patient engagement in his recent book, *The Patient Revolution: how we can heal the healthcare system* – a collection animated by the wisdom of 13 patient leaders' experience in the UK – Part One contextualises the hazardous fragmentation and acute disconnect with patients created by a siloed approach to healthcare. Here, Gilbert confronts why patient leadership matters – not only in ascribing agency to patients – but widening the very definitional notion: "As a society we have so debased illness as weakness or as a problem to be fixed – we have also inadvertently turned patients away from their own agency." Part Two reimagines healthcare through the Patient Leadership Triangle. Emerging from peripatetic beginnings and "swathed in good intentions", the Patient Leadership Triangle is an engagement model that serves to equalise power across the executive, corporate governance and design and delivery levels. Part Three reflects on next steps for this new approach to engagement, which, Gilbert acknowledges, is "an experiment". But, taken as a foundation for systemic change, *The Patient Leadership Triangle* rhetorically asks, is it an experiment we can't afford to take?

The critical juncture Gilbert brings into focus is the equal involvement of patients and carers as an integral, respected part of decision-making – an inclusion that not only leads to better awareness but, ultimately, more humanity in healthcare for patients, staff and health professionals. While significantly contributing to the over fifty-year history of public participation models, this landmark engagement model squarely faces an overwrought healthcare system offering deep implications for engagement – not only around transparency, but also "reflective governance".

For more than two decades, Gilbert has convincingly – and mindfully – critiqued patient and public engagement as, he writes, an "industry that fails to deliver". The transactional nature of public and patient engagement that "buffers power" is here undercut by an insistence on authenticity. For Gilbert, "Patient leadership has to be an authentic journey".

Indeed, reading this ebook, you feel the "authentic journey" of Gilbert: from his journey to the first appointed Patient Director at The Sussex MusculoSkeletal Paternership, where he forged a non-traditional model of engagement, to his poetic renderings of patient suffering. The emphasis on personal voice not only leans into the very notion of humanising healthcare but speaks to Gilbert's 35 years' experience as a mental health care user. Like the patient leaders who have been affected by lifechanging illness and, in their dedication to changing the system, want to change the life of others – Gilbert confronts, with generousity, the current impasse of patient engagement. As he states: "Overall, the notion of patient leadership demands a *new approach to engagement* – one that values the jewels we bring from the caves of suffering. It requires a recasting of engagement away from an industrial, transactional activity 'done to us' and a refashioning of roles, opportunities and investment in skills building."

Among the most powerful meditation in this ebook is that, ultimately, the fear of sharing power serves as the only barrier to true patient-centred care. As such, Gilbert's *The Patient Leadership Triangle* truly presents "a revolution in healthcare."

Sally Hussey

Sally Hussey is Bang the Table's Principal Writer and Editorial Director. She has an extensive background in the publishing, academic and cultural sectors. She is also recognised by the Who's Who of Australian Women*.*

About the Author

David Gilbert was the first Patient Director in the UK Health Service. He is author of *The Patient Revolution: how we can heal the healthcare system* (Jessica Kingsley Publishers, 2020).

He was a pioneer of the concept of Patient Leadership and has worked for 35 years in healthcare at a local, national and international level – originally as a patient-consumer activist and latterly as a patient and public engagement specialist. His work spans roles within commissioner, provider, third sector, academic and regulatory organisations.

David is a mental health service user, poet and Writer-In-Residence for the Bethlem Gallery. His first full poetry collection, 'The Rare Bird Recovery Protocol', was released in April this year.

He is Founder and Director of InHealth Associates UK, who provide support, research and training on patient-citizen leadership, coproduction and patient and public engagement.

Background

The Engagement Industry

In *The Patient Revolution*,[1] I describe a Patient[2] and Public Engagement (PPE) industry that fails to deliver. I also outline the emergence of 'Patient Leadership'.

The roots of this critique began in 1996 when I was working at the Commission for Health Improvement (CHI) – the UK government's first healthcare inspectorate. CHI published *I2I – Involvement to Improvement*, a report that shared learning from over a hundred inspections of hospital care providers. We found that despite involvement activities across the country, few led to improvement.

Over the years, my understanding as to why this was the case has crystallised. The limitations of traditional PPE are now better understood.

The concept of traditional PPE rests on the notion of a professional or institutional cadre that 'does' the engaging and we patients who are subjects to 'being engaged'. It gives primacy to being engaged on experience of using services, rather than a wider discussion of what matters to us in our lives, community or society. At its core, it fails to value the "wisdom and insight forged in the caves of suffering,"[3] as I describe in my book *The Patient Revolution*, and is often a retrospective look at what has happened in the past rather than privileging what we know for the future.

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[1] Part One borrows and adapts text from Gilbert, David, *The Patient Revolution: How we can heal the healthcare system*, Jessica Kingsley Publishers, London, 2020.

[2] Rather than 'consumer,' the term 'patient' is used in this article to describe someone who is affected by life-changing illness, injury or disability and/or someone who regularly uses health-related services and/or someone with a long-term condition.

[3] 'The Tale of The Jewel Merchants,' Gilbert, *The Patient Revolution*, p.239.

PPE can buffer power by distancing patients from decision-making. It maintains the status quo by preserving the institutional authority of professional system leaders. Ironically, when engagement is seen to fail, as it often does, this can be attributed to the lack of value that patients bring rather than to faulty mechanisms. The engagement industry focuses largely on inputs, activities and processes (the methods of gathering data, how to capture views etc.) over impact and outcomes.

The approaches and methods used in traditional patient engagement rely on two main styles. The first is feedback: patients are invited to fill in questionnaires, attend focus groups or tell their stories (if they are lucky) at board meetings or the like. Here, the focus is what happened to us in the past (rather than a discussion about what needs to be done). It's mostly about our experience of services (rather than living with a condition, or about lives beyond the institutional scope of interest).

The meaning of data is left to professionals to assess through their own lenses, based on their own assumptions and often narrow institutionalised thinking. I have seen clearly that professionals will often veer towards what is seen as feasible from their own vantage point, rather than work harder to do what is necessary from patients' point of view. To caricature the process: *I provide you with my data. You (professionals) decide what to do and how to do it. Patients excluded.*

This is a mirror of the paternalistic style of clinical consultation: *I provide you with my symptoms. You analyse and interpret through your professional lens and decide what to do and how to do it.* This is not shared decision-making. It means that you and I are stuck in child–parent mode and structured dependency.

The second style of engagement is scrutiny. Whenever there is a governance committee, an advisory group or the like, the call goes out for a lay representative. I know a patient and public involvement lead who likened her role to that of 'lay rep pimp'. Without clarity of role, support or training, a representative is expected to bring the patient perspective to the decision-making table.

I was once asked, "So David, what do patients think?" "What, all of them?" I thought. In search of credibility and leaning on what we know, we tell our stories, and half the people in the room applaud this 'telling truth to power' and the other half fall asleep ("another patient with an axe to grind" or "personal agenda," they mutter later in the corridors). If we wise up and come to the table next time wearing a suit and tie, brandishing data, those that were awake last time fall asleep and accuse us of 'going native'.[4] I have written about this representative trap in more detail elsewhere.

The consequence of failed representational mechanisms is that committees lapse into a default 'us and them' mode.

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[4] Gilbert, *The Patient Revolution*, p.23.

"If we are serious about partnership, then we need to overhaul the engagement industry. "

> **“True patient partnership has deep implications for transparency, governance and accountability. ”**

Frustrated, marginalised and unprepared representatives start finger-wagging or fall silent. This is adolescent–parent style engagement. If we are serious about partnership, then we need to overhaul the engagement industry.

