Making Sense and Making Use of Patient Experience Data

June 2015

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Foreword

The NHS in England is good at collecting feedback from patients. The national patient survey programme – the first of the kind internationally – has been producing high quality publicly-reported information about the quality of patients' experience in NHS trusts and in primary care for more than ten years. More recently, and more controversially, NHS trusts have been required to collect so-called 'near real time' data from patients in the form of the Family and Friends Test which asks "Would you recommend this ward/department to your family and friends?" A great many trusts also use other, more qualitative methods to collect information from patients about their experiences, from focus groups to mystery shoppers, and more interactive forms of engagement with patients and the public.

This report usefully investigates just what is happening on the ground in relation to listening to patients, collecting feedback about their experience of services and putting the intelligence that is gathered from different approaches to use. Based on interviews with patient experience managers and others in NHS trusts closely associated with the work of collecting, analysing and using data from patients, it provides answers to questions about: Who is doing this work? What kind of training and preparation do they have for the tasks? Who supports them? Where do they fit in their organisation? To whom do they report? And how do they feel about their roles?

Ten years ago, there were only a handful of patient experience managers in the NHS. Today, almost all NHS trusts have someone with responsibility for patient experience in their title, often reporting to the Chief Nurse but occasionally reporting directly to the Chief Executive. In the main, it's these individuals who are responsible for the full cycle of data related to patients' experience of care. As with most areas of activity in the NHS, there is tremendous variation between organisations in how they do this work and whether they are really listening to and acting on the feedback from patients, or whether the activities are tokenistic. Some trust boards and executive teams are very clear about why they want patients to tell them about their experiences and what they can and will do with the intelligence. Others seem to see measuring patient experience as a thing in itself – an obligation or perhaps a requirement imposed by outside bodies, rather than as the route to information that is fundamental to the business of offering a service to the public.

The report raises important questions. Is the collection, analysis and reporting of data on patient experience being done by people with the right skills and knowledge to do this work? Are these activities merged with responsibilities for reporting on activity and clinical quality, or are they carried out separately? Is the activity related to patient experience linked to feedback from staff about their experience and well-being and how – if at all – does it contribute to strengthening staff engagement and providing them with effective support? What are the pros and cons of the different arrangements? Does patient experience, and improving patient experience, command the same level of organisational resource as other dimensions of quality of care? Does it have equal status and priority to other dimensions of quality that require continuous improvement such as patient safety and clinical quality? And if not, why not?

The report offers useful and timely insights into a previously hidden area of activity and deserves to be widely read.

Jocelyn Cornwell
Chief Executive

The
Point of Care
Foundation

Executive Summary

Patient experience data is increasingly valued by Trusts, partly due to national initiatives (such as the Friends and Family Test [FFT]: see page 7). There are many examples of organisations getting better at reporting on data, and using it to improve services. However, there is significant variation between, and within, organisations as to how well they use data and in how they approach patient experience work.

There is no one model for the way in which patient experience work is organised. The size of a Trust, dispersal of sites, history, demographics and corporate culture play a huge part in how well the work is undertaken. Critical success factors include:

- Clarity of the patient experience team's role and purpose
- Good relationships with other stakeholders (e.g. service improvement, corporate and communications, membership and volunteering, information services)
- Supportive culture and clinical and corporate leadership
- Ability to make space for work on improvement (rather than merely focusing on data gathering and reporting)

Patient experience managers and teams are enthusiastic and passionate about the work they do. But, as small teams with limited resources, they are often frustrated by an ever-increasing workload. Particular challenges include:

- 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
- Having the time to make sense of data (particularly qualitative, and that coming via informal routes)
- Capacity and capability to analyse data and generate insights
- Engaging staff in improvement work

Staff and patient experience teams are sometimes so busy gathering data and compiling reports, that less time is available to do something with the data – efforts to improve services are in danger of being squeezed out.

Many Trusts are re-thinking their assurance systems. They want to balance the need for providing assurance that targets are met with taking local action to improve things.

