



Harnessing the Power of Patient Experience

2019

Membership Engagement Solutions (MES) was acquired by Civica UK Ltd, in December 2018. This publication was released prior to the brand integration into the business.

Credits and thank you

We would like to thank the following people and organisations for their contributions to this white paper:

- ▶ Ruth Evans and Louise Blunt, Patient Experience Network
- ▶ Amy Gaskin-Williams and Paul Sanguinazzi, Nottinghamshire Healthcare NHS Foundation Trust
- ▶ Tracy Young, Northumbria Healthcare NHS Foundation Trust
- ▶ David Gilbert, InHealth Associates
- ▶ Eleanor Barlow, Pansensic
- ▶ Leroy Binns, Mencap
- ▶ James Munro, Care Opinion
- ▶ Professor Margaret Greenfields, Buckinghamshire New University
- ▶ Dr. Kath Maguire, University of Exeter's European Centre for the Environment and Human Health
- ▶ Lynnette Charles, Mind in Haringey
- ▶ The team at MES for their hard work in putting this together

This paper has been produced in partnership with:



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Foreword

Four years ago, we presented our white paper 'Making Sense and Making Use of Patient Experience'. In it, we surmised that in some ways the work was still in its infancy: there was no common model applied across the sector and sometimes staff were unclear as to the purpose. The reality was that huge resources were spent on the collection of the data but not enough on the analysis and implementation of learnings from that same data. In short, there was a lot of activity and reporting but it was less clear on how improvements were being made on the basis of the work.

It has taken us four years to follow that report up – perhaps because we, as a supplier to the sector, also struggle to dig ourselves out of the trenches of data collection to take a broader view and look at how best to drive improvement outcomes and results. 'Harnessing the Power of Patient Experience' seeks to do just that and I am proud to present this bookend to the work we presented in 2015.

This report furthers our insight into the challenges and obstacles NHS patient experience teams face and, importantly, things that can be done to get boardrooms onside and champion the work - by evidencing and reporting the outcomes faster and more clearly, and working far more in collaboration.

We also take a closer look at what role there is for patient leaders to embed themselves within NHS organisations, even at Director level, with a view to truly placing the patient at the heart of an organisations' culture, as such increasing the opportunity for greater and longer term impact.

The tools and techniques used to effectively capture and report on qualitative rather than quantitative data have moved along at a pace, and we assess the benefits of looking more closely at the feelings and emotions in a patients' feedback to deliver faster and more effective improvement programmes. Our research into 'seldom heard' or 'hard to reach' groups provides further insight into what can be done better through patient experience initiatives to address health inequalities in society, and that by thinking of this broader remit in one's day-to-day patient experience work, further solutions can be found to deliver system improvements.

To summarise, in producing this report we hope to have taken the conversation on that much further, with a closer look at the 'what next' and 'what could be' once we have our patient experience data. Our business always strives to go beyond being just a supplier but to help drive and challenge the discussion too. This report is, I hope, a useful addition to that philosophy.

Nick Goodman

Managing Director – Civica

Executive Summary

In our 2015 publication 'Making Sense and Making Use of Patient Experience Data' we explored whether the vast amount of patient experience and data collection activity was actually making a difference within health organisations. We concluded that, although there were many trusts using patient experience work to improve services, there was significant variation between (and within) organisations as to how well they did this. We outlined the critical factors for success, the challenges that needed to be overcome and several action points that could help organisations use patient experience activity effectively.

'Harnessing the Power of Patient Experience' continues that exploration into what is required to unlock the benefits. It is an attempt to bring together the areas of work that we consider crucial for the successful creation of good patient experience. The chapters cover a wide range of topics and issues. This may seem disparate but, as was identified in our last paper, patient experience is an area of work that touches many communities, people, teams and work processes. Indeed, one of the main themes of this paper is ensuring proper attention is given to the many aspects that good patient experience depends on.

We are not building the case for patient experience here. We consider that job already done as there are plenty of good papers published which cover the benefits and the 'why'. Instead, this is an exploration into how the patient experience community can do things better with the resources available to them.

In chapter one we look at how patient experience staff can 'keep the energy going' in the face of challenges, obstacles and frustration. We also discuss what can be done to elevate the importance of patient experience work in the board room. We learn that collaboration is key, as is the seeking out of 'champions' and networks to broaden the reach of work and potential for success. We also highlight the intrinsic link between good staff experience and good patient experience, and how the two should be thought of in tandem. Above all, we stress that the success of patient experience work is as dependent on people as it is on systems, structure and data.

Chapter two is written by David Gilbert and focuses on patient leadership. He takes us through the seven benefits that patients bring to improvement work. He sets out the barriers to patient involvement and how organisations should seek to address this. Patients should not be restricted to a 'feedback mode' where they're asked for their opinion but no more. Likewise, their role should go beyond one of scrutiny where one or two patients are asked to bring 'the patient perspective' to other people's interpretations. Instead, patients should be involved in the analysing, interpreting and decision-making surrounding patient experience data. David discusses the emergence of new roles, such as Patient Director and Patient Partners and how these roles present new opportunities for patient involvement. We discover that any learnings to be taken from patient experience data are dependent on the involvement and empowering of patients.

In the third chapter we look at the importance of questioning data and how, if care is not taken, quantitative data can provide skewed insight. Taking our lead from previous research, we look at a small data set and, using research methodology, explore how demographics and method of collection can affect results. We note that the best decisions are the best informed ones. As such, the information gathering process must contain an element of scrutiny about what data is telling us – to ensure we are, indeed, well informed. We conclude that qualitative data has a big part to play in this.

Chapter four explores, through a series of interviews, what can be done in patient experience work to address health inequalities. We interviewed several people working with groups often referred to as 'seldom heard' or 'hard to reach' to understand what the common barriers are and, importantly, what can be done to address inequality in health. While our interviewees pointed to changes at national level as crucial to addressing this problem, the chapter highlights the things that can be done at the micro level by teams and individuals, including those working in patient experience. 'Reasonable adjustments' can be made that will make a big difference. Patient experience staff can ensure that engagement activities go beyond a 'one size fits all' approach. Effort should be made to facilitate meaningful conversations with those who could be marginalised via the confines of 'the system'. The chapter highlights that patient experience teams should seek to address health inequalities not just because it's the right thing to do, but because they will find solutions and results that will benefit their wider work.

Finally, Eleanor Barlow from our partner organisation Pansensic looks at how technology can help organisations harness the power of patient stories and patient comments. Eleanor discusses how, with new advances, we can bring qualitative analysis at scale into patient experience work (as opposed to solely focusing on numbers). Such technology can avoid decision-making which is subjective or based on a hunch. It also brings a much more realistic picture of the patient experience and standards of care – Eleanor explores cases where quantitative analysis alone has provided unwarranted assurance to NHS organisations. There are, however, certain things that must be considered to make the use of tech effective in qualitative analysis. We learn that context is everything and using technology that can analyse patient experience in context is key to making this work.

Overcoming the Challenges – there’s power in people

Harnessing the power of patient experiences is not an easy task. There are plenty of challenges to overcome and potential pitfalls to tumble into. We looked at several of these challenges in our previous paper ‘Making Sense and Making Use of Patient Experience Data’, namely:

- ▶ Gathering an ever-increasing amount of data
- ▶ Coordinating and keeping up with data-related activities across the organisation
- ▶ Bringing data into one place or inputting it into central systems
- ▶ Keeping up with reporting requirements and ad-hoc requests for data
- ▶ Capacity and capability to analyse data and generate insights
- ▶ Engaging staff in improvement work
- ▶ Having the time to make sense of data (particularly qualitative data)

With regards to the last challenge (making sense of qualitative data) we look at this in more detail in the final chapter, ‘Harnessing the Power of Patient Stories’. For this chapter though, we have decided to focus on challenges where, up to this point, commentary has been relatively small.

To that end, we teamed up with Patient Experience Network (PEN) and asked them ‘What are the common challenges for your members – the ones that have not been discussed so much in papers to date?’ On 30 January 2019, together with PEN, we hosted an event in Leeds for patient experience staff that looked at:

- ▶ **Keeping the energy of patient experience going** – how to avoid burnout, being resilient when faced with challenges, being valued, how to avoid going into ‘auto-pilot’ and how to avoid becoming part of ‘the patient experience industry’.
- ▶ **How to get patient experience into the board room and on a par with finance and quality** – moving patient experience from being merely an agenda item to driving real interest and passion at the board level and an ambition to improve.

We were joined on the day by speakers from Northumbria Healthcare NHS Foundation Trust and Nottinghamshire Healthcare NHS Foundation Trust – two organisations at the forefront of patient experience practice. The day involved much discussion, workshoping and honest appraisal. Below is a summary of what we discovered.

Keeping the energy going

Why did we focus on this particular topic? It is because there is a sense amongst the patient experience community that too many colleagues feel fatigued by the work. Now we should not mistake ‘fatigued’ for ‘tired’. Tiredness, due to an increased workload and being asked to do more in the same amount of time, is a more common trait in the NHS and beyond. ‘Fatigue’, in this context, has more association with frustration, weariness, annoyance or unhappiness. This fatigue stems from a lack of visible progress following the considerable amount of time and effort that patient experience leads are putting into their work. They will work tirelessly to ensure feedback is collected, but their reward can often feel disheartening. At best, it will be a ‘no news is good news’ type of affair where the feedback collected is simply processed and then largely left alone. At worst, their efforts will create the stick to be beaten with, where the only result will be a message to ‘do better’. Perhaps even ‘do better’ with neither the control nor influence in just how to do that. In this situation, fatigue can develop quickly.