The Rise of Patient Leadership

Over the past decade, I have met hundreds of people like me who have been through stuff, who knew stuff, who wanted to change stuff. This remains the simplest definition I have been able to conjure for the notion of patient leaders. That is, people affected by life-changing illness who want to change the lives of others of our ilk. Or, more poetically, those who bring “jewels of wisdom and insight” back from “the caves of suffering.” [5]

For us, focus groups just would not do. Here were brilliant, entrepreneurial, passionate people, desiring purpose and wanting to connect their life and health wisdom. For a Jew, like myself, it felt like the diaspora. Or my gang. I was part of a group of misfits, mischievous and mavericks on a pirate venture.

Despite our wanting to help – and knowing we can – we are habitually prevented from doing so by a system that has, until recently, not valued what we bring. *The Patient Revolution* describes what we have learned at personal and professional level. It leans on detailed exploration of the stories of a dozen allies who have tried to change the system in different ways – why they tried, what it is like for them to do this difficult but necessary work and their hopes, fears, opportunities and challenges.

Out of these stories comes a more distinct understanding of why the notion of patient leadership is of critical value – what is its ‘unique selling point’ if you like.

True patient partnership has deep implications for transparency, governance and accountability. At local level, I have seen and heard about dozens of changes in policy and practice as a result of patients being partners in improvement work: making guidelines more flexible, better ways to tackle access and equalities, tackling attitudes and behaviours, different ways of meeting unmet need, the list is endless.

One service found that people weren’t turning up for scans. So, they spent £10,000 on leaflets reminding people on why scans were a good thing. And saying that if people did not turn up, they would go to the end of the waiting list. I was in the room with the head nurse, when one of her colleagues came rushing in saying “we’ve got it all wrong.” They had found that most of those who had not turned up were scared of going into the machine. So they talked with patients and changed things – music, soft lighting, better explanations of what would happen… *voila!*[6]

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[5] Gilbert, *The Patient Revolution,* p.254. Gilbert writes “What if the jewels of wisdom and insight people bring back from the caves of suffering were truly and universally valued?”

[6] Gilbert, *The Patient Revolution*, p.21.

There are benefits beyond the project. When people see the advantages of patients as partners for improvement and change in one area, they help spread it to others. It is a virtuous cycle with implications for scaling up improvement processes, spreading good practice and sustainability. I have seen neurologists come into great conversations on diabetes between patients and staff, and think, "OK, I will try that in my team." It could help heal healthcare systems at so many levels.

Crucially, the concept of patient leadership bestows value on us as 'patients', as people affected by illness, injury or disability. We know intimately what it is like to feel vulnerable and powerless, the effect of pain and suffering on lives, the primacy of healing relationships in care and what good and poor services look like. This combination of vision, humanity and integrity are essential components of high-quality leadership. But are seldom attributed as such.

Connection is critical. With ourselves, others and the world. Losing connection with – being at odds with – our previously balanced mind or healthy body is the epitome of pain and suffering. Losing connections with others during illness can be devastating. Losing who we are in the world, equally so – who we were is not who we are; who we will be is not what we had hoped. Loss of meaning, purpose and identity are at the black heart of ill-health.

And our deep understanding of the above is one reason why patients value healing relationships, why they know so much about trust (and distrust), vulnerability and power, fairness and unfairness. Regaining connection is critical to healing. And a connected human health system is what we need. Who better to lead that movement than us? Those with skin in the game.

Why Patient Leadership Matters

Moves us beyond narratives of weakness.

We need to stop seeing 'patients' as only weak. The pain is real. But we are strong by dint of what we have had to face. This is not so much 'resilience' as moving through territories of immense danger. This is archetypal. In some senses, people who have been affected by life-changing illness, injury or disability are the 'wounded heroes' of myth. This knowledge is akin to shamans and visionaries. As a society we have so debased illness as weakness or as a problem to be fixed – we have also inadvertently turned patients away from their own agency.

We have designed and delivered healthcare services that are systematically unable to be patient-centred because they dismiss the value of the knowledge we bring. I have come to believe, after 35 years working in and around the UK National Health Service, that it can at times practice what I would term institutional discrimination at the level of of patient and public engagement - let's call it 'patient-ism'.

Reinforces our value, wisdom and insight we bring.

Further, patient leaders who go back into the fray to surface deeper meaning from their everyday heroism tell a tale of moving beyond 'ego' towards a collective strength and belief in wider humanity.

The magic then comes when the wisdom gained during suffering meets the wisdom that had been lost when one got ill in the first place (life experiences, capabilities, professional expertise). In *The*

Patient Revolution, each contributor harnessed what they have learned during illness together with their 'previous' life skills to create something deeper – an enriched expertise in order to help others. It is as if the heat of forged wisdom through suffering melts the 'frozen assets' and releases action in a new way.

Acknowledges our roles beyond engagement.

Patient Leaders (and of course, carers) can have many roles though, not just in patient and public engagement. Some are entrepreneurs. Others are campaigners or activists, online dialogue specialists, improvement advisors or help organisations as governors or are part of inspection processes. They work at local, regional and national levels. But the overall direction is the same – to change health and healthcare, to reap the benefits of our wisdom and expertise.

Provides the foundations for learning and development.

In creating the former Centre for Patient Leadership (CPL) to support patients and carers to be influential change agents, Mark Doughty and I tried to underscore learning and development. CPL trained over 1000 patients and carers to develop the capabilities to work with professionals as equal partners.[1]

Underlines the need for support and networks.

Meanwhile, the work is largely unsupported. We do not have a 'royal college' or any kind of infrastructural support. It is lonely and isolating work. Some agencies have given us resources, many have denied us help. Others have, in my opinion, poached our ideas and/or taken credit for it. That is the story, unfortunately, told by many outsider voices in history.

Forges powerful opportunities and roles.

In patient leadership, there has to be an equal emphasis on creating the right opportunities. For example, in governance, research and audit, service improvement and training and education. This could be at a local or national level, but needs to be where professionals are willing and able to work as partners too. Opportunities must also be created at a senior level. It is not right that a service purporting to deliver 'women-centred care' is led entirely by men. In a few years' time it will seem odd that we have ever had a patient-centred National Health Service (NHS) run entirely by clinical and managerial leaders.

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[1] Further information on patient leadership is available at http://www.inhealthassociates.co.uk/patient-leadership-articles-and-reports/.

> "Focusing properly on what matters to patients can only be done if patients are part of decisions."

How We Can Help: the Benefits of Good Engagement

Having patients as partners in the room means looking at problems differently. If you get a bunch of doctors and nurses talking about why people don't turn up for appointments, the likelihood is that they will focus on people needing to take more responsibility. Or they will say we should use text reminders. Fine.

But, what if it is about inflexible appointment systems, people having too much pain to negotiate buses or the bus stops being too far away from the surgery? Having patients who know about real access issues changes the discussion. It draws attention to who is not in the room, including the local authority, for example.

Focusing properly on what matters to patients can only be done if patients are part of decisions. It leads to better awareness of how people get to places and when (access issues), information and explanations needed at each stage, more humanity and better customer care.

Patient engagement also promotes finding potential solutions to problems. Patients have the passion, insight, imagination and freedom from institutionally limited thinking to ask, "What if?" They also widen the array of options for improvement and change. This process changes relationships. With patients in the room, others are given permission to explore. Dynamics change, trusted relationships develop, people work together and move beyond 'us–them' conversations to dialogue. Shared decision-making emerges. Power shifts.