Staff engagement in patient experience work is critical. There are many good examples of patient experience teams working alongside staff to improve services. But increasing operational pressures are making it difficult to embed the work. There are many things that can help:

- Making relevant data available at team and ward level
- Persuading staff that patient experience is as valuable as – and can contribute to – clinical outcomes and safety
- Supporting and engaging with staff – building relationships and using influencing skills
- Project-based approaches whereby staff carry out patient experience work (gathering and using data)
- Local leadership – from clinicians and/or senior managers
- Involving patients and carers in dialogue about what data means and what can be done about it

Patients are becoming more involved in patient experience work, from gathering data to providing insights and working with staff on data-led improvement work. The ways in which patient experience work is carried out is changing the nature of patient and public involvement work and the potential roles for patients.

There was heavy criticism for rigid performance monitoring of the FFT (i.e. measuring and incentivising FFT response rates as a marker for success) and relationships between Trusts and commissioners around patient experience work are inconsistent.

Why this work?

Our work on patient experience and patient and public involvement is about making a difference – to people's experiences of care, their health and their lives. It is also about supporting organisations, staff and patients to work better together in order to achieve this common goal.
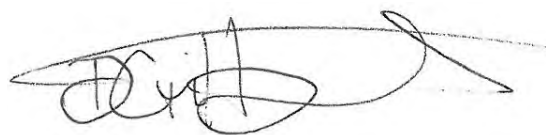
Our two organisations have come from different backgrounds to ask a common question – is all the activity going on to find out what matters to patients actually making a difference? We did not know the answer, so we wanted to find out.

We know passionate and committed people undertaking excellent patient experience initiatives. However we also know of the frustration and dead-ends – how there is an industry growing around patient experience, that it can sometimes feel like it is focused on inputs and processes, rather than impact and outcomes. So, we also wanted to help share learning about what works and who needs what support to improve things.

We realised that little is being done to explore these sorts of questions, possibly because this new 'patient experience industry' is at an early evolutionary stage. Indeed because it is at an early stage, the Foreword rightfully points out that we highlight a lot of new questions too; we didn't know what we didn't know.

We know that this is a niche area for some – the work of a small group of patient experience managers and their committed teams. But at its heart is an endeavour that seeks to improve the quality and safety of care and transform services. At this period in NHS history, what could be more important?

We hope that the report is useful to those working directly in the field of patient experience data, and also to clinical and non-clinical staff, patient and citizen leaders, managers, provider organisations, commissioners, the third sector and national agencies.

David Gilbert
Director
*In*Health Associates

Nick Goodman
Managing Director
Membership Engagement Services

Background

The NHS is increasingly focused on improving the quality and safety of services. Over the past decade, there has been a greater focus on patient and public engagement, partly as a result of the creation of the Foundation Trust model. The 2010 White Paper *Equality & Excellence: Liberating the NHS* set out a commitment to 'No decision about me, without me' as the underlying principle and vision for the NHS. Significant events, such as those seen at Mid Staffs, have also contributed towards the emergence of efforts to shape the service around the needs of patients. As a result, more and more data about patients' experiences is being collected by NHS Trusts.

National surveys, the Friends and Family Test (FFT)[1] and numerous formal and informal data collection mechanisms mean that the system is awash with feedback from patients. The aim is to use this data to check what is happening, ensure that services are meeting the needs of patients, and to help improve them.

But what is happening to the data once it is collected? How is it being used and presented? How is it then being fed back into the system to address findings and experiences? Is it helping? There have been no studies thus far that explore this vital next stage, yet that is in many ways the key objective, to understand and use that patient experience data. We conducted in-depth telephone interviews with 20 patient experience managers from 19 NHS Trusts in England in order to find out.

The sample comprised 14 Foundation Trusts and five non FTs. 12 were Acute Trusts (including two specialist Acute Trusts), two were Community Health Trusts and five were Mental Health Trusts.

The sample was obtained by writing to over 100 patient experience leads at Trusts, inviting them to participate in the study which was to consist of an hour-long telephone interview with each participant.

Participants included people in different roles at different levels of the organisation. They all had either direct responsibility for gathering and/or using data, or for overseeing this function, or they had a significant connection to the work.