“But why does that matter? The NHS employs 1.5 million people. There will be good practice and bad practice. As such, fatigue is going to be par for the course.”

Fatigue matters here because the success of patient experience work depends on tackling it. As was mentioned at our January event, and as we noted in our last paper, patient experience should be

embedded across organisations and across teams – involving many people at all levels. However, responsibility for leading on patient experience work usually rests on the shoulders of just a few individuals. If you lose these people to feelings of frustration, weariness or fatigue, there will be no chance of unlocking the benefits that patient experiences can bring.

When we talk about maintaining energy in patient experience, we're talking about how we tackle fatigue within patient experience staff and, indeed, those defeatist feelings of 'what's the point' among the front-line teams asked to gather feedback.

The answer to tackling this problem is probably the worst kept secret in this area of work. Something that those who work in patient experience have known for some time but has yet to be formally recognised and integrated at national level. **A good staff experience is crucial to harnessing the power of patient experience.** If we energise and motivate those who are tasked with discovering what the patient's experience is, we have a good chance of creating real, meaningful change. Conversely, if we don't put effort into giving staff a good work experience, we have little to no chance of enabling that change.

So what will improve the experience of staff who work in this area? First we need to recognise that good staff experience is a 'must have' rather than a 'nice to have' - for all sorts of reasons, including its connection to better patient experience outcomes. Secondly, we have to talk to staff and ask them what they need, what's important to them and what could be done to help them in their job. Thirdly, where at all possible, we should seek to meet their requests and empower them to approach their job and individual tasks with enthusiasm.

But beyond these top-line steps to achieve good staff experience (of which there is an entirely different paper to write) there are specific things that can be done in patient experience work that would help.

For those aforementioned handful of patient experience leads at each organisation, there are things that you can do to maintain energy in your work. Indeed, one of the main messages from our January event was to focus on what can be done rather than the challenges and obstacles in front of you. It is important to acknowledge the things you can't do – the immovable barriers that will block a route or two to progress - but, having done so, focusing on areas where there is progress to be made will help combat fatigue, and break you out of the 'autopilot' trap. This may be recognisable to you as 'appreciative enquiry'.

Our attendees at our Leeds event spoke of the need to have time to stop, pause and reflect with a view to reconnecting with what's of most importance. To ask ourselves, why are we doing what we're doing? That is, of course, easier said than done. But if we don't take that time we risk sleepwalking into work processes that, while an important part of achieving better patient outcomes, are just that – only a part of what needs to be done to achieve the goals. We'd recommend that those working in patient experience, in whatever role, build in that time for reflection. Better still, meet up with your patient experience colleagues in neighbouring organisations. The result, as we found in Leeds, is a renewed and positive energy to take into the workplace.

The other main message from the event was don't attempt to do this work on your own. Don't martyr yourself for the cause. Instead, patient experience leads should be looking to build connections throughout their organisation and beyond. Collaborate with different people, teams and even organisations to spread both the workload but also the enthusiasm and energy for working with patients to improve outcomes. To that end, two phrases from our speakers come to mind. Northumbria told us that they "collaborated within an inch of (their) lives". In doing so, they discovered new ideas, new resources (sometimes money) and new energy. Nottinghamshire introduced us to the phrase "drop the anchors", i.e. find those champions and supporters who can help progress patient experience and discover positive outcomes. Energy will breed energy, so find those people who are keen to help, spur them on and work with them. This includes finding those patient leaders and making them a full part of the process. David Gilbert looks at this in more detail in the next chapter. The message here is not to look for help when you need it, but rather to setup those support networks from the word go. Do this to spread the workload, enthusiasm and energy outside of the walls of the patient experience office. Do this to ensure that the work is given the fuel it needs to succeed, and to mitigate against those times when you and your patient experience team feel fatigued, frustrated or overwhelmed.

Collaboration though raises its own questions, namely “how do you get people to work with you”? As mentioned above, identifying those champions who share your commitment to what you’re trying to achieve is a great start. But there will be those teams and individuals who may require some more persuasion. This is understandable – at our event we heard of teams reluctant to help because they perceived the request to be one of many additional things that they’ve been asked to do. To put it another way, when patient experience tasks are mandated to teams it can often be perceived as the latest in a long line of ever-changing things demanded from on-high. In this context, such tasks are viewed as additional burdens rather than a core fundamental of providing care, i.e. to improve the lives of patients.

To combat this, organisations should take note of a suggestion from Nottinghamshire Healthcare – “be more carrot than stick.” Instead of telling teams to do tasks ‘because that’s the way we do it’ or ‘because that’s the way the system works’, ask them what they want to do. There will, of course, always be national metrics and board requests that have to be met but we shouldn’t fall into the trap of believing these structures determine the methods or approaches we can take – there are more options on the table. Once you’ve asked the teams what they want to do, try your best to say yes rather than no. This will mean some work for the patient experience lead in taking the results and presenting it for a senior audience (as we discuss below). However, doing it this way and keeping the enthusiasm going is preferable to enforcing structure onto teams and jeopardising success. Above all, make it as easy for teams to collaborate as possible.

The final part to maintaining energy is closing the feedback loop. This was referred to by Northumbria as ‘The Empowering Loop’. On occasion, we’ve heard patient experience being referred to as ‘an industry’ or ‘systematic’. When it’s painted in such terms, it’s usually with a finger pointed at a conveyor belt method of feedback collection. This sees plenty of effort made in collecting responses from patients, only for them to be moved up the chain of organisational hierarchy, never to be heard of again. To be effective, both for patients and the staff working in this area, a loop needs to be created whereby those involved in the response get to hear what’s happened since. It engenders accountability and keeps front of mind the ultimate aim here.

Patient experience leads can help by championing the importance of feedback to patients and staff. As we explain below if we leave it solely to senior management and/or the board to decide how outcomes are fed back, we risk it not happening at all (or channelled exclusively as negative). Patient experience leads can maintain the energy for both themselves and other staff involved by constantly searching to close that loop and by sharing what has happened since. So, yes, information is given to management but the responses given back are also owned by individual teams.

Finally, when there is positive news, share it! The best way to maintain energy and enthusiasm is to expose your patient experience teams and champions to praise. In doing so, you remind them why they do what they do.

Getting Patient Experience into the Board Room

There is a thought that a main obstacle to harnessing the power of patient experience lies in the board room. The argument goes that board directors pay little heed to the findings from patient experience efforts, instead focusing on ‘bigger ticket’ items such as quality and finance. When attention is paid, this tends to lean towards response rates rather than results, focusing on the bad over the good. There’s also a frustration surrounding the use of ‘patient stories’ at board, where a patient is invited to tell their story in an attempt to close the gap between directors and patients. While the intent here is honourable, it rarely leads to meaningful change and can be seen as tokenistic.

A word in defence of ‘the board’ before we begin though – above we talk about the need to “be more carrot than stick” when it comes to engaging staff in patient experience activities. Alas, board rooms are beaten with a lot of sticks from national level. They’re told to simultaneously find efficiencies and savings, while improving (not just maintaining) good quality care. Multiple metrics and figures need to be reported on, on a regular basis. Where those metrics fall below a required level, attention will be placed on the board to explain and ratify the situation. As such, it’s understandable that most attention will be given to the things that will cause the most trouble if they fail to meet a required mark. As an extension of that, it’s understandable yet no less frustrating that the efforts of patient experience teams are often reduced to tables or a sole ‘patient story’. Put simply, there are too many sticks and only a certain amount of time.

However, as was mentioned at our Leeds event, 'time' is not the same as 'priority'. It would be churlish to say that NHS boards don't see patient experience as a priority. If we were to ask them, they would surely argue against that assertion. But currently, structures and systems at national level encourage boards to prioritise other things over improving patient experience and the connection between patient experience and so many other priorities and agendas is simply not seen. Or, more accurately, the system is driving attention away from using patient experiences to improve provision of care. The Quality Improvement work stream and the Patient Experience work stream are often far too disconnected – progressing at different paces, on different tracks even though they are inextricably linked; the success of one impacting on the other. 'Quality', with its broader scope encompassing 'safety', 'respect', 'governance', 'staffing', 'premises' etc. often trumps patient experience work just because of the sheer size of the topic. When viewed this way, it's easy to see how patient experience efforts can become 'stuck' at senior level.

But we also know, from organisations such as Northumbria and Nottinghamshire, that having a champion for patient experience at board level is one of the main factors in achieving the best outcomes. Results are possible without one, but they are much more difficult to achieve as the board will have plenty of other items to distract them. What each organisation should be searching for is a person, or persons, at board level who can look beyond the statutory frameworks and structures, recognise the potential of patient experiences to improve quality and standards of care, and then set about bringing patient experience work to the forefront of the board's consciousness. The task of 'getting patient experience into the board room' is actually one of creating or discovering these type of people.

How do we do that? Do we wait for that change to come from national level? Do we wait for new legislation or guidance that will encourage that drive to put patient experiences at that heart of quality improvement work? If that looks unlikely, do we simply hope that such a person takes a job at our organisation, and kick-starts the patient experience revolution amongst our board? If we do that, given the current number of such people working on NHS boards, we could be waiting a while indeed.