One woman came up to me after a focus group and said, "Can you stop using the word 'discharge' as if I am effluent or snot to be got rid of. That is all about your efficiency targets. For me, it is about 'coming home'."[7] The conversation then focused on what it feels like when you come home from an operation or how it feels when someone says you are discharged. We saw it from the point of view who used the service, not through an institutional lens that had a blind spot. How does it feel to be ejected, alone, still in pain, unused to being back in the community, perhaps without support? Not only was this a more patient-centred conversation, but the social workers and district nurses around the table started to chip in because they could see the problem – it was about everybody working together.

There are also individual benefits to good engagement. Patients feel more confident, develop new skills and build on those skills buried during times of illness – and come to feel better. Recently, in Sussex, we interviewed people for Patient Partner roles. One said of the information for applicants: "I was gobsmacked. I have never been asked what I have learned during this period of pain and suffering, let alone someone asking me to bring those skills to the table. It's obvious, isn't it? We are people still…illness has not robbed us of our intelligence."[8]

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[7] Gilbert, *The Patient Revolution*, p.18.

[8] Gilbert, *The Patient Revolution*, p.19.

Staff gain too. Morale is lifted as conversations become about what can be done, they can feel that we are truly all in this together. This sort of work rehumanises healthcare. Time and time again, I have seen health professionals light up when patients talk about themselves in a way that sparks discussion on what it is like to be ill and what matters. And what could be improved.

Not only are conversations quickly brought down to earth by people who cannot – will not – use jargon. But patients provide permission for the barriers to come down. For professionals, this can reconnect them with the passion they have for healing, why they came into the realm of service in the first place. The result is better quality decisions. If people know why decisions have been made and been part of that process, this generates trust, confidence and it becomes easier to build consensus.

I was once part of a mental health 'blue skies' thinking exercise. We were asked to imagine how many community mental health teams we wanted in our area. "As many as possible – eight?" I said. The Finance Director broke rank:

We can afford two at most. This blue-sky thinking stuff is BS. Let's be honest and have proper discussions. We in the management team are just scared of having grown up discussions with service users.[9]

We hated him for five minutes. Then realised that this is what we wanted and valued as service users – straight talk, honest, authentic, vulnerable. The rest of the day, we talked about thresholds and how ill you had to be to get into the service, and what happens to those left behind. We designed ways of supporting people.

Difficult discussions – but unavoidable. I think patients and communities are ready. If we continue to hide in obfuscation and the institutional fear that lies at the heart of impenetrable guff in documents, then we are all losers. And the anger will mount.

Decision-making is being made behind closed doors, partly because of fear about grown up conversations. Yet, managers go on courses about collaborative leadership and are encouraged to be 'authentic'. The tension between that and what they find when they come back to the ranch is stark. They go back to find behind-closed-doors discussions about targets, mysterious policy pronouncements about 'new models of care' (not discussed early on and openly with communities). It seems to me that decisions and discussions about the NHS and its future are often made by a small cartel of policy makers.

> **"Dynamics change, trusted relationships develop, people work together and move beyond us–them conversations to dialogue. Shared decision-making emerges. Power shifts."**

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[9] Gilbert, *The Patient Revolution*, p.19-20.

In my opinion, we need adult-adult conversations about difficult issues, for example, what to do with limited resources, in order to avoid stealth-like changes to the NHS.

The challenges of implementing patient leadership, I have come to see as four-fold:

- **Value the work we do** – why being affected by illness, injury or disability is an 'essential' role specification for the job of improvement and what the benefits are of having patient leaders involved.
- **Invest in learning and development**[10]
- **Recognise the emotional labour** - Build in emotional, practical and learning support so that our value can be fully realised.
- **Develop a systemic approach** – this includes developing the right culture and systems, policies and processes and ensuring pathways of opportunity, the creation of senior roles and true power sharing.

In the next section we describe one model that tackles all these challenges.

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[10] *The Patient Revolutio*n discusses in detail the hard and often unrewarded and unsupported nature of patient leadership work.

Seven Benefits of Patients and Carers as Partners for Change*

1. Richer insight

Patients and carers shine a deeper and broader light on problems. This helps to reframe issues so as to be more amenable to solutions that will tackle what matters. A service improvement project might initially be aimed at tackling what happens in an out-patient clinic. With patients or carers in the room, the goal posts shift – people might talk about access (transport, parking), inclusion, diversity and/or different aspects of customer care (staff smiling or looking up at people when they come in at the reception desk).

Limitations of narrow thinking and pet assumptions may be challenged or revealed. The improvement work to be done will be on a better track and people involved more confident in the benefits.

2. Potential solutions

Patients and carers often have the guts, insight, imagination and freedom from institutionally limited thinking to ask "what if?" They widen the array of options for improvement and change. They help empower other staff – who may also feel powerless to influence change – to challenge what is 'feasible'.

They will often focus on issues such as coordination, consistency and connection across the system that often fall between teams, departments and institutions, or those that stretch the professional thinking. Patients may not bring *the* answer. No one party holds the whole truth. However, they help to generate a wider set of solutions that can be explored and tested against what matters.

3. Changing relationships

Healing is about relationships. With patients in the room asking questions, challenging assumptions, being vulnerable and human – using narratives grounded in a shared humanity, they give permission for others to explore and go beyond defensiveness. The nature of patient-professional relationship alters as people come to respect each other and work together on problems and solutions.

Without blame, particularly if the conversations are well-facilitated, people help each other move from 'us and them' conversations to a different and more productive relationship – one that supports conversation that produce outcomes. Power shifts and relationships become more equal. In this sense *the process is the outcome* – the nature of the conversations and relationships are important in and of themselves.

4. Individual benefits

Patients benefit from being involved. They can feel more confident, develop their skills and expertise and actually feel better. This means people not being narrowed to 'telling their story', but being able to call on 'frozen assets' – those qualities and traits that may have been buried for years while ill. Of course, some talents develop anew as a result of having experiences and insights into what could happen in healthcare (or what should have happened).

Staff will gain too. Professionals come to reconnect with their own humanity. Morale can be lifted when they see that patients do not ask for the impossible and when they witness support directly from those who receive services. As conversations become deeper about what can be done, they can feel that we are truly 'all in this together'. True involvement in service improvement could benefit everyone, particularly if patients can be seen as 'supplying help' rather than as the 'demand problem' to be solved.

5. Better quality decisions

If people are meaningfully involved as equal partners in decision-making, then trust and confidence can be enhanced or restored. If people know why decisions have been made and have been part of that process – have had the chance to explore assumptions and being in a space where honesty about difficulties is apparent – then consensus is easier.

Having difficult conversations and remaining at the table is critical for transparency, governance and accountability. Just as shared decision-making is key to supportive relationships, and just as honesty in the consulting room about 'breaking bad news' is hard but worthwhile, so this is the way to rebuild trust and confidence in healthcare decision-making.

6. Changing practice

I have seen and heard about dozens of changes in policy and practice as a result of patients being partners in improvement work: making guidelines more flexible, better ways to tackle access and equalities, tackling attitudes and behaviours, different ways of meeting unmet need.

If only the staff on my psychiatric ward had involved us in making the ward safer, we would not have restricted our thinking to removing ligature points and locking doors at night. Instead, I would have recommended more activities, better food (so I didn't have sleepless hungry nights), and more staff to talk to. Instead, the nights were longer and three of my friends died away from the ward anyway.