We do not claim that the sample is representative of all Trusts or encompasses the full range of functions undertaken by patient experience teams. Indeed, one of the key pieces of learning is that patient experience managers can come to occupy different roles and teams can cover a broad range of responsibilities from Trust to Trust. They also have different relationships to other teams and respective functions (e.g. patient and public involvement, membership teams, communications, etc.).

Despite this diversity, we hope to have presented a rich, compelling and coherent picture of how the NHS is trying see the wood for the trees; how Trusts are making sense and making use of the data they are all collecting, from the perspective of those most intimately connected with the work.

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[1] Friends and Family Test (FFT)

The test was originally launched in April 2013, initially across all inpatient and A&E departments followed by maternity services six months later. In January 2015 it was extended to include community and mental health services and in April 2015 was rolled out to the remainder of general and acute care, NHS dentistry and ambulance services. A staff FFT was introduced across trusts providing acute, community, ambulance and mental health services from April 2014.

From April 2015 the standard FFT was amended to include a mandatory secondary open-ended comment question that asked the respondent why they had responded to the statutory question in the way that they did.

NHS England Definitions April 2015

Background

The research was undertaken by David Gilbert of *In*Health Associates in February and March 2015. We asked people:

- What information is being gathered on patients' experiences of services?
- How is information gathered?
- What happens to data after it is collected? For example, how is it analysed and how are insights into that data formulated?
- What happens to data after analysis? For example, how is it reported to boards and for assurance purposes and how is it fed into service improvement activities?
- What's working and what needs improving most?
- What helps and gets in the way of effective use of data?
- Who needs to do what to improve the way that data about patients' experiences is used effectively?

We also probed on particular issues, such as

- Connections between patient experience work and membership activities (in Foundation Trusts)
- The role of patients in patient experience work
- The local and national context, for example relationships with commissioners and views on national agencies

We want to thank the organisations listed below and their participants, and acknowledge their passion and expertise. This is a group of (often hidden) practitioners who seldom have their views heard. Their enthusiasm for the job and their commitment to serving the needs of patients and carers shone through.

Participating Trusts (in alphabetical order):

Ashford and St. Peter's Hospitals NHS Foundation Trust

Black Country Partnership NHS Foundation Trust

Central London Community Healthcare NHS Trust

Central Manchester University Hospitals NHS Foundation Trust

Devon Partnership NHS Trust

Frimley Health NHS Foundation Trust

Guy's and St Thomas' NHS Foundation Trust

Hertfordshire Partnership University NHS Foundation Trust

King's College Hospital NHS Foundation Trust

Leeds Community Healthcare NHS Trust

Leicestershire Partnership NHS Trust

Royal Free London NHS Foundation Trust

The Christie NHS Foundation Trust

The Ipswich Hospital NHS Trust

The Leeds Teaching Hospitals NHS Trust

The Royal Orthopaedic Hospital NHS Foundation Trust

The Tavistock and Portman NHS Foundation Trust

United Lincolnshire Hospitals NHS Trust

University Hospitals Coventry and Warwickshire NHS Trust

1. Where the work sits and fits

This section looks at the roles and responsibilities of patient experience managers and their teams, where they sit within an organisation, some of the challenges they face and critical success factors for their work.

1.1 How patient experience work is organised

The rising importance of patient experience work has not yet been matched by a universally accepted model of how to undertake the work. Different Trusts have different ways to organise how they gather and use data.

The way teams are structured or positioned seems to depend on local history, culture and context. There does not seem to be one 'right' way of doing things. But there are similarities emerging in terms of functions required, team roles and relationships, as people learn about critical success factors. These include: capturing meaningful data, bringing disparate sources of information together, being able to make sense of different sorts of data and ensuring it gets used as a basis for taking action. These were recurring themes throughout our interviews.

Most patient experience managers and their (usually small) teams now sit within a nursing and/or quality directorate and report via that route to the board. How many levels of management sit between them and the board varies:

"I used to report to a Director of Nursing who understood. Now there is such a gap between the top and bottom of the organisations, there is no way of filling it by reporting."