This is the trap that patient experience teams, and patient experience leads in particular, need to be careful not to fall into – the belief that creating or discovering those champions at board level is beyond them. The best way to drive that passion and understanding of patient experience at board is through the experts, i.e. the people who work in patient experience day-in, day-out; the people who understand the potential and power of patient experience work, and are passionate about making it work - the patient experience leads. They are ideally placed, and close enough to the board, to drive this agenda and find those board champions.

Some will have stopped themselves from engaging with the board in this way through fear or respect for hierarchical structures: a reverential "I can't tell them what to do" approach. But this notion should be turned on its head. Patient experience leads are the experts in this field and should have confidence that their knowledge and understanding will be of use to the board, and the challenges they face. The alternative is to let things remain as they are, and that's where we risk patient experiences falling off the conveyor belt, without producing a result. The key question then becomes, 'how do you approach this task of driving patient experience at board level'? At the Leeds event, we identified five different areas:

1. Know your board – the first thing to identify is what your board is trying to achieve. In doing this, you can identify what's of most importance to them at any one time. Put this together with what's of most importance to you, in your patient experience role, and you will have prepared a way forward – ready for that time when you're given an opportunity to share your thoughts. Preparation is key here. Both Northumbria and Nottinghamshire told us that you never know when you're going to 'bump into' one of your board members, and have their ear. When that opportunity comes, you'll need to know both what you and they want to achieve, and then ask them to approve an action. Think about it as preparing for your 'elevator pitch'.

2. Be elegantly disruptive – all credit to Northumbria for this phrase which nicely sums up the balanced approach needed. As identified above, board members (understandably) can cling to structures and processes. Part of your task will be to gently nudge them away from that at times without causing aggravation or pushback. It was noted at our Leeds event that board members may be reluctant to do this because of a fear of 'losing focus', i.e. we can't steer away from targets and metrics. The key here is to show them the potential benefits in a way that doesn't disrupt them from

their work, but assists it. To do that, you have to view patient experience as a cooperative arena, not a competitive one. It's not a zero sum game, where there's only so much pie to go around. If you can frame it as a win-win situation and identify solutions that are mutually beneficial, then you're more likely to progress.

3. Educate them – this requires confidence that you know your stuff and that you have the evidence to prove it. The task here is to own your area of work with confidence. Having done that, boards should be encouraged to not solely focus on figures (the quantitative stuff) but give time and understanding to what matters (the qualitative stuff). The first step is to reassure them on the figures. As Nottinghamshire told us, the message to the board should be “Don't worry about small variation in figures. If there's a real drop or increase in score, we will tell you.” Also, “Don't worry about response rates; it doesn't say anything about the improvements we've made. Focus on the data we have got, not the data we don't have.” Having gained their confidence and trust, expose them to real people and real stories. Preferably get them out of the board room, meeting patients and listening to them directly. There is an element here of helping them to connect the dots also, as statutory requirements will tempt them into working in silos, as mentioned above. Make that link between patient and staff experience. Some ideas on this from Leeds were to mirror activities and outputs between patient and staff experience. Or, bring a 'staff story' to board to complement the patient version. In doing all this, and educating the board, you will encourage a more thorough, holistic understanding of patient experience – one that combines both stories and data, one that combines patient and staff, and one that provides real results.

4. Structure – having spoken about the freeing from prescribed systems, it is important to acknowledge that structure plays an important role here too. Boards need structured approaches to deal with the many issues that they face at any one time. So one of the tasks for the patient experience lead is to take the knowledge and insight from their work and frame it in structures that the board will a) understand and b) find useful. There are many ways that this can be done. Nottinghamshire, for example, focus on one of their twelve service areas per monthly board meeting, working collaboratively with that service area to present the case to board, and generate actions to be followed up. Whichever structure you choose to promote, the key is to attempt to link the work to the board's main items and priorities. Make it useful, make it strategic and use it to drive action. How you present the message will be important too. Helping the board to visualise the findings from the experiences you've collected, and linking that to the bigger items such as quality improvement priorities, will go a long way. Just make sure that any visualisation is as rich in knowledge as it is in data. Finally, with regards to structure, always keep pushing for those actions to be assigned to a person with backing at executive level. This makes progress more likely to happen.

5. Keep going (there's no quick fix) – the final message from our Leeds event was to keep going, as discovering and encouraging those champions to emerge can take some time. As such, we've come full circle to the start of our chapter and the thoughts on 'keeping the energy going'. The message here is to keep searching for those small wins that, over time, will have promoted a new way of working at board level. Keep using that positive, 'appreciate enquiry' to push for improvements.

It's interesting to look back at what was discussed in Leeds and what connects the two challenges described above and, indeed, the solutions to overcoming them. These problems arise when we forget about people. Patient experience work is a complex and complicated thing to do well – it requires a lot of data, and a lot of competence to collect, analyse and action that data. Hence why systems, structures and processes are an important part. But problems arise when we focus solely on these systems, structures and processes, i.e. when we focus solely on the health of the machine rather than why the machine exists in the first place. To harness the power of patient experience we need to remember that success is also dependent on the people who touch this area of work – the staff leading on patient experience, the board who will ultimately action progress, the teams collecting data and, of course, the patients themselves. Time needs to be invested in those groups and individuals to make sure they are empowered and armed with what they need to truly deliver the benefits for all.

Patient Leadership – taking action together

This chapter is a collaboration with David Gilbert: patient director, author, and advocate of making patients partners in decision-making and healthcare improvement. David was integral in conducting the research for, as well as writing our report 'Making Use and Making Sense of Patient Experience Data' and we are grateful to have him as a collaborator again here.

1. The emergence of patient leadership

In our report 'Making Use and Making Sense of Patient Experience Data' we noted that patients should have more of a role in:

- ▶ Deciding what measures of experience should count
- ▶ Helping to gather, analyse and interpret data
- ▶ Deciding what to do about it • Co-designing and supporting improvement

Since then, the emergence of patient leadership has highlighted the various ways in which people who have been affected by life-changing illness, injury or disability can help.

Patient Leaders can have many roles. Some are entrepreneurs like Michael Seres, a patient who had undergone a bowel transplant and then invented a Bluetooth sensor-enabled colostomy bag that does not overflow. Denise Stephens, who has relapse-remitting MS, set up an online community and assisted living organisation 'Enabled By Design' after sensing, as a designer, that her room had become like a hospital ward. Ceinwen Giles set up 'Shine Cancer Support' for young people affected by breast cancer, following her own life-threatening experiences. Others are campaigners or activists, online dialogue specialists and improvement advisors.

While there needs to be wider investment in skills development, 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. And, critically, in the patient experience field.

2. Seven things that patients bring

If patients were more involved, the benefits are seven-fold.

a. Richer insight

Time and time again, I have seen patients shine a different light, often deeper and broader, on problems to be tackled. A service improvement project might initially be aimed at tackling what happens in an outpatient clinic. With patients or carers in the room, the goal posts shift for the better and parameters broaden – people will talk about themes of access (e.g. transport, parking) or humanity and different aspects of customer care (staff smiling or looking up at people when they come in at the reception desk). The vision for the project and its intended outcomes shift. The 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.

b. Potential solutions

Patients often have the guts, insight, imagination and freedom from institutionally limited thinking to ask 'what if...'? They also widen the array of options for improvement and change.

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. Patients have lots of ideas for improvement. But those moments can be fragile or fleeting. I once thought it would be a good idea for nurses or healthcare assistants to close the window above my dying mum's bed, as she looked freezing. When my dad had cancer, we asked staff to stop letting the doors bang closed as this shocked him out of his snatched moments of sleep. These are ideas that could easily be put into practice and become part of routine 'culture'.

Ideas from patients can also be about deep system change. Patients as partners in change projects could contribute so much. One patient on a diabetes improvement project persuaded GPs that flexible prescribing guidelines were a good idea. Another held out for better out-of-hours services. Another for more accessible outpatient clinics for people from Asian communities.

Having patients in the room at the beginning of an innovation process, helping to sift data, analyse it, think about what to do with it, sparking the energy for ideas based on 'what if...' is only the start. They can continue to ask questions about whether all the best ideas have been found, and whether anyone is missing from being part of the solution. Some patients go further to become real entrepreneurs, and have the energy and will to take ideas all the way, working with professionals as partners in implementing change. Others would love it if their ideas were taken up by others. It all depends on who we are, our circumstances and what support and opportunities there are.

Wouldn't it be fascinating to set up an 'ideas from patients' pool, where staff and patients could work together to identify the best ideas and carry them forward together. Pie in the sky?

c. Changing relationships

Healing is about relationships. With patients in the room asking questions, and moving beyond their own agendas and wanting to 'give their views', others are given permission to explore and go beyond defensiveness. The tone of the relationship may alter as people 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' as Mark Doughty has called it – one that supports conversation that produces outcomes. Power shifts and relationships become more equal.

This is about 'modelling the sort of relationships' that are at the centre of healing experiences. In this sense the process is the outcome – the nature of the conversations and relationships are important in and of themselves. I've witnessed one doctor come away from such a shifting conversation to say that this is how she will work with patients in the future.

d. Individual benefits

Patients benefit from being involved. They can feel more confident, develop their skills and expertise and actually feel better. A friend of mine said that being involved was important to her recovery from mental health problems, particularly because she felt valued for her contribution.