Many academics would like to measure the impact of involvement on 'downstream' markers of success. These include patient experience, quality, outcomes, utilisation and cost. However, this search is hindered by the problem of causality and attribution – was it only involvement that caused the change? It is more reasonable to look at changes in policy and practice. Seeking to attribute better health outcomes through involvement diverts attention from getting on and doing it.

7. Benefits beyond the project

If it is done well in diabetes, it can be done well in neurology. When people see the benefits of patients as partners for improvement and change in one area, they will help spread it to others. It is a virtuous cycle with implications for scaling up improvement processes, spreading good practice and for sustainability. People will be confident in the methodology if it has the benefits above, and organisations will find ways to develop the cultures and systems that support involvement in improvement.

*Originally appeared in Gilbert, David, thefuturepatientblog, 22 March, 2015

The Patient Leadership Triangle

The Sussex Musculoskeletal Story

Five years ago, I got a call from Steve Laitner. Steve is a GP and passionate believer in patient leadership. He had previously commissioned the Centre for Patient Leadership to run a series of patient leadership training programmes in the East of England. Now he was advising four organisations in Sussex to form a partnership that would oversee and run services for people with Musculoskeletal (MSK) conditions.

Those partners were bidding to get £45m a year for five years from three Clinical Commissioning Groups (CCGs) in the South of England: Brighton and Hove CCG, Mid-Sussex and Horsham CCG and Crawley CCG.

During the partnership discussions, they made a commitment to ensure that "patients were at the centre;" that "people who use services should be in control of their own care and choices;" and, that "shared decision-making" and "self-management" should be cornerstones of the treatment offer within the local MSK clinics they wanted to set up.

Steve told me that during the discussions they were talking about how to do this properly, to go beyond the 'tick-box' engagement and traditional ways of doing things. They had been talking about how Trusts usually have someone overseeing complaints in one department, someone working on patient engagement in another, and someone setting up self-management programmes in another, and so on. This is a mirror of how services fragment people's journey through the system. And all these sorts of roles are lowly paid and without much status. Furthermore, they usually report into different directorates and each may be

only a small part of any one director's portfolio.
They were beginning to draw one of those 'organograms' – diagram of structures with lots of dotted lines that tried to prove how everything links up. Then, Steve said, "Well, if you want to do things differently, and you really want to be patient-centred… how about doing this?" Then he drew a box alongside the two boxes that contained the words 'Clinical Director' and 'Managing Director' and wrote 'Patient Director'. Different. Equal. Shared decision-making manifested at executive level. And one element of the Patient Leadership Triangle was born.

Credit to those around the table – those from Brighton Integrated Care Services (BICs, now called HERE), from Sussex Partnership Foundation Trust, Sussex Community Foundation Trust and Horder Healthcare. They smiled and said, "Let's go for it."

They also created another important role – that of 'Supported Self-Management Lead' with the primary responsibility of supporting clinicians to work in partnership with patients. This post holder supported clinicians and champions to embed new skills in shared decision-making by drawing on evidence-based behaviour change techniques. This role was filled by my close colleague and now friend, Chloe Stewart. In this way, I believe that the Patient Leadership Triangle can also be viewed as a way of embedding shared decision -making across all levels of the healthcare system.

The Sussex Musculoskeletal Partnership

The Sussex Musculoskeletal (MSK) Partnership (Central Sussex) receives referrals from general practitioners of people who have joint, muscle or bone problems. The service stretches from Brighton and Hove, through Mid-Sussex and Horsham to Crawley. Clinicians screen referrals, and many are offered an appointment at our specialist clinics, with advanced MSK practitioners or physiotherapists (often working alongside consultants and others, such as psychologists).

Sussex MSK Partnership Central (SMSKP) brings together four organisations: Sussex NHS Community Trust, Sussex Partnership Trust, HERE (a social enterprise) and Horder Healthcare (a charity). It delivers a £45m per annum prime contract for musculoskeletal (MSK) conditions; providing a specialist community service and sub-contracting secondary care surgical activity to local hospital providers.

The prime contract is commissioned by Brighton, Horsham and Mid Sussex and Crawley CCGs. The partnership serves a population of approximately 650,000 and sees 51,000 patients per year in the community service. We want to get it right first time, so that people do not have to go here, there and everywhere for different diagnostic and treatment interventions. And we want to work with patients and carers as equal partners in order to provide the best service possible.

The Patient Leadership Triangle: An Overview

The Patient Leadership Model in Sussex MSK Partnership (Central) – or Patient Leadership Triangle – can be seen as a triangle that represents the roles of, and relationships between, Patient Director (at executive level), Patient and Carer Forum (at corporate governance level) and Patient and Carer Partners (at design and delivery level, or improvement and team governance level). Together, these sets of people oversee four programmes of 'patient-centred' work.

The model has emerged, as many things do in the health service, from a combination of good intentions, experimentation and gradually evolving clarity of purpose. It has been messy. As Lesley Preece, a Patient and Carer Partner has said, "We are busking with purpose."

This work has been developed during a period of intense operational pressures and as we transform how local MSK services are delivered. As one person said, the Partnership "is trying to change the fuel of the aircraft whilst in flight."

The Patient Director

In 2015, The Sussex MSK Partnership (Central) appointed me as the first Patient Director.[11] The role required someone who has had a life-changing illness, injury or disability – not necessarily a musculoskeletal condition – and can bring patient-centred strategic insight in at senior decision-making levels.

One of the main tasks was to put into practice the principles of patient leadership and forge a non-traditional model of engagement with patients and carers.

I am part of a Leadership Team that includes a clinical director and managing director. We report to a Partnership Board and a lead commissioner from the CCGs. My role ensures that patient leadership is embedded at a senior level and that the Partnership models shared decision-making at corporate level.

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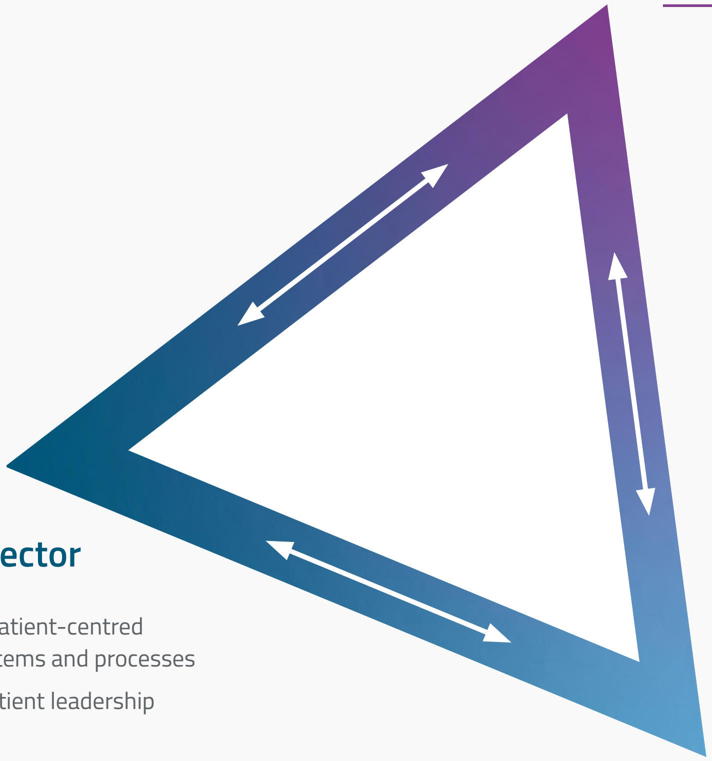
[11] The Sussex MSK Partnership (East) made up of the same four partner organisations appointed a Patient Director, Anne Sabine, a few months later.