Much also depends on the nature of the organisation and wider context. Patient experience managers we spoke to came from a wide variety of Trusts. For some, the challenge was the sheer size and volume of patient numbers (from whom to gather data). For others it was about co-ordinating work across different sites and locations, or having a coherent approach to gathering data across different types of services (mental health and community, for example).

Many are trying to work with divisional teams, often within more devolved corporate cultures. This seems to work well for some who have built good relationships, but can pose challenges:

"There's a tension between having a common approach (for patient experience) across a devolved directorate leadership culture."

The huge variation in demographics within a patch makes for particular challenges for inclusion – how to ensure people from different walks of life and parts of society are able to feedback their views (see also section 2.2).

The emergence of the patient experience 'agenda' has led to a recasting of roles:

"I am still Head of PPI but with a different name now. I don't see any difference, it's just bigger. Seven years ago, PPI was nothing, low ranking, now patient experience is at the top of the agenda. You change the name and add lots of survey stuff and suddenly it's not pink and fluffy any more."

1.2 What patient experience teams do

All patient experience managers we spoke to mentioned that they or their team covered a multitude of tasks.[2] For many, the core work is surveys and, increasingly, overseeing the FFT. It should be noted that, for many, roll out of the FFT was at an early stage (either in the Trust or in particular services). The few that did not carry out this work directly had close links to it. The nature of national survey work (i.e. the non-FFT work) seems to be shifting, with several saying that they were focusing more on FFT work and trying to align other surveys more usefully or reducing (non-mandatory) survey work.

Many teams spoken to, but not all, oversee PALS (Patient Advice and Liaison Services) and/or complaints services. As one person said: "How

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[2] It should be noted that our sample was unable to represent the full range of patient experience activities going on across each Trust

we work, it's been pragmatic. I did not want to look at complaints as I wanted to focus on working with patients to improve experience." However, another Trust said: "We get an awful lot of intelligence via complaints, managed through divisions. We log them, and there is a lot going on behind the scenes. We translate them into cross cutting themes that can turn into action." A few teams stressed the importance of gathering compliments too, particularly to lift staff morale. Most people report themselves and their teams being under pressure: "I am doing this work by the seat of my pants. For such a hugely important thing, that's now connected with Trust income… it is not being done well, and the buck may stop with me."

One or two people reported that other important work was being squeezed out:

"People did not think PALS inquiries were important, seemed like soft information. But if you have ten people, it tells you a lot. We don't do that any more, we don't record them. We used to tackle complaints early and set up 'concerns recording' system with dates, but it is not seen as important. Targets are all about complaints…bit of a struggle and disappointing."

Many, but not all, patient experience managers have links to Patient and Public Involvement work: "The role of Head of PPI has been separated out. There's now a confusion of roles, it's not always joined up." (see also section 5.2). One or two explicitly mentioned inclusion as part of their remit.

Some teams are set up with a formal role to oversee volunteering. This also relates to how Trusts see the role of volunteers in data gathering (see section 2.2). A few from Foundation Trusts had a formal link to its membership and governors, but most said they don't (see also section 5.2). One or two mentioned important links with health and patient information services and communications or marketing teams.

Some Trusts have separated functions in ways that allow patient experience managers to focus on using (rather than gathering) data. One or two

others have focused on qualitative data work over quantitative and on local improvement work: "We are responsible for qualitative work and our model focuses on ward and team level work. Another service improvement team is responsible for the FFT, National Patient Survey, tracker devices, corporate service improvement…".

Many reported that they struggle with how to handle qualitative data, online feedback via social media, community conversations or intelligence from the voluntary sector. Some stressed the need for better links with communications or Patient and Public Involvement teams who can pick up on this 'third party' data. However, some are doing well here: "We use Patient Opinion. NHS Choices is not fit for purpose. It only allows one posting for example, and is not user friendly. I send comments to the relevant ward manager and they respond directly. I had one recently about privacy on an emergency ward and the comment has come back that they've moved microphones, and set up a privacy room."

A few Trusts mentioned the importance of linking to staff experience and engagement work, and one or two mentioned the need to make solid links to work on staff surveys and staff FFT. But none of the teams we talked to reported a formal role in doing that work (see also section 4.3).