This means people not being narrowed to 'telling their story' but being able to call on, what Alison Cameron has termed, '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. Morale can be lifted if they see that patients are not asking always for 'the moon on a stick'. As conversations become deeper about what can be done, they can feel that we are truly 'all in this together'.

e. Better quality decisions

If people have been involved as equal partners and are partners in decisions – not just feeding back for others to go away and make them – 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. Note that consensus is not that everyone has to agree firmly, but that all can live with it.

This has deep implications for transparency, governance and accountability. I once went to a 'blue-sky' event on Community Mental Health Teams and we were asked as users how many teams we wanted. 'Loads' was the answer, until the finance director was straight with us about resource

constraints. Then the real discussions started and, while disappointed, we understood limitations and appreciated honesty.

We need to have difficult conversations and remain at the table. Just as honesty in the consulting room about 'breaking bad news' is hard but worthwhile, honesty is the way to rebuild trust and confidence in healthcare decision-making.

f. Changing practice

I have seen and heard about dozens of changes in 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.

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? I think it is more reasonable and practical to look at changes in practice. I have also seen the search for the Holy Grail – seeking better health outcomes through involvement – diverting attention from getting on and doing it.

g. 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 the board will find ways to develop the cultures and systems that support involvement in improvement.

I've seen doctors mandated to take part in projects. At the beginning they sit, irritated, with their arms folded or looking down at their smartphones as patients are 'allowed in'. By the end, they want to bring patients in properly – not just as feedback fodder – to try it in their own areas. Voila! Clinical engagement.

3. The barriers to patients being more involved

However, the traditional approaches to involving or engaging patients do not work, and so we fail to value the jewels offered or to change the 'currency' of healthcare toward what matters. The approaches and methods used within the engagement and patient experience industry rely on two main styles.

a. Feedback Mode

The first is that of feedback: patients are invited to fill in questionnaires, attend focus groups or tell their stories during training and education programmes or at board meetings or the like.

There are some conceptual difficulties that serve to limit the nature of the usefulness of data that is sometimes gathered.

Firstly, most of the data gathered focuses on what happened in the past. This data might be useful to an institution as part of its governance processes in order to provide reassurances about meeting standards or targets. But it limits people's broad expertise to a retrospective glance over the shoulder.

Secondly, much feedback that is sought is restricted to people's experience of services, again perhaps useful to an institution. However, what matters to people is as much about living with a condition, or about their lives beyond the institutional scope of interest. Patients' experiences are one (sometimes small) part of 'what matters' – we need to broaden the agenda.

Thirdly, and most critically, analysis of the data, its interpretation – what is important and what is not – and ensuing narrative about what the cause is and solution should be is largely in professional hands. The meaning of data is left to professionals to assess through their own lenses based on their own

assumptions and sometimes narrow institutionalised thinking. What is 'feasible' rather than necessary.

b. Scrutiny and representation

In order to understand why patients are not partners in analysing, interpreting and making decisions on data, one has to understand the second style of 'engagement' – that of scrutiny. Patient representatives are asked to 'bring the patient perspective' to strategic conversations and committees. Without clarity of purpose or support, all around the table can make assumptions as to how the rep should do this.

The role of 'representative' is often divorced from the work to learn from patients' experiences and what matters. The oversight of engagement and experience mechanisms are usually also done by different teams, directorates and do not join up as well as they should.

There are three sorts of 'traps' for a patient or lay representative – all of them leading to an undermining of associated work on patients' experiences.

Trap 1 - Surrounded by powerful professionals and seeking legitimacy, a rep can overly rely on their own experiences or stories. But some may dismiss the 'representativeness' and thus legitimacy of such a view –contrary to the storyteller's intention.

A committee is not a focus group. Judicious use of storytelling has its place, if accompanied by strategic insight that helps the group move towards joint solutions. But, if used as an end in itself, may accomplish little. But feedback of this sort is relegated back to the 'proper' patient experience feedback channels.

Trap 2 - Sometimes, the rep works hard to 'gather' patient perspectives to bring back reliable 'data' about the patient experience. This may make them more credible with professionals accustomed to the arid zones of evidence-based decision-making. But it lets the group off the hook. Patient and public engagement and learning from patients' experiences is a collective (often statutory) duty and the rep should not be used as a free, quasi operational lead for engagement. Many reps find their goodwill taken advantage of, and have found themselves isolated and exhausted.

Trap 3 - More 'experienced' reps can come to be seen as a one-stop shop, able to address all problems generated during an initiative. "What do patients think?" I was once asked. "What, all of them?" I thought. This can be flattering, but assumes one person (or two if the committee is generous) can be 'the expert'. This mirrors the medical mind-set that we may want to challenge – 'doctor knows best' flipped to 'patient knows best'. Instead of a conduit capable of opening doors to others, reps can unwittingly close those doors and the group can tick the engagement box and move on, unruffled.

All these traps illustrate how 'feedback' and patient experience work is often poorly managed from within the system; and how it is buffered.

Thus, these 'feedback' and 'scrutiny' modes maintain 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.

4. New opportunities – the Patient Director and Patient Partners

The Sussex MSK Partnership (Central) made a brave decision to appoint the first patient director – someone who has had experience of a life-changing illness, injury or disability (in my case, mental health problems) and can harness these experiences at senior decision-making levels.

This role ensures that patient leadership is embedded at a senior level, within an executive team that includes a clinical director and managing director. This models shared decision-making at corporate level. The patient director's role is to help the Partnership focus on what matters. This includes embedding patient-centred cultures, systems and processes such that they become 'hardwired' and making sure we learn from, and act on what patients think about services. The patient director will also support patients to enable them to be influential and valued partners in decision-making.

Being the patient director has enabled me to experiment with a different approach to engagement. For example, we have eight patient and carer partners. They bring professional and personal wisdom alongside their experiences of using our services. Patient and carer partners are not representatives or there to provide feedback, but are 'critical friends' who check assumptions, ask questions, provide insights into reframing issues or identifying problems, change dynamics and model collaborative leadership.

My role is to broker opportunities in improvement or governance and support them to ensure they have the capacity and capability to be effective. Patient and carer partners augment other involvement and feedback work. This work has been developed during a period of intense operational pressures. During the past three years, the Partnership has transformed the way MSK services are delivered and patient partners have been alongside as we have done so. We wanted them to be partners in every multi-disciplinary team (MDT) that oversees quality in each of our musculoskeletal pathways (orthopaedics, rheumatology, pain management and physiotherapy).

Slowly, 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 and trust - all things the NHS has precious little of. We are ready for the next step – for partners to move from an improvement role into a more steady-state governance role as members of MDTs.

Meanwhile, we have tried to make sure our work to learn from patients' experiences dovetails with the engagement work.

We have developed a 'Data Action Group' comprising patient partners, support staff (call handlers, administrators, clinic centre managers and receptionists) and clinical staff. This takes the free text comments from the PREMs (Patient Reported Experience Measures) survey (grouped under 'what worked' and 'what needs improving') and looks at whether action is needed based on those comments.

The work is not without its challenges. The group thinks through whether comments are 'actionable' – that is whether comments suggest 'desirable' improvements, and whether any such improvements are 'feasible' to make. Should we? Can we? Those are the two questions we contend with.

It is interesting that some comments are contested. That is, some people around the table will think a suggestion arising from a comment is 'desirable' but not 'feasible'. While others will say it is feasible. We have not studied this in detail, but it is my strong hunch from what I have seen that staff may sometimes say an action is not 'desirable' because, when further questioned, what they mean is that it is not 'feasible' to carry out.

Furthermore, reasons for lack of feasibility may, in turn, be more to do with their own sense of lack of power in the system, rather than a judgement made on the organisation's overall capacity to change things. In other words, 'feasibility' and 'desirability' of action is critically dependent on who is in the room, and who is in a position to lead change.

More difficult still is when a judgement comes in – good or bad; intentional or not; individual versus system attribution; where accountability fits and what accountability actually means (people to be punished; people to take action on improvement).

Without patients in the room, without them in these difficult conversations, without patients having decision-making power, then any work on learning from patient experience data and improving things that matter to patients will be a largely futile exercise. We are getting over some of these challenges, slowly.

The Importance of Questioning Data

Improvement and positive change is dependent on good decision-making, and the best decisions are the best informed ones. To that end, data (both qualitative and quantitative) is incredibly useful. Data helps us to answer the questions necessary to improve the world around us: 'what is the current situation?', 'why is that the case?' and 'where can we begin to make the situation better?'. Technological advance has meant that we can now collect and analyse data on a scale previously unheard of. This has meant that we have the potential to be more informed than we ever have been before. However, there is a potential downside to the ease with which we can now process 'big data'. It is possible that, in our comfort and routine of producing results, facts and figures, we have forgotten that data is fallible.

Not always (not even most of the time) but, sometimes, data can give us a 'skewed' result. This is because of how data is affected by variables. Variables could include the method through which that data is collected, the location where the data is collected, the type of individual providing data, the type of individual collecting data etc.

There is already research published (see for example Sizmur, Graham and Walsh, 2014) within the patient experience community that suggests that these variables could have a bearing on how patients respond to questions. Why does this matter? Well because it would suggest that the playing field of patient experience is not an even one and that a simple reading of scores, without further questioning, may lead to a distorted (if not misinformed) view of the actual state of affairs. It would suggest that, to harness the power of patient experience, organisations should take this into account.