The Patient Leadership Triangle



Patient and Carer Forum

- Formal governance committee (alongside Finance and Performance, Clinical Quality, Operations groups)
- Provides reflective governance – oversight of Patient Director programmes and space for dialogue
- Mixed stakeholders (including patients and carers, clinical and support staff, external stakeholders)

Patient Director

- Hardwiring patient-centred cultures, systems and processes
- Modelling patient leadership principles
- Brokering space and opportunities for dialogue between staff and patients/carers at all levels

Patient and Carer Partners

- Equal partners in decision-making at all levels (e.g. training, improvement, governance)
- Paid, supported and trained - each has portfolio of activities
- Drawing on life and condition-specific experiences (of living with MSK condition and using services) to provide strategic insight

My role is to help the Partnership focus on what matters. This includes:

- **Hardwiring patient-centred cultures, systems and processes** – developing policies, procedures and corporate practices, such as a reimbursement policy, training for patient partners, ensuring patient partners are part of corporate priority projects at an initial stage and raising awareness of the work.
- **Modelling patient leadership principles** – I am there also to practice what I preach – the collaborative behaviours implied within patient leadership principles.
- **Brokering space and opportunities for dialogue between staff and patients/carers at all levels** – governance, improvement, education and training, audit and research and delivery. This means also that much of my work is about building trusting relationships with clinicians and support staff and having to persuade people of the benefits of the work.
- **Turning involvement into impact** – making sure that data and dialogue lead to improvements in our services, better outcomes and a better experience for patients.

This has been a personal as well as professional journey. At first, I felt thrust into leading programmes of work that felt beyond me. I picked up the baton of formalising contracts with the voluntary sector around strategies for well-being. And dropped it. I came to see the contrasting cultures of the statutory and voluntary sector at close quarters. And my lack of operational understanding and clinical and IT systems meant I was on too steep a learning curve when it came to integrating these activities (e.g. how precisely might we embed referral processes so that a rheumatologist can easily signpost people to community resources).

Meanwhile, not having been a Director before (or only briefly) meant my grasp of corporate governance requirements in the NHS was sorely tested – how for example to ensure that the Patient and Carer Forum was more than a talking shop and had some formal accountability for work programmes.

I also had to set up a survey programme from scratch across our dozens of locations and learn about MSK pathways (we have seven of them) that stretched from Brighton to Crawley (a population of about three-quarters of a million people) and inject patient and public engagement into our various pathway redesign projects.

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> **"How was I to straddle the role of being an insider (the helper) and of wanting to shift culture to one that was more 'patient-centred' (the critic)? This is a classic patient leadership dilemma!"**

Early on, I was somewhat divorced – perhaps protected – from the operational challenges of meeting early Key Performance Indicators (mostly about waiting times) but felt that the action was 'elsewhere' and sometimes felt isolated.

Over the first and second years I had bouts of mental health problems – related to being overwhelmed and a heavy dose of 'imposter syndrome'. Until recently, I have struggled to feel my own worth. Being part-time and travelling from London to Brighton have not helped. I only had one person for two days a week dedicated to supporting my portfolio of work (Jo Howe then Anna Roberts now Lee Morgan) thus did not feel I belonged to any one staff team.

None of my problems were due to any evil intent or a work culture that was malign. The very opposite! They would not have employed me if they did not want to embed an innovative approach. The very culture of openness and flexibility has been liberating, if contradictory at times, and sometimes the systems of support felt lacking. I love the autonomy, even if at times it has felt lonely.

The Partnership has shown immense love and support when I was struggling and I have become more empathic to staff cultures and well-being. There are many who now confide in me because I have been open about my mental health problems. This has also been a particularly satisfying part of my informal role.

I gradually got to grips with this new Patient Director role. How was I to straddle the role of being an insider (the helper) and of wanting to shift culture to one that was more 'patient-centred' (the critic)? This is a classic patient leadership dilemma!

I have always talked openly about my emotional and cognitive struggles. This is a personal labour of love as much as a professional one – patient leadership has to be an authentic journey. There is no point otherwise. But I can also be too down on myself. We need to be valued and acknowledged. Just because one is a 'director', please do not imagine one ever feels sorted. Maybe this is particularly true for people who have gone through difficulties.

Thus, this message from one of our Patient Partners helps: *It is a measure of all you have done that it is now possible to stand back a little. There was no blue-print. There still isn't. This is action research. Your action in endlessly building relationships, making connections, thinking things through, testing stuff against your extensive experience, being perceptive of what is actually happening, etc. is the fuel that keeps things going.*

Another saving grace has been an ability to forge relationships with staff and to build the 'gang' of Patient and Carer Partners. I have found ways to say 'we can help' and try to position the role almost as an internal consultant – something I have done previously at other organisations. But I am also a Director and have slowly found ways to step into my own authority.

Over time, the role has become clearer and my professional confidence has grown as the work becomes more recognised and demonstrated benefits. I have felt better able to support my amazing colleagues, strategically and operationally. I like to think I am now more creative, solution focused and insightful. I enjoy the work more and look forward to going into the office.

We now have systems and processes in place, such as an agreed reimbursement approach, role descriptions and person specifications for Patient and Carer Partner roles (below) and are pulling together a 'pack' for PCPs. This includes information governance and confidentiality agreements, shared understanding of behaviours, agreements with project managers around integrating PCPs on projects, better communication protocols and, crucially, plans improving parking arrangements – not one to be sniffed at for people with mobility and access problems.

I have found myself being able to give advice to other organisations about the role of a Patient Director and to build the legitimacy for such positions. There were times when I wanted to give up. I am proud that I have not.

Patient and Carer Partners (PCPs)

I have an annual budget of £25k allocated to a group of (currently nine) Patient and Carer Partners. This is the second point of the triangle.

PCPs participate in improvement programmes and, more recently, governance committees, as well as other activities like training, recruitment and input into academic papers. They are paid the NHS England recommended £150 per day though, personally, I think they deserve a rate beyond this and more akin to a proper consultancy fee.

We call them 'partners' largely because I felt that the phrase 'patient leader' would be too radical within the organisation and would entail me having to spend most of my life explaining the concept! But just like all patient leaders, they bring professional and personal wisdom alongside their experiences of using our services.

They are not representatives or there to provide feedback (we have other mechanisms for that) but are 'advisors' and 'critical friends' who check assumptions, ask questions, provide insights into reframing issues or identifying problems, change dynamics and model collaborative leadership. They are akin to clinical advisors.

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> **“PCPs were more than storytellers. They were not there to recount their own experiences so much as be ongoing partners in the room, able to reframe problems, generate new solutions, model collaborative leadership and shift dynamics.”**

Early on, I needed to be clear to project managers leading redesign work (and PCPs themselves) that PCPs were more than storytellers. They were not there to recount their own experiences so much as be ongoing partners in the room, able to reframe problems, generate new solutions, model collaborative leadership and shift dynamics.

An early experience helped us to demonstrate benefits. We were discussing how to communicate with patients about booking appointments. We were receiving lots of calls to cancel or change inconvenient appointments that we had booked for people.

A woman who had been through our service, told us that our team phoned at inconvenient times to book appointments. She suggested that, instead, we send opt-in appointment letters and put her in the driving seat. Let her phone back when she had her diary in front of her and she could plan out her week. We experimented with the idea and it was successful, with patients and call handlers alike delighted with how it worked. If this approach were rolled out, we would save an estimated 3500 cancelled appointments per year.