Clarity of roles and good relationships underpin success:

"We sit comfortably alongside colleagues who know we'd be involved."

Conversely:

"Relationships across (to those gathering data) is frustrating, we don't talk to each other as well as we should – we should encompass all that's going on."

Connection to those close to power was also mentioned, with some feeling lower in the pecking order than others.

With a multiplicity of tasks, and lots of ad-hoc requests for work coming in (from teams wanting to do patient experience work, corporate requests for stories at board level, CQC planning, for

example) it feels as if patient experience teams are often balancing spinning plates.

Teams are usually still relatively small, while their work has grown immensely. Only a minority sense that their team has grown sufficiently to deal with the task in hand – its volume and complexity:

"It's frustrating when you see how much money goes to other corporate functions such as comms. We are supposed to be top of the agenda, but we are not valued."

1.3 Key Messages

There is no one 'model' for how patient experience work is undertaken. Much depends on local history, culture and context. Patient experience teams cover many areas of responsibility for gathering and using data. This creates a real challenge in trying to apply national frameworks and approaches.

There is a clear sense of passion and commitment for the work within teams and across many Trusts. Clarity of role and good relationships with other teams (e.g. communications, patient and public involvement, service improvement, membership, HR) are critical success factors.

Patient experience teams are faced with gathering, and reporting on, an increasing volume of data coming via a broader range of channels and the 'patient experience industry' is still at an early stage in its evolution. Teams are finding themselves stretched and under enormous pressure.

Case Study

The Royal Orthopaedic Hospital **NHS**

NHS Foundation Trust

As part of its Strategic Transformation Programme, the ROH is committed to provide exceptional patient experience at every step along the patient's journey. The Public and Patient Services Department collects analyses and triangulates data from a variety of patient experience sources (PALS, Complaints, Friends and Family Test, Real time and National Surveys). Due to the richness of data it is possible to focus on specific causes as part of a larger issue.

Why can we never get the food right?

This has seemed an insurmountable issue! Patients have always indicated, through a variety of channels, that they didn't like the food much. No matter what we tried (and believe me we tried!) we seemed unable to make a difference.

The hospital has, over the years, looked at food storage, transportation, menus, options, plate warmers and has even participated in programmes about improving hospital food with the celebrity chef James Martin. Corporately, the feedback was being reported monthly to the board and sent out to departments, who were clearly concerned that improvements were not making a significant difference.

Then a new Head Chef arrived – Mr Himadri Ghosh, who really wanted to find out what was happening. Co-incidentally the Friends and Family Test Survey arrived at about the same time.

Himadri came to Public and Patient Services to find out what we knew. Together we read, observed and tested out theories, which resulted in us noticing trends that we hadn't seen before. Some wards' feedback was about the temperature of hot food, whilst others were about the size of the portions offered. Further analysis showed that some areas were not clear about what could be offered 'off the trolley' for patients who required meals at different times or made in a different way.

We realised that there was no one specific cause of the dissatisfaction. This took us down a different road. There is no such thing as a standard patient, so it should hardly be surprising that there could not be a standard solution! However, where a need was identified in one particular area, the solution was applied across all areas to ensure that the provision of food to all patients was of the highest standard.

Actions taken:

A photo representation of a 'small', 'standard' and 'large' portion size was created alongside the food trolley so patients could indicate how much food they required (obvious when you think about it, but a large portion will look different to many people!).

Ward staff were retrained on how to use the food trolley to ensure that hot food remained at the right temperature for serving. Spot check temperature audits are now undertaken at the point of dispatch and at the end of the meal service on a ward. Results are shared with matrons and ward staff.

Laminated cards on availability of additional menu options were placed with the meal sizes card.

Friends and Family Test feedback is monitored daily for comments about food, and any feedback is

dispatched to the Catering Department and the Ward on the same day for corrective action if it is needed.

All food comments, positive and negative made on feedback surveys are collected and fed back to departments, matrons and the catering team to ensure that the positive changes are sustained.

How has it changed?