This idea intrigued us and so we asked our Research Team to conduct a small investigation. We deliberately kept the scope small (using just two sets of data) as we wanted to see whether conclusions could be drawn even at that scale. Our team's efforts were inspired by the previously mentioned paper written in 2014 by Sizmur, Graham and Walsh. That paper tested the impact of age on patient experience feedback and determined that older patients were more likely to score 'Extremely Likely' compared to younger patients. A further finding from their study suggested that online surveys received a significantly less positive response than telephone and postcards. Their research suggests that Friends and Family Tests are vulnerable to bias and administration effects. Interested by this, our team explored two things. Firstly, the relationship between FFT and other forms of patient experience questions (to ensure that they broadly correlate). Secondly, to test the theories put forward by Sizmur, Graham and Walsh.

Their work and findings are detailed below. A note that, as the team conducted this as a research piece, the writing is more academic than commentary in style. As such, we comment on their findings in the end of chapter summary.

Methodology

To ascertain whether demographics have a similar effect on other patient experience questions as the Friends and Family Test, an Analysis of Variance was conducted on patient experience data. The data was obtained by two consenting NHS trusts, which had comparable survey questions (these being questions outside of the FFT). Before any data analysis, all identifiable information was anonymised to ensure that no personal information can be attributed to individuals or indeed to the trusts. The premise of this work is not to assess individual trust scores but to understand the impact of demographic information on obtained scores.

In order to fairly compare our results to the Sizmur et al paper, we adopted the same Net Promoter Score (NPS) analysis to FFT as the Sizmur paper did in 2014. However, we recognise that FFT results are presented and published in a different way today.

Data

To assess the potential influence on survey responses, two unrelated datasets were obtained from two mutually independent anonymous trusts. The data used covers the period of time from 31st August 2014 to 30th January 2019.

The number of responses for the experience surveys were, for Trust A, 13,434 and, for Trust B, 7,325. The responses were not disaggregated by ward level and the data was used as a cluster of all responses. This approach follows the methods used by Sizmur, Graham, and Walsh (2014), who measured the influence of patient age and sex on the results from the NHS Friends and Family Test. To come up with FFT scores that are comparable with the Sizmur et al study, we used their approach (and the one that was previously used at national level), i.e. the percentage of detractors was subtracted from that of promoters to give a score within the -100 to 100 range. We then produced scores for both response methods used (online and post). The mean FFT score for Trust A's online response was 61.11 (from 756) and, for paper, 62.33 (from 12,121). For Trust B the online mean score was 71.24 (from 2,387), and the paper response mean score was 64.9 (from 2,894).

Analysis

Here we explore the relationship between the effectiveness of other patient experience questions on overall FFT score, which trusts use to monitor improvements to treatment and care. Due to limitations of space, partial results are presented here. A series of cross-tabulations, independent T-tests and Analysis of Variance were used to assess the possible relationship between other patient experience question responses and FFT results.

Results

1. What is the relationship between other patient experience questions and FFT?

To initially explore if there was indeed any relationship between FFT scores and other patient experience questions we ran a series of cross-tabulations. This analysis allows us to cross one set of responses against the other (i.e. FFT responses vs. other PX responses). The result of which demonstrated that there were several positive relationships between the two (see Table 1).

		Information was given in a way I understood.	
		No % (number)	Yes % (number)
How likely are you to recommend our Emergency Department to friends and family if they needed similar care or treatment?	Extremely likely	44% (218)	72% (8,783)
	Likely	19% (96)	22% (2,626)
	Neither likely nor unlikely	11% (53)	4% (504)
	Extremely unlikely	15% (73)	1% (143)
	Unlikely	11% (55)	1% (138)

Table 1 An example of Cross-tabulation results

The data across several metrics suggests that there are positive relationships between those that score 'Extremely Likely' or 'Likely' on the FFT to the positive scores for other patient experience questions. As an example, from the table above we can see that respondents who answered 'Extremely Likely' on the FFT question are highly likely to give a positive result to the 'Information was given in a way I understood' question. To test whether the relationship occurs by chance or, in this case, because of mutually positive responses, an independent t-test was conducted. The t-test also known as the independent t-test or student's t, is a statistical test which determines whether there is a statistically significant difference between the mathematical averages in two unrelated group scores. In scientific analysis we often seek to reject the null hypothesis, which in our case is that patient experience and FFT mean (average) scores are equal, and so any relationship seen in the data can occur by chance. Here we demonstrate that the mean scores are significantly different. In the example above, the result ($F= 441.5$, 2-tailed $P \text{ value} < 0.01$) strongly suggests that there is a significant difference between the means of the two groups. Hence this relationship between positive patient experience and positive FFT scores are unlikely to occur by chance.

The test results were consistent throughout the remaining questions of Trust A and all of the questions of Trust B. There is significant evidence to suggest that positive responses to patient experience questions in general are likely to influence a positive FFT score.

2. Can demographics influence other patient experience scores in the same way as has been shown to influence FFT?

The second phase of analysis for this paper is to replicate the findings of Sizmur et al. (2014) which suggest that patient age is an influencing factor for FFT. After that, we wish to examine whether the same effect is also true for other patient experience questions. The results of the analysis could demonstrate a need for trusts to control for age by introducing sampling strategies which are more representative of hospital patients. With that said, this analysis only looks at the data from a trust perspective. Therefore, further analysis of the data by ward and location could be needed.

i. The impact of demographic factors and delivery modes

Age:

The investigation by Sizmur et al. (2014) warrants further analysis as the impact on age could significantly affect the FFT of other patient experience scores. The result of which could affect how trusts plan for improvements. In our analysis, Trust B data shows a generally positive correlation between the age and the satisfaction of respondents. We are suggesting that the higher age group tends to reflect a more amenable patient experience. However, as we see in figure 1, this tendency is not valid for patients aged 85 and over. We further explore these results by applying the analysis to the scale questions below. Figure 1 shows the curve line on FFT score is fundamentally synchronising the curve of the “Extremely likely” response. This is due to the response bias of “Extremely likely” being selected, i.e. if you are 65-84 years of age, you are more likely to present a positive FFT score. The positive correlation is also proved statistically significant (Pearson’s $R^2 = .071$, $P < .0001$).

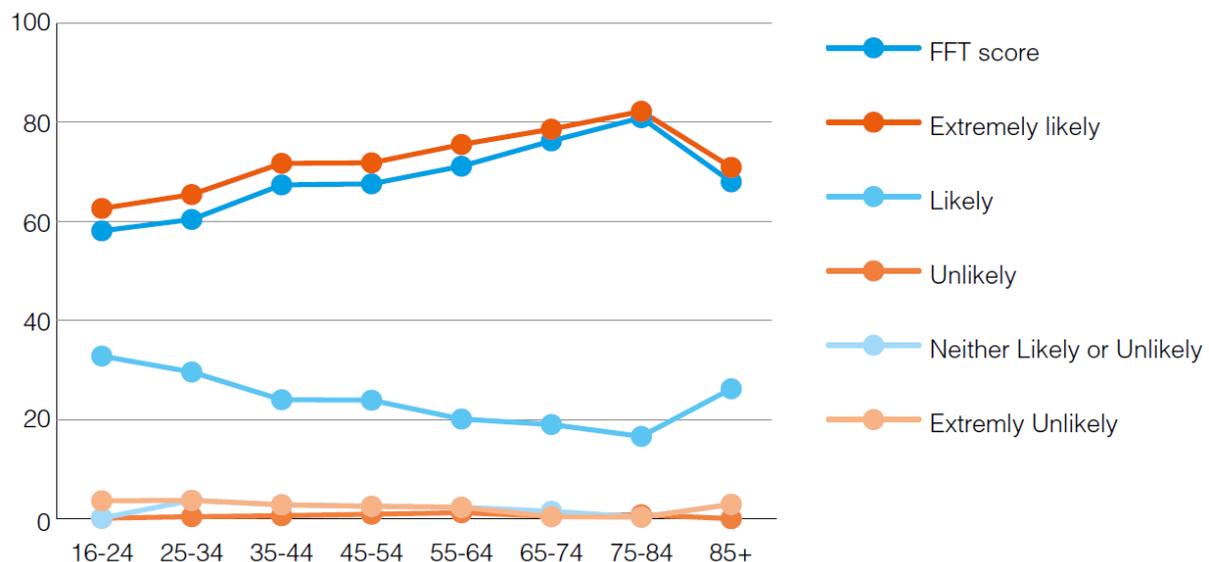


Figure 1 Age of patients and FFT score

Gender:

Interestingly, our analysis indicates that gender may also play an influencing role in patient experience. Although the direction of the correlation was different between Trusts (Trust A Pearson’s $R^2 = -.036$, $p < .0001$; and Trust B Pearson’s $R^2 = .030$, $p < .05$). From our restricted data set, those who identified as female were more likely to have a more negative FFT score.

Mode of delivery:

In contradiction to Sizmur et al. (2014) results, evidence here suggests that there is an increase in positive responses where the surveys were conducted online (Trust B Pearson’s $R^2 = -0.46$, $P < .0001$). Although, the results are not significant for Trust A (Pearson’s $R^2 = 0.005$, $P > 0.606$).

Regression analysis:

The results were verified using a multiple regression with the FFT score set as the dependent variable and other patient experience questions, demographics, and delivery methods set as the predictors. Overall there was goodness of fit for both models ($R^2=0.18$). Table 2 shows regression analysis for Trust A; Table 3 shows regression analysis for Trust B.