Since then, PCPs have been involved in several major improvement programmes: redesigning services (e.g. pain, fibromyalgia), improving shared decision-making, developing self-management programmes, designing apps, improving administrative systems (appointments) training (for receptionists and call handlers; physiotherapists on integration of physical and mental health provision), helping plan and run public events (e.g. on support for people with fibromyalgia) and sitting in on recruitment panels (including for our next Managing Director).

In the last two years, they have led on their own projects – one on accessible communication and information and one alongside clinicians on the quality of shared decision-making.

The former began as part of a Commissioning for Quality and Innovation (CQUIN) – a project that garners additional resources from commissioners. They helped support administrative staff (call handlers and receptionists) to enhance patients experiences, for example, triggering improvements in waiting room environment, changing role descriptions for receptionists so they could focus on patient-facing duties and also helping to design call handling training.

The work on shared decision-making has evolved from two PCPs advising on an improvement project to, recently, six PCPs, each sitting in individually on clinics for people with shoulder and elbow problems as 'observers' alongside a clinical peer-reviewer. The aim was to assess the quality of shared decision-making. This is spawning development of a new 'measurement tool' for shared decision-making and has given us loads of learning about how staff and PCPs can work well together. One clinician said last week: "This stuff is bloody revolutionary…we should be telling the world about it."

Over the first two years, they have relied on me to broker opportunities and those opportunities have been ones that the Partnership has as priorities, often influenced by operational demand, performance requirements or generated by clinicians' views of what was needed. And usually, individual PCPs were working on their own.

Over time, they have wanted to work more collectively, and as their confidence has grown they want to influence what opportunities they create. My job is also to match their passions and expertise with the right role. Some are good with data, some prefer being involved in outward facing events and to have an ambassador-like role. They have all had working lives and want their talents to be appreciated. On January 27 this year, PCPs and staff joined together to plan how 2020/21 corporate and patient-led improvement priorities can be even better aligned. There will be one set of priorities, jointly planned, jointly designed, jointly delivered.

As the work becomes more established and recognised, so PCPs are more in demand. They have designed and delivered sessions at staff training events and begun to be involved in area-wide discussions on integration. The fact that two clinicians approached us with the idea that PCPs should help assess the quality of shared decision-making shows how far we have come. PCPs are now seen as trusted equals in improvement and delivery of services.

By the time this ebook is published, patient partners will also have provided the key note opening session for a service-wide learning and development day for physiotherapists, advanced practitioners and administration staff. And, we will have met in order to discuss and commission a dedicated 'patient leadership in action' learning and development programme.

The Patient and Carer Forum

I report quarterly to a 'Patient and Carer Forum' that sits alongside the other key 'governance committees' (e.g. Finance and Performance, Clinical Quality, Operations). This is the third point of the triangle.

We have tried to develop The Forum as both a place of formal governance and oversight of operational programmes and an informal safe space for dialogue. Perhaps this might be termed 'reflective governance' and itself provide a different approach to oversight.

Each Forum allows time and space for patients, carers, staff (support, clinical, managerial) and partners

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(statutory and voluntary, commissioners and providers) to discuss issues of care quality and experiences of both staff and patients. It is a space in which we try to model collaborative behaviours and equal partnership in decision-making between patients/carers and staff. It is important that an organisation provides these sorts of spaces, given the time, resource and regulatory pressures that services are under.

Formally, the Forum oversees three programmes of work – our three I's:

- **Information**
- **Insight** – how we can improve based on data based on learning from patients' experiences.
- **Involvement** – how we involve patients, carers and the public meaningfully.

The Forum also provides a critical connection to the Supported Self-Management work led by Chloe Stewart. We talk about each of these below.

The Four Programmes of Work

Information

In a complex service developed in partnership, the development of user-friendly evidence-based information for all stakeholders is both crucial and tricky. The Partnership believes in the principle of delegated authority and trusts clinical and support staff to deliver to be as autonomous as possible – in teams and as individuals.

This delegated authority needs to be balanced with a coordinated approach to internal communication and information development in my opinion. I have always worked in organisations that have a dedicated communication function for internal and external communication and information provision. At SMSKP (Central) we do not have that. I have found that difficult.

Information provision functions have not been under the ownership of any one person. It is my intention that this portfolio of work is formally overseen by the Patient and Carer Forum.

The work includes information *from* patients (e.g. gathering information about what matters to people prior to an appointment in order to foster shared decision-making) and for patients and carers (e.g. appointment letters, website, signage, etc).

We know that all of this work must emphasise
(a) accessibility of information; and,
(b) information that supports accessibility and inclusion.

Initial efforts to improve communication and accessible information in 2018 included :

- Improvements in signage and access to our clinics (not an easy thing to do when the clinics that we work from are not owned by us!).
- Improving access to information (e.g. that provided to patients after physiotherapy about exercises, text reassurances for patients that we have received a referral from their GP).
- Applying the government Accessible Information Standards to information provision.
- Linking with other corporate projects, such as improving initial letters to patients about their appointment (including information that helps prepare people for shared decision-making) and 'clinic outcome letters'. The latter are letters that we now write to the patient, copied to GPs and that provide user-friendly information about what happened at the clinic consultation.

In late 2019, this work has evolved into a more coherent programme that includes:

- Redesign of our website
- Improving letters that go to patients
- Taking action on patient feedback related to information issues

I am proud that this work has become owned and led by both patients and staff – particularly by hard-working administrative staff who pick up so much everyday intel from patients and families. We have moved to a much more coordinated and coherent programme of work.

Insight

From the beginning, like others in the NHS, we have gathered people's views about our services through a questionnaire sent to people after they have left our service. Much of what we do is standard practice – the survey has included questions about pre- during- and post-care experiences (quantitative and qualitative).

The key is to ensure that data leads to improvement. Without a 'patient experience team' we have relied on getting additional internal capacity to help analyse data, particularly qualitative data about 'what works well' and 'what needs improving'. Over the years, I believe we have improved our systems and processes to make sure data is reported to the right people at corporate and pathway team level. And that something is done about it

Clinical leaders report that plaudits are used both to boost morale and identify key features of good practice at multi-disciplinary teams. More widely, we report weekly comments to clinical leaders and have discussions about what is done – whether an issue is worth further exploration at pathway or corporate level for example, or whether there is something that is immediately actionable.

For me, the critical exploration is *bringing patients and staff together to discuss the data*. And providing power to patients about what is done. After all, one of my key objections to traditional forms of engagement is that it is professionals who filter data about patients through their own lenses and decide what can be done without patients in the room. This has been a slow process. Again, simple is not easy.

> **"The key is to ensure that data leads to improvement."**

> “In 2019, 98% of the patients accessing the service felt involved in a shared decision.”

However, we now report weekly comments to both patient partners and clinical pathway leads (these are leaders of Multi-Disciplinary Teams (MDTs) across our pathways of care that include upper limb, spine, lower limb, rheumatology, physiotherapy, pain). We also bring data about information issues, to the group on communication, information and access.

For our recent CQC inspection process (where we received an ‘outstanding’ rating), we produced a report that showed we had made 27 specific improvements based on what patients have said over the last two years.

By the time this ebook is published, we will have made some critical improvements around the way we gather and use data about patients’ experiences. These changes are being made based on conversations between PCPs, staff and our current survey provider.

Firstly, we are *revising the measures and questions* we use. We have found that we receive consistently high scores on reported measures of ‘patient satisfaction’ – that is measures on compassion of care, involvement in choices, information for self-management. We also have decent scores (not always brilliant) on processes of booking an appointment – views on waiting times and follow up seem correlated to what we know about lengths of waits in some pathways. These scores are not changing much over time against our statistical benchmarks. We are removing these measures so as to insert a rolling programme of snapshot measures aligned with improvement projects. Thus, our Patient Forum will be invited in the new year to think on the issues we should focus on in 2020 and generate new measures for this rolling flexible programme of work.