The challenge in an institution as large and complex as the NHS is to engage across departments and environments to ensure that all this happens in the most meaningful way for the benefit of patient care. Good Patient Experience can only be achieved by paying attention to every detail, including the smallest. The saying, you can never please all of the people all of the time may be true – but it shouldn't prevent us from trying.

According to the National Inpatient Survey, the Trust showed no improvement in food related questions from 2010 to 2013. But in 2013 there was significant improvement against the following questions:

- Food being fair or poor
- Healthy food on the menu
- Being offered a choice of food
- Getting the food that they ordered

The initial results for the 2014 survey show significant improvement again from the previous year against the following questions:

- Food being fair or poor
- Being offered a choice of food

Similar questions on the Trust's internal real time patient survey show a 98% satisfaction with the hospital food now compared to 70% 5 years ago.

All Friends and Family Test comments are read daily and evaluated monthly. During March 2014, we received 24 comments, of which 10 were positive, including:

'Nice food'

'Even enjoyed the food!'

'Meal was too cold – couldn't eat it' (negative)

'Crackers and cheese after my op when I was finally allowed to eat – not enough!' (negative)

A year later, 16 comments were made, 12 of which were positive, including:

'Great staff and even the food is good!'

'Very high standard of food'

'Menu Choice' (negative)

2. The data journey

This section focuses on the first 'stage' of the data journey – gathering data, bringing it together, inputting it into systems and analysing it in order to generate insights. It focuses on some of the issues and challenges faced by those who undertake this work.

2.1 What data is being gathered?

A huge variety of survey work is being undertaken and the work is increasing. Several Trusts are trying to rationalise survey work, either by integrating FFT questions into other surveys, or by dropping (optional national) surveys they see as not adding value: "We do the mandated one and get offered the voluntary ones, but to be honest, there is so much going on, we don't feel the need to do more." Some resist the urge to integrate the FFT within other surveys, seeing both as useful for different purposes (i.e. corporate benchmarking or local improvement).

One person voiced concerns about the nature of data being collected:

> *"Are we collecting the right stuff? Most things we struggle with are about attitude and behaviour. These are hard to measure, hard to show on dashboards."*

Another, particularly interested in improvement work, said:

> *"The nature of questions are about perceptions, how do you feel, etc. It's hard to then identify solutions and actions. That's more subtle. It could be about the way an individual member of staff approaches someone, others could be about systems."*

While many are adding free text opportunities to surveys (i.e. 'explain why…' type questions), several said that it is difficult to ensure that people's comments get fed into the system. Some sense that quantitative data is taking precedence over qualitative work, this at a time when patient experience managers are getting more concerned about how to value qualitative data for use in improvement work (see section 5).

Many said that work to gather patient stories and narratives is valued, and a few said this was part of their team's work: "We trained 300 staff to collect stories within their own service. We

support people to do that and are rolling this out properly now." People mentioned stories as part of education and training or as input into the beginning of board meetings, for example. However, it felt that many were struggling with this side of things and that this work was not being treated as seriously at corporate level as survey data.

Coordinating the work going on at different levels of the organisation and across teams is a big challenge: "Knowing what's going on is a problem, others going off and doing their own thing… disjointed data gathering activities… We have five versions (of our survey) across different business units, mostly on paper, some easy read, some online via websites." But the main issue for most teams is the amount of data that has to be gathered:

> *"Data gathering. Such a big beast, so many streams."*

2.2 How data is being gathered

Many mentioned they use a range of data capturing mechanisms (paper-based or electronic, online or text, etc.) and we heard lots of examples of adapting formats to suit context (e.g. comment cards for blood clinics where people come in and out) or imaginative ways to gather feedback from particular client groups (e.g. children and young people).

A few saw the value in retaining paper-based surveys or face-to-face data gathering. This is often to do with local context or demographics: "This (Community Trust setting) is more free-flow, we need a range of methods to capture for different clients in different settings. We use mobile tablets, kiosks, paper-based, shortened comment cards (e.g. for blood test visits)."