Other patient experience questions are observed to have significant explanatory power to the variance of FFT score which measures the respondents' necessary viewpoints, as all the coefficients are positive and significant. There is strong evidence that the age of respondents has a substantial effect on reported patient experience. This finding is in line with Sizmur, Graham and Walsh (2014). Two-way effect of gender is found. Trust A data demonstrates that women would be more negative, but Trust B data leads to an adverse conclusion. Data cannot support the finding of Sizmur, Graham and Walsh (2014) which states online responses were negative compared to the postal method. Delivery Method is not significant in Trust A model and Trust B model suggests the online process is associated with more positive responses.

	Trust A	Coefficient	Standard Error	t	Significance
Intercept		-17.453	4.346	-4.016	.000
I was made to feel welcome		60.163	2.849	21.115	.000
Information was given in a way I understood		9.816	3.274	2.998	.003
I was verbally informed of the waiting time		19.130	1.135	16.858	.000
The Emergency Department appeared clean		7.459	3.118	2.393	.017
Age		3.353	.283	11.831	.000
Gender		-7.098	1.016	-6.989	.000
Delivery Method		-.300	.244	-1.231	.218

Dependent Variable: FFT R Square=0.18, Sig. F Change<0.01

Table 2 Trust A Regression Analysis FFT and Patient experience predictor variables

	Trust B	Coefficient	Standard Error	t	Significance
Intercept		-269.164	9.244	-29.119	.000
Overall, did you feel you were treated with respect and dignity while you were in the hospital?		25.928	2.540	10.207	.000
Did you have confidence and trust in the staff treating you?		40.493	2.498	16.211	.000
How much information was given to you about your condition or treatment?		10.274	1.417	7.250	.000
In your opinion, how clean was the outpatient department?		27.267	1.411	19.318	.000
Are you?		4.090	1.174	3.483	.000
In which age group are you?		1.632	.315	5.177	.000
Delivery Method		-1.799	.467	-3.852	.000

Dependent Variable: FFT R Square=0.18, Sig. F Change<0.01

Table 3 Trust B Regression Analysis FFT and Patient experience predictor variables

Discussion

The analysis of the research confirmed the results of Sizmur et al. (2014), which indicates that the demographic profiles of patients influence the Friends and Family Test scores. However, given that the results of the FFT scale question (see Figure 1) were so heavily skewed toward "Extremely Likely" it is unlikely to cause the FFT scores to be dramatically affected. As such, trusts may need to dig

deeper into their local demographic data by question and by service to truly understand what different patient groups think, and avoid lumping them together as one.

Concerning the mode of delivery of patient experience, the results of this research do not have the same conclusive results of the Sizmur et al. (2014) paper. Here this research indicates that online surveys are likely to receive positive scores as opposed to the slight decline in scores found in the Sizmur et al. (2014) paper.

Limitations

It is important to note that the results discussed here are based on the responses of two trusts, despite having large response sizes and cannot be viewed as representative of all trust results. More work is undoubtedly worthwhile to explore more deeply what the findings seem to suggest. Similarly, the data used here has not distinguished by ward or department to understand other possible influences on the FFT. Therefore, there is a possibility of hidden effects which were not accounted for.

Summary

So what does our small, testing of the water tell us? Well, even taking into account the limitations of the research due to its size, it is clear that demographics will have an effect on how patients respond to questions of experience. Interestingly, it suggests that the effect may be different depending on the trust. The effect of age was consistent with previous research on the topic (with older patients more prone to respond positively), but there was variation when it came to gender. There was variation too in how the method of delivery effected responses, with one trust showing that online surveys actually led to a more positive outcome, when research elsewhere has suggested the opposite.

Confused? At this stage, we would forgive you if you've become a little data-giddy. But there is an important point to make here – variance and bias exists in patient experience data. This bias may be comparatively small, but it is there. Furthermore, that bias may differ in its character from trust to trust.

The best decisions are also the best informed ones. Part of that information is knowing what bias exists within your organisation, and on what scale. To do that, organisations should analyse their data sources, and the environments in which data has been collected, to discover the trends and patterns. Making time to periodically question the genesis of your data will help you to understand its true meaning.

Qualitative data has an important role to play here. It's the qualitative information you collect, in the form of patient comments (sometimes referred to as 'free text' or 'open text') that will allow you to test the assumptions drawn from quantitative scores. These two forms of data, used in tandem, are the best way of achieving a true picture of your organisation. We look at the use of qualitative data in our final chapter, 'Harnessing the Power of Patient Stories'.

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Addressing Health Inequalities in Patient Experience Work

We know that the benefits of understanding patient experience can and should bring about positive change. Simply put, patients should feel listened to and be able to work in equal partnership with service providers to re-design services if it is clear that improvements can be achieved. This is at the heart of our 21st century NHS and indeed built into its constitution.

On 7th January 2019, the NHS long-term plan (formerly known as the ten-year plan) was published setting out key ambitions for the service over the next ten years. Part of the publication is dedicated to 'more NHS action on prevention and health inequalities.'

In this chapter, we explore what health inequalities mean to those who work with individuals and communities who experience a lack of equal opportunity related to health care. Our aim is to shed some light on what the commonalities are in health inequality and what those people and teams working in patient experience can do to address them.

To help us gain insight, we interviewed several individuals with an interest in this area. MES selected the interviewees as we recognised them as highly experienced and knowledgeable in their field of work. We acknowledge that those interviewed do not represent all individuals and groups who experience unequal opportunity. However, representation is not what we are looking to achieve in this chapter. Instead, we wish to use their experience and knowledge to provoke a conversation on what should happen to achieve the 'action' described in the NHS long-term plan. Importantly, we want to provide the reader with some thought on how they could assist this aim in their area of work.

Addressing health inequalities will be of benefit to patient experience staff beyond the wider scope of it being 'the right thing to do'. At a recent event MES held in Manchester, we invited Laura Neilson to speak. Laura, as well as being project lead for the Shared Health Foundation, is the CEO of Hope Citadel Healthcare CIC which runs several GP practices in some of the most deprived areas of Greater Manchester. What Laura told us, from her experience in proactively addressing inequality, is that if you get it right in this challenging area, you will get it right across the board. The lesson for patient experience teams is that the results gained by addressing health inequalities could be successfully replicated in other areas of the work. It may be the most challenging area to address but the biggest rewards and lessons are to be found here.

We want to thank the following contributors for their time in participating in the interviews and for sharing their views:

- ▶ James Munro, Chief Executive Officer, Care Opinion
- ▶ Dr. Kath Maguire, Research Fellow, University of Exeter's European Centre for the Environment and Human Health
- ▶ Leroy Binns, Campaigns Assistant & Office Assistant, Mencap
- ▶ Lynnette Charles, CEO, Mind in Haringey
- ▶ Professor Margaret Greenfields; Ph.D.; SFHEA, Professor of Social Policy & Community Engagement & Director: Institute for Diversity Research, Inclusivity, Communities and Society (IDRICS), Faculty of Society & Health, Buckinghamshire New University.

Defining health inequality

Health inequality can often be wrapped up with (or hidden by) other terminology used to identify people and groups who are deemed 'distant' from health services – e.g. 'seldom heard' or 'hard to reach'. The issue with these phrases is that they can paint a limited and unhelpful picture of what the issues are and which people are affected – a particularly dangerous thing for patient experience professionals who will not have regular exposure to health inequalities. To help address these inequalities, we must first have a good understanding of what we're looking out for. James Munro of Care Opinion summarises them well:

I have three disparate answers. Firstly, there are socioeconomic inequalities such as income and wealth which are fundamental to health and healthcare.

Another inequality is between the people using and the people providing healthcare services. Even if we addressed all of the socioeconomic inequalities, we would still have to deal with the fact of the inequality between people providing and using services. The people providing services may often feel that they are powerless, but they have much more power than people using services.

There is another dimension of inequality which is across the many different kinds of people accessing services. Here the inequality is in the voice that people are able to have, and the degree to which people are heard: there are differences in the abilities of those living with a learning disability, mental health issues or those whose first language is not English, or those with low literacy or cognitive or sensory impairments.

Of these three (which we could refer to as socio-economic, power-based and lack of voice), the first and last may be more recognisable to readers than the second. We would suggest this is because, in part, awareness of diversity in the NHS has been framed in demographics – i.e. what ethnicity you are, what disability you have and what area you live in. Of course this is no bad thing and much work and effort has been made, at both national and local level, to ensure care is considerate of these issues. However, there is more work to be done and awareness to be raised about the second point – the power balance between patient and provider of care. This should be viewed with real importance in the patient experience community, as it potentially has great impact on the way patients interact with services and how forthcoming they are with their views. Dr Kath Maguire told us:

I am aware through my work with people without higher education experience, communication difficulties or emotional difficulties that when dealing with power or institutions that they are disadvantaged in accessing the support and care that they need. They are disadvantaged in putting their experiences into health research, so their questions are not raised let alone answered.

Healthcare professionals providing help and support are, by definition, in a position of power. They are providing something that the patient needs. As such, there has to be awareness of this dynamic and how it can, in the worst cases, effect the experience of patients. Dr Maguire told us of a past experience of hers:

The treatment that I received as a single parent living in a deprived inner city area, with no educational qualifications was a seminal experience. As a parent of a sick baby, I was treated as somehow at fault and excluded from care decisions and marginalised in my child's care.