Secondly, we have got to a position whereby we can *better analyse the qualitative data* as per above. We now will assess different sorts of comments, not only by theme and origin, but also as to their different natures – that is, whether they are potentially ‘low-hanging fruit’ (specific, actionable) like coffee machines in waiting rooms; whether the action is under our control (i.e. in one of our directly run clinics or is an issue that we can only indirectly influence, such as customer care within a larger hospital setting) and/or whether it is a systems issue that requires further exploration.

Thirdly, I am now better at *aligning corporate monitoring processes* and will be providing a summary of each quarter’s patient survey results to go into our corporate quality report, rather than duplicating the reporting processes. I should have done that earlier, but it has taken a while and I have had limited capacity (analytical and administrative) to get myself in a position to do this. This also means that the Forum and PCPs will have sight of one document quarterly that aids decision-making.

Supported Self-Management

Patient and Carer Partners are supporting Chloe Stewart, our Supported Self-Management Lead, in various ways. For example:

- PCPs are part of the project group helping to redesign our Pain Management Programme and seeking to develop a more coherent offer across all our self-management work. Several PCPs are participants in self-management programmes and are feeding back their reflections to the relevant clinical leads.
- PCPs are supporting Chloe informally around the possibility of developing a 'generic' self-management programme that might provide core skills for looking after oneself.
- PCPs are involved in the design of a tender for Link Workers who will better signpost people to community well-being programmes.
- PCPs are inputting into the redesign of the SMSKP website so as to articulate a coherent self-care offer and aligning this with better information.

But the main work that Chloe Stewart has been leading is around ensuring that patients are in control of their MSK care, embedding Shared Decision-Making (SDM) and supported Self-Management. MSK conditions affect one in four adults in the UK. Many MSK conditions have surgical and conservative treatment options. Surgery can transform lives, but for many the expected health improvements are not seen, even when the surgery was technically a success and without complications. For these patients, the full impact of surgery, including post-surgery commitment to rehabilitation in the context of their lives, has not been fully considered by the patient. For these patients, conservative options may well have been a better option, delaying or eliminating the need for surgery.

To date, the work in this area has:

- Provided expert training in SDM and Motivational Interviewing (MI).
- Created Clinical Champions who offer peer support, reflective practice and live feedback.
- Involved patient partners in both the design and delivery of the training.
- Developed condition specific Harms/Benefits information.
- Transformed how we provide patients with information, e.g. writing directly to the patient after their appointment rather than sending them a copy of a letter addressed to their GP.
- Shared this learning with others, including other MSK services and East Sussex and Surrey STP unwarranted variation programme group.
- Offered SDM mentoring funded by NHSE Personalised Care Group.
- Used real time data to review clinical decision-making providing clinicians with up to date referral data.

Patients have reported an increase of Shared Decision-Making by 22%. In 2019, 98% of the patients accessing the service felt involved in a shared decision.

The measured financial impact of this project is a 7% reduction in referrals and reduced secondary care surgical spend. This equates to a £8.3m saving compared to projected spend over 3 years. There has been an increase in conversion to surgery from hospital outpatient appointments from 70% to 85% with year on year improvement. A high conversion to surgery

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indicates that appropriate patients are being referred and, therefore, high cost hospital resources are being used effectively.

Involvement

The Forum oversees the work of PCPs and involvement activities – both those that the PCPs are working on, and more ad-hoc engagement activities, such as public engagement days, training staff, being part of recruitment panels etc. We have discussed some aspects of the work above (Patient and Carer Partners).

The intention has always been to develop 'career pathways' and a wider menu of opportunities for PCPs. Also, for engagement to be more influential and be applied at more senior levels of decision-making.

This has seen us piloting having PCPs as equal members of Multi-Disciplinary Teams (MDTs) with clinical staff that oversee each of our 'clinical pathways' (in orthopaedics, rheumatology and pain and physio) and discuss issues of quality and safety. We have piloted having a PCP in two MDTs and will be moving into other MDTs this year. For me, this is shared-decision making writ large. Patients modelling 'collaborative and reflective dialogue.'

PCPs have helped ground the service in what matters. As one clinician noted:

This (patient and carer partner work) does improve relationships, but more importantly for me it simplifies processes, bringing everything back to our main purpose of care. We can easily become wrapped up in our medical mind and 'fix it' mentality without much reference or consideration to our actions, all with extremely good intentions.

One member of an MDT noted:

It is possible to have a more person-centred health care service, if people are open to working differently and widening their horizons as to where solutions to improvements may be. Patient partners hold an experience of the systems that we want to improve. We need commitment and adequate time allocated to exploring this from both sides to ensure that roots can grow, and that they become part of the make-up of the health care service as much as any clinician or admin team member.

As Lesley Preece, a PCP, says:

Improvement skills are complementary to governance skills, but somewhat different. Like 'Leadership' and 'Management'. One doesn't necessarily progress from QI to Governance. And it is certainly not done without care and support. Both sets of qualities are equally important and require skilled consideration.

The work is not easy. PCPs get frustrated that their work sometimes does not 'land' properly. Systems can thwart the best intentions – they can be left off email distribution lists or assumptions can still easily be made about how much they can or can't do. We have learned to try to get expectations and communication channels clear at the start.

PCPs can also get frustrated, like many staff, at the slowness with which things happen. It took months to get proper chairs for MSK patients into our clinic waiting rooms, as we tried to work out who held the budget for this (Answer: No-one). 'ChairGate' has become shorthand for patient-centred implementation work that is 'simple not easy'.

At other times, the NHS moves fast and PCPs have struggled with being on the outside of rapidly changing decisions and operational and structural changes. Being part-time, I have not had the capacity always to keep people abreast of things. We are now beginning to use a project management system, but it requires IT understanding, and accessibility arrangements. One of the PCPs cannot use a keyboard due to pain, another is sensory impaired.

Despite the huge challenges, they have become trusted equals. It has not been easy and is dependent on clarity of role, shared understanding of purpose, demonstrating benefits and the perennial time, money, space, trust - all things the NHS has precious little of. I am particularly proud that, in declaring the Partnership outstanding, inspectors went out of their way to provide praise for the Partners.

Reflections and next steps

It strikes me that there are five things to think about as a result of our work in Sussex. These will deeply affect the evolution of healthcare. We discuss each of these below.

Transforming Engagement

The Patient Leadership Triangle and each aspect of it – Patient Director, Patient and Carer Partners, Patient and Carer Forum overseeing the four programmes of work – is an experiment. It has taken a long time to build relationships, doing the ground work and making the case for a different model of engagement.

One member of a MDT noted:

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There are still challenges. We need to better communicate the work of the PCPs so people know what they can do (and can't sometimes, because they don't have the support that staff take for granted). We need to make sure we close the loop on data – to monitor actions and impact. We need to make sure that patient engagement is built in at the beginning of all corporate improvement projects. And, for patient partners, we need to put in better learning and support so that they can be even more effective.

It is worthwhile remembering that long-term improvements take time, space and trust. There are no quick fixes. Our work in Sussex demonstrates one novel approach to the challenges of rethinking engagement. It is predicated on the four steps necessary to renew engagement – to value what people bring, establish different mechanisms for dialogue, to develop people's capabilities and provide new opportunities for the new breed of patient (or carer) leaders.