Many teams want staff to play an active role in gathering data, and said that this was crucial for staff engagement, as well as for maximising return rates. Several are also turning to volunteers, with

one or two organisations training and supporting them to do this.

Lots of Trusts try to collect data when people are leaving hospital and going home, but this can pose challenges, for example if people just want to get out of hospital quickly. Other challenges include catering for people who come in and out of services (e.g. blood tests, A&E), have sporadic contact (e.g. with school nurses) or for whom FFT questions are not mandatory, such as those in secure settings (e.g. prisons).

Community Trusts in particular face the problem that they operate across many different sites which are often spread out in the community. It may be that staff are not working out of their own organisation's premises, so questions about experience are being routed to the wrong organisation or are not actionable by those staff.

For those with long-term conditions, who use many services, or come in frequently, the problem is about asking too much and too often: "The FFT has become a bit of a beast, the requirements to get lots of responses. Across maternity, people are asked for their views at four different points across the pathway." We heard about innovative ways that might deal with this. One community trust is looking at linking the FFT to care planning. On the other hand, we heard that when people have ongoing relationships with staff, it can be easier to gather data and use it for improvement.

The people we spoke to were serious about inclusion, often emphasising the need to get feedback from people from different sections of their communities, and from people speaking different languages, or from people who may not be able to read or write well enough to fill in a form: "There is great work going on (with interpreters). Yes, the client groups are challenging. But some staff claiming that it is not easy may be an excuse."

2.3 Systems for inputting and bringing data together

Teams are struggling with the sheer volume of data having to be gathered. The following quotes were typical:

"Knowing what patient experience work is going on is hard; relationships across teams, frustrating. We don't talk to each other as well as we should. We should encompass all that's going on. We still hear from a (professional) who goes on his merry way and does a survey but doesn't tell us. 3000 staff...Lots of duplication."

"It's mad. We need to rationalise what we ask."

"We are data rich, but we don't bring it all together (national surveys scores and comments). It's a nightmare to see what's going on. Trying to triangulate between 12 different data sources coming from different angles, presented differently…".

Finding the time to input the large volumes of data coming in is a huge challenge. Several organisations are utilising in-house or outsourced systems into which to feed data. A few report problems with team capacity to input data and the quality of any input, with one saying (for complaints) "It is subjective, lots of different ways that treatments have been recorded."

Many people want more time and space in order to take stock of the data they have, rather than set about gathering more. Several Trusts are in the process of changing or upgrading systems, and live in hope that new systems can make their lives easier: "We've been promised functionality, hopefully to feed information in and do spectacular things. I'd be free to help take action."

The advantages mentioned regarding better systems included: high quality data input, ability to take stock of what is going on, bringing together different data sources, generating more meaningful data (e.g. at local/team/ward level), allowing teams to do more improvement work and the ability to track whether improvement actions had taken place. But there were also warnings about being in thrall to (expensive) technical solutions: "There is a tendency to latch on to more data gathering tools and whizzy stuff." A few warned that the infrastructure to manage the FFT was itself becoming a significant resource burden.

2.4 Friends and Family Test [3]

Different Trusts are at different stages of rolling out the FFT. Many (in the acute sector) are now getting familiar with what the FFT can bring. Overall, it felt during interviewing participants that people see the FFT as a mixed blessing. Patient experience work – or at least data gathering – is rising up the agenda with the arrival of the FFT initiative. Many said this was due to the national and corporate drive that has also raised the profile of their own team's work. The FFT is now ingrained in many Trusts: "People see the value and understand the scores more. They know we are kind of performance managed on it. Every breath we take it's FFT, FFT, FFT."

Several spoke highly of how they are using it, often in conjunction with other sources of data (such as the staff FFT): "We have good analysis and trend reporting. The FFT and other data are used to dig deeper, for example we used it to tackle issues of ward nutrition."

For some, the FFT 'journey' has been tough but worthwhile:

> *"It was hard, the logistics across three sites, staff did not value it, it was paper-based, people input was difficult, no software. Now it's electronic, we get results, word-clouds, action planning… reporting is brilliant and seamless. The comments are more comprehensive. Staff are more engaged. Clinicians ask to