In an earlier chapter we discussed how systems and structures, while necessary to deliver the vast amount of work undertaken within the NHS, can alienate those (or fail to represent those) who don't fall into the system's remit. Health inequalities come into play here. While 'the system', framed by policy and regulation, has tried to address demographic equality through the Equality and Diversity systems and 'protected characteristics', inequality still remains – especially in the socio-economic and power-based causes defined above. Professor Margaret Greenfields told us:

Often policy has been driven by quantitative measures and metrics which don't take into account the lived experience of people most impacted by legislation and enacted policies as operationalisation takes place.

And later, Professor Greenfields said:

There are also fundamental issues with the fact that health services are set up with a 'one size fits all' model.

There is a lesson here for patient experience professionals. Firstly, to keep on fighting the good fight and pushing for patient experiences to be used effectively and meaningfully to improve the provision of care. Secondly, to

ensure that patient experience activities are not confined to a systematic work stream that may marginalise those vulnerable to the causes of health inequality. This requires some flexibility in approach and delivery, but perhaps not as much as may be feared. Leroy Binns told us:

Everybody needs equal healthcare and the right care with reasonable adjustments. Reasonable adjustments are things such as needing more time with the doctor or a quiet space to be alone.

'Reasonable adjustments' is an excellent way of describing it. A lot will be achieved by bending ever so slightly to the needs of those who require something outside of the normal process. Importantly, it's something that can be done without the need for policy change or national guidance.

The contributing factors

We asked our interviewees what things are contributing to health inequality. Income inequality was often cited and its effect on how difficult it becomes to access services. This is, quite clearly, an enormous problem and one that our interviewees stated has got worse over the last few decades. However, the solutions required to meet this problem go beyond local organisations and staff. As such, we'd like to focus here on the contributing factors that can be addressed by patient experience staff and the leaders they report to.

That said, money is a factor; the elephant in the room we cannot ignore. As we know, the NHS has had to meet challenges caused by a restriction in funding and spending in recent times. That has led to extra pressure on staff when it comes to delivery. This is something Professor Greenfields addressed in her interview:

There are issues both ways – healthcare providers are under pressure with set appointment times which are often inadequate to deal with patients. There is often a lack of translators and the time to properly explain things to patients. As such I'm not simply saying that health providers 'get it wrong' – but the combination of pressures on staff and lack of cultural competence or sometimes poor patient care or reluctance to engage with a stigmatised population have an enormous impact on health outcomes, patient wellbeing and sense of being treated with dignity and respect.

Professor Greenfields mentions a 'lack of cultural competence' here, which could also be described as a lack of understanding or awareness for how certain groups susceptible to health inequality should be engaged. This is a theme that ran through our other interviews. Leroy Binns stated:

I think that inequalities happen because hospital staff are not trained – they need mandatory training. The government has just put this in place as part of the ten-year plan but just for hospital staff. The hospitals are where we think the main problem is as reasonable adjustments are not happening.

It is of no surprise that a lack of training has correlated with a restriction in funding, and the added pressure on services that comes with that. Dr Maguire told us of another contributing factor prevalent in our interviews (and an issue raised by David Gilbert in his earlier chapter). That of a lack of patient engagement in decision-making:

Also, patient voices are not sufficiently heard in policy-making processes. Things are designed in a way that suits the middle classes much more than it does the poor.

Health inequalities over time – where are we now?

So how big is the issue of health inequality? Have things improved over time or got worse? What is the scale of the task that health organisations are faced with? Our interviewees described a mixed state of play. Many pointed to a more 'open' culture in healthcare. Lynnette Charles told us:

I think that people are more open – there are more meetings with statutory organisations in health looking at how we might resolve problems.

James Munro talked of a 'greater transparency in healthcare':

I think we are seeing a gradual move towards greater transparency in healthcare and awareness that people using services may have a very different perspective from those providing them. We are seeing a bit less defensiveness on the part of health service providers, but as I said that type of awareness fluctuates.

Professor Margaret Greenfields agrees that there is greater awareness of health inequality, and a willingness to be more open to these issues, but there is still some way to go in acting upon that:

There is now a greater awareness and attention in terms of practitioners and policy makers being alert to the fact that some communities are underserved and have poorer outcomes. But how that awareness translates into practice depends on committed individuals with an interest in a particular population and the make-up of local Clinical Commissioning Groups and what they want to prioritise.

This would seem to be the crux of the matter: there is generally more understanding of health inequalities and a willingness to address them but not enough action to progress that will. Lynnete Charles gave us this thought:

What is the point in recording that an area is high in deprivation if we aren't doing anything with it? We need to be tackling that. We should either be celebrating if things are improving, but we need to use that data and be proactive.

As such, our interviewees suggested that health inequalities have worsened in recent times. The finger of blame for this was pointed at 'cuts' in healthcare resources. Dr Kath Maguire considered this:

I think that things have got worse as services are under greater pressure. Some of the things that supported people to access services have been seen as peripheral and have been cut, and this makes things more difficult.

Professor Greenfields suggests that the pressures on staff, resulting from a restriction in funding, also manifests itself in another way, detrimental to health equality:

High staff turn-over and greater demand for services also means that there is rarely a personal relationship or any standing between staff and patients – for example within local GP surgeries or clinics.

And so the situation the sector finds itself in at the moment is one where health inequalities have been able to increase and deepen. The challenge to all those who work in healthcare is how do we address it? That is, of course, a huge question and one that has to be addressed by many players. But if we look at this within the confines of patient experience, there is something to think about. Do we leave it to those at national level to kick-start that shift, or can we find ways to progress these issues within our own localities and communities? Lynnette Charles told us:

Like everything at the moment, there aren't enough resources – we need to be more creative and clever to think about how we use what we have got.

A theme of this paper has been 'focus on what you can do rather than what you cannot'. This will require, as Lynnette Charles suggests, some creative thinking. However, it is not the case that addressing health inequality is beyond the scope of the individuals and teams involved in patient experience. There are things that can be done.

What can be done within patient experience work?

At national level, a change in priority coupled with renewed investment will make a considerable difference in health inequality. As Dr Kath Maguire stated:

It is all about investment. Investment in services, training, staff and supporting communication with those who are finding it difficult to access services. It is about making this a priority.

However, a positive message from our interviews is that there are many things that can be done to address health inequality, including at local level. Indeed, there will be no 'silver bullet' that will eradicate inequality. James Munro told us:

There is no one thing that can create this broader cultural shift, not technology or policy. It is not that health services can come up with a policy that means suddenly people using and providing services understand each other differently. We are talking about healthcare culture that has grown up gradually over centuries. The way that culture changes will be slow and will require many people doing different things to all work towards greater understanding between users and providers.

Lynnette Charles took this further:

It is about respecting that no one approach will meet the needs of all and we need to share the expertise across all agencies in the way that we work.

'Respecting' that the responsibility to address health inequality is one shared by all is a very useful way of looking at it, as it opens us up to trying things, to 'play our part' in combatting inequality. This change in mind-set can happen at the individual level. To prompt that change, many of our interviewees pointed to meaningful training. Professor Margaret Greenfield said:

Healthcare providers need to be alert to the issues experienced by marginalised groups and receive training in working with them collaboratively. This must not be just 'tick box' training for a couple of hours, but something more meaningful which involves hearing from the barriers they face.

This quote nicely sums up the approach that patient experience teams and the organisations they work for should take in addressing health inequality. Yes, train your staff in how to interact and engage with different groups. But, above all, encourage meaningful dialogue and conversation with these groups to close the gap between provider and patient. This will improve the experience of the patient and the service they receive.

James Munro offered this thought:

On a micro level, everyone working in health and social care has opportunities every day to promote and demonstrate respectful, open interactions where people feel listened to and respected. These individual interactions make a difference to thousands of people every day. When people are not listened to, it negatively affects their health and wellbeing.

Some final thoughts

Awareness plays a big part in tackling health inequality. Firstly, awareness that health inequalities exist and that they manifest themselves in different ways. They could be characterised as socio-economic, power-based or lack of voice (amongst other things). It would seem that progress has been made regarding this type of awareness. Health organisations and the staff that work for them seem to be more aware of the issues, contributing factors and effects of health inequality.

However, there is a second kind of awareness – an understanding of how these things should be addressed and by whom. This is where there is still much work to do. Indeed, the lack of progress regarding this second element has arguably seen health inequalities deepen in recent times. For their part, those who work in patient experience should be aware that there are things that they can do to help address inequality. In fact, in doing so they may find solutions and results that benefit their wider work.

Patient experience professionals should seek to make the 'reasonable adjustments' that will help break the barriers to involvement that those susceptible to health inequality face. They should seek to stretch patient experience activities beyond the boundaries of a systematic approach that could alienate certain groups. Above all, they should facilitate dialogue between staff and the communities that face these intrinsic barriers, with a view to understanding each other more and, ultimately, improving their experience.

The NHS long-term plan provides an opportunity to launch a sustained effort to tackle health inequality. Its success, however, will require awareness that we all have a part to play and a commitment to make sure that happens.

Harnessing the Power of Patient Stories

This chapter is written by Eleanor Barlow from our partner organisation, Pansensic.

There are mixed emotions regarding the organisations in control of monitoring, analysing and safeguarding patients within our UK healthcare system. Many parties including the Care Quality Commission (CQC) and the individuals put in charge to uphold patient care have typically proven to be subjective. There are several reports to substantiate this. Three documents in particular (that will forever be engrained in the history of healthcare) are provided by Robert Francis, Sir Bruce Keogh and Don Berwick.