Overall, the notion of patient leadership demands a *new approach to engagement* – one that values the 'jewels we bring from the caves of suffering.' It requires a recasting of engagement away from an industrial transactional activity 'done to us' and a refashioning of roles, opportunities and investment in skills building.

It means a revolution in healthcare. It also needs us to build our own support networks. Unfortunately, I have seen at close hand the way a patient-led national network, inspired by the generosity of individual professionals and fuelled by about 50 good souls, has been man-handled by national agencies and usurped.

But I am also seeing fresh inspiration, in Australia, in Canada (in particular through the work of the Patient Advisers Network) and closer to home, for example, via a London-based coalition of lived experience practitioners. And more and more, I am being approached by all sorts of people – professionals too – about the work.

The Advent of Patient Directors

I have lost count as to the numbers of senior leaders who have contacted me to talk about the role of Patient Director. And done nothing. I have lost count of the number of conferences I have spoken at regarding the role. And how much back-slapping we have had about the role and what we are doing in Sussex. And how the hope I had over coffee breaks has dissolved like the sugar in it.

Yet, there are now seven patient directors, or it is more proper to say, people with roles that are similar. The Sussex MSK Partnership in the East of the patch has been fortunate to have Anne Sabine as its Patient Director, who has had to operate a different model to ours – she does more with a rolling programme of Patient Forums, partly due to the rural nature of the area. And she has had to cover the 'supported self-management role' as she does not have a 'Chloe'!

The Sussex Partnership NHS Foundation Trust – a large mental health provider – has adapted my role description and created two roles for 'user leader' in its forensics team and clinical quality team respectively – Deb Owen and Louise Patmore. Meanwhile, Cristina Serao is the first non-Sussex based Patient Director within a North London healthcare provider and specifically helping to oversee its MSK programme. The Devon Partnership Foundation Trust has also recently employed two 'Together' Associates who lead on user and carer-centred work.

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> “[T]here is a need for promises of new ways of working to be matched by real new ways of working – patient directors would be one manifestation of a system that wants to share power.”

I have no doubt there should be more of us. And as wider strategic arrangements and new structures are designed, there is a need for promises of new ways of working to be matched by real new ways of working – patient directors would be one manifestation of a system that wants to share power.

A Systemic and Embedded Model

In formal language, the Patient Leadership Triangle is both ‘relational’ and ‘systemic’. Our early days at CPL were about developing the relational skills of patient leaders. This work takes it a stage further, by embedding the concept of patient leadership into practice in an operational setting.

Our experience shows that patient leadership can and should be part of the everyday business and practice of healthcare. There are no more excuses for delay. The only excuse I can think for not doing this work is fear – fear of sharing power.

I am encouraged by two other places in the UK (and there may be more) where such systemic models are emerging. In Central and North-West London Mental Health Trust, Melanie Ball oversees the work of some sixty peer support workers, who are aligned to the NHS formal pay-band structures, albeit at quite low salaries. But at least they are there – providing a portfolio of work across areas of their won and supported expertise.

For me, coming from a mental health background, it seems that the user movement needs to build on this wealth of expertise in rights-based advocacy that evolves naturally into a form of peer support founded on a recognition of shared values and common experiences of marginalisation. This is a different route to ‘patient leadership’ or the term preferred in mental health circles ‘lived experience practitioners’. Melanie Ball and I have discussed how the model she is developing can align to the Sussex Model. In particular, some of these peer support workers are entering strategic discussions, perhaps as improvement partners – and thus entering the realms of a Sussex approach. And, of course peer support working is not unique to mental health.

Conversely, in our MSK service, peer support is not yet widely recognised as a need, but it soon will be. Some of our PCPs have expressed a desire to go into that realm and/or help design peer support services. We need to learn from Melanie Ball.

> "PCPs have entered our pool of opportunists and brigands because they have wanted to share their experience and expertise."

Meanwhile, in the South-West of England, Karen Owen has helped developed a model called 'HealthMakers'.[12] Her vision, that is coming alive, is that of people learning to self-care better through an array of self-management and community well-bring practices. Some of these folks then flourish by supporting others and becoming peer-support workers. Then some might emerge to play a role in systems improvement (the territory of our Sussex MSK Partners). One of the beauties of Karen's work is that it is not condition-specific and that she is finding ways to get the model implemented across a wide geography and integrated within funding and commissioning structures.

I believe that the combination of our three approaches provides a bedrock for systemic change across the health system – our learning, pooled, will provide an evidence for policy makers that is too good to ignore. Then, we shall see whether existing power structures trump patient-led movements for change. It will be crunch time.

Patient Leader Progression

Our experience of developing PCPs reveals the nature of a 'career progression' for Patient Leaders, several of whom seem to be exploring how their returning sense of value can be aligned to a return to a career – perhaps as a patient leader, perhaps in other areas. To lead patients up a blind alley in terms of roles and opportunities seems an abrogation of my responsibility – and ours.

Thus, it seems that PCPs have entered our pool of opportunists and brigands because they have wanted to share their experience and expertise. This begins in articulating their own experiences – the "judicious use of story-telling,"[13] often in training events or as part of feedback work. This is vulnerable and hard work. It means exposing the fullness of you in an unequal setting to an audience of professionals.

The next step for us has been to shape the PCP contribution so that it is apposite in improvement settings. (For instance, the above story that led to the changing of appointment systems.) Being an improvement partner means couching one's own experience in the context of an overall framework of what matters[14] and using tactical influencing and relationship building skills in productive ways.

And this is different again to entering the arid zones of governance meetings and committee structures – not all of us want to do this, not all of us will be good at it. Being

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[12] See Owen, Karen 'HealthMaker,' *The Patient Revolution*.

[13] This phrase was given to me by Anthony Hewson when I was working at the Commission for Health Improvement.

[14] See https://futurepatientblog.com/2015/05/14/the-patients-dozen-what-matters-to-patients-and-carers/

in a learning and improvement forum with an enthusiastic professional who wants to learn with you, is different to dealing with an orthopaedic consultant who enters the room in a suit and sits at the head of the table in a multi-disciplinary team meeting and does not make eye contact before the meeting pursues a fixed and ruthless agenda so that he can make his next appointment.

This three-step pathway is crucial for us to consider – how do we create opportunities and progression, and timely learning and development alongside these roles? And what then? What is the next step for a PCP? Could one of our PCPs become your next Patient Director? Or ours?

Power: One Final Thought

Does the system – do you reading this – want to share power? This is a critical stage in the evolution of patient-led healthcare. The patient and user movement has seen many ups and downs – this is a fragile time, given political and economic turbulence, and volatility and austerity in health sector policy and practice. Crisis. Or opportunity?

Epilogue

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 those of us who have been vociferous about patient leadership or 'lived experience' or 'experts by experience' know that, along with the pain of suffering and loss of identity and purpose, comes a deep knowledge of what matters in our lives, the primacy of relationships, and vision of what good care and treatment looks like.

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

However, the optimist in me welcomes some countervailing trends. Firstly, that community connectedness has risen visibly to the fore. Secondly, 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 the 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". Thirdly, there is a cadre of health professionals whose lived experiences are valuable and needed more than ever right now. And fourthly, the activating of peer support networks in mental health trusts shows just how integral this emerging work force 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 and the well-being of healthcare systems.

We need to re-inject patient leadership into policy and practice, now more than ever, where valuing 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.

This virus might serve to amplify our common vulnerability, fallibility and suffering. But also the jewels of wisdom and insight that are dug from the caves of suffering. Lockdown can unlock our human potential.

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Selected Reading

David Gilbert has written the following articles that relate to this e-book:

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