Written and published by Francis, 'The Report of the Mid Staffordshire NHS Foundation Trust public inquiry (2013)', otherwise known as the 'Francis Report', is an account of the treatment received by patients at Mid Staffordshire hospital between the years 2005 and 2009. Francis recounts and archives the experiences of over 900 patients who were provided with subpar care. He highlights a 'culture of fear in which staff did not feel able to report concerns'¹ which, in turn, underlined a 'culture of secrecy in which the trust board shut itself off from what was happening in its hospital and ignored its patients'² Francis also identified a 'culture of bullying, [not just towards patients but between staff members themselves] which prevented people from doing their jobs properly.'³ He goes into further exploration of the workplace culture and how it did not provide a supportive working environment for staff, in which 'there was an atmosphere of fear of adverse repercussions'.⁴

These repercussions were far from minor. In fact, Radford and Johnson argue that there 'may have been up to 1,200 'unnecessary' deaths caused by a combination of incompetence, lies, denial, professional negligence, avoidance of responsibility, cover-ups, delusion and poor systems'.⁵

As Francis details, 'the NHS system includes many checks and balances which should have prevented serious systemic failure of this sort. There were and are a plethora of agencies, scrutiny groups, commissioners, regulators and professional bodies, all of whom might have been expected by patients and the public to detect and do something effective to remedy non-compliance with acceptable standards of care. For years that did not occur.'⁶

Similarly, in his 'Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report (2013)', Sir Bruce Keogh provides an equally fruitful insight into the effects on patients and employees within not one, but fourteen individual hospitals with persistently high mortality rates. In his review, Keogh highlights how each of the trusts analysed had a similar barrier, in that they all had 'limited understanding of how important and how simple it can be to genuinely listen to the views of patients and staff and engage them in how to improve services.'⁷ He goes on to argue that 'we know from academic research that there is a strong correlation between the extent to which staff feel engaged and mortality rates'⁸ and, because of this basic lack of understanding, the 'NHS fell short of what patients and the public rightly deserved'.⁹

The Berwick report, entitled 'A promise to learn – a commitment to act. Improving the Safety of Patients in England. National Advisory Group on the Safety of Patients in England (2013)', by Don Berwick, is a testimony in response to the Francis Report, detailed above. In this paper, Berwick provides more of a call to action to 'engage, empower, and hear patients and carers at all times'.¹⁰

These three papers are imperative because they accumulate the experiences of both patient and staff, through first-hand data provided by patients and employees, rather than assumptions made by senior management. Patients and employees experience every challenge and issue that can arise within healthcare, at every level, on a daily basis. It is why these first-hand voices, views and opinions provide the most valuable data.

Many organisations will use patient and employee experiences in board meetings to support their arguments. These experiences are useful, but this information is often cherry-picked and anecdotal. It is not a collective analysis of understandings, but rather individual experiences. While using patient or employee experiences as examples in the boardroom is a great step forward, it does not provide you with the whole picture. To acquire a realistic depiction of the whole picture, you would need to collect the opinions of dozens of people.

From medical journals to peer reviews, healthcare and the NHS has been debated, reviewed and scrutinised by members outside and inside the organisation since its birth. As a result, there is a large critical literature devoted to the analysis of healthcare, its services, management, employees, finance, training and more. There is an even larger and more detailed analysis of the NHS itself. Yet, while there is an ever-expanding critical literature, there is little, in comparison, devoted to the actual analysis of patient and employee opinion.

This is because, more often than not, data collection within healthcare is quantitative (numbers), rather than qualitative (emotions and experiences). What's more, only a few organisations in healthcare actually analyse the voices, stories and emotions of the patients themselves in any appreciable volume.

Organisations, especially ones as large as hospitals, typically sit on terabytes of unstructured text. This text is named unstructured text because no one really knows what information is contained within it. But because it typically contains the views and opinions of patients and employees it provides extremely useful accounts of their experiences with a product or service. The issue is, however, that few know how to analyse and use said data properly.

General Data Protection Regulation (GDPR) is another reason why this data is often not used properly. Because unstructured text may contain information that, when collected, could be in breach of GDPR, people are often scared to delve in. But, with the right technologies, such issues can be resolved and GDPR should not be a reason to not get the most out of your qualitative unstructured text.

At the beginning of the data journey, numbers and figures usually take precedence. Initially, data analysts input these numbers into spreadsheets. But many organisations have no idea where to begin with the plethora of data they have access to and can often try to sort everything out in one go. What's more, this approach can often result in organisations analysing a small amount of data-sets and, from this, make large assumptions, right or wrong. This, more often than not, results in projects and initiatives being unreliable and ineffective and have very little buy-in from staff, which can be detrimental to any organisation large or small.

While you might have an idea of the problems your organisation may be facing, without reliable evidence to back it up, vital business improvements are often made solely on the instincts of managers, which can be highly subjective. Not only can assumptions made on exclusively quantitative data be inaccurate or insensitive, but the wrong item may get actioned altogether.

'A good decision is based on knowledge and not on numbers.' Plato

There are a multitude of instances, within healthcare, in which quantitative data analysis has led to the wrong conclusion. As the single independent regulator of care for all hospitals, ambulances, dentists, care homes and homecare in England, the CQC holds a great deal of authority and control. According to Primary Care Direct, the CQC reached 'a milestone last year [2018] of having rated every practice in England, 91% of which were found to be either good or outstanding'.¹¹ Yet, despite these statistics, if we delve into the data, these impeccable rankings don't always add up.

For instance, when the CQC reports were brought alongside Dr Foster Intelligence Unit accounts (Dr Foster being a provider of healthcare information, monitoring the performance of the NHS), the scorings from both parties varied dramatically. Whilst the CQC marked some trusts as good or excellent the Dr Foster Intelligence Unit ranked the same trusts in the lowest category.¹² Such a discrepancy between the two rankings can be observed in cases such as the 2010 University Hospitals of Morecambe Bay analysis. Following a series of inspections, the CQC graded the NHS Trust with 'A clean bill of health'¹³ and registered it alongside other good and outstanding hospitals. Despite these positive reports from the CQC, during this period the organisation had the highest mortality rate in the country, preventable deaths of over eight mothers and babies, and potentially over six-hundred avoidable deaths and 'never events' throughout the hospital.

Negative cases such as these are too common within healthcare. Newspapers, in print and online, are abundant with headlines such as 'Man dies due to overcrowding at A&E department'.¹⁴ 'Patient safety getting worse, says two-thirds of NHS doctors'¹⁵, and 'Ward attack Patient 'Utterly neglected'.¹⁶

But why, we must question, are such examples of deteriorations in healthcare not spotted earlier? The very first step in attaining insights from your data is in the understanding that you have to also analyse words (qualitative) rather than simply numbers (quantitative). In order to do this, the first thing you have to have is the Artificial Intelligence (AI) and Natural Language Processing (NLP) capability. In other words, you need to have a text analytics tool. This is very much an emerging technology as it was not available, or even existed ten years ago, in organisations such as Mid Staffordshire.

Once you have the right technical capability, we come to our first problem in that the machine does not understand the meaning of words and phrases in differing contexts. For instance, the machine is unable to determine the context of the word 'cross'. It does not know the difference between 'I am cross' or 'I will cross the road'. The word cross can be used in many different contexts at any given time, and it is the human that has to teach and train the machine these contexts. An age-old problem since AI and NLP was first created.

Thus, while AI already has a formidable reputation as an amazing capability when used on quantitative data, what few people realise is that its capabilities with unstructured text is known by the experts to be poor. The real issue is that if you are using purely AI and NLP, you then have to have a lot of gold-standard training data in order to train the machine without any bias. But obtaining such a high volume of gold-standard data is next to impossible.

So instead, effective qualitative data analysis utilises a wealth of datasets from valid sources; patient and employee feedback surveys with open-ended questionnaires. Which results in carefully-considered insights and useful analytics. Organisations in healthcare are now understanding how to use qualitative data effectively and, while many decisions are currently based on quantitative data, in coming years that balance will be readdressed. Many organisations are already using their qualitative data that has been turned into a quantitative number, to improve working environments and services.

One such example can be observed with the thought-provoking technology of The Happy App. The Happy App transpired when Anne Frampton and Andrew Hollowood, of University Hospitals Bristol, the driving forces behind the creation, wanted to see how employees moved through hospitals and observed the issues that faced them on a daily basis. It soon became apparent that they:

- a. Needed a tool that was quick, easy and intuitive to use.
- b. Had to be accessible to everyone – porter, cleaner, nurse, consultant, or manager.
- c. The feedback had to be anonymous.

The app worked by collecting qualitative data (experiences, stories and emotions of employees) and used Pansensic technology to analyse the text in minute detail. Transferred into local dashboards, this data could then be taken to board level. In turn, the board could learn what was really happening on the front-line of health care, which lead to more informed decisions about what steps to take and where to take them; resulting in an increase of productivity.

Many trust boards are disconnected from what is actually happening within an organisation. A common assumption from senior management, for instance, was that employees and patients were asking for lots more of everything when, actually, once they dug down into the comments, this was not the case. What the employees included in this analysis actually wanted, above anything, were aspects such as rotas to be out on time, or to have good notice about whether or not they were going to be given leave or not. These organisational issues were paramount yet not being sorted, despite being quite deliverable features.

In our ever-expanding healthcare system, we need to find ways to work smarter and faster, not harder. Asking those who experience the front-line, its highs and its lows, and documenting and analysing these experiences with the right technology is, arguably, the most cost effective and constructive method to make vast positive changes and generate a realistic, reliable and actionable picture of our healthcare systems.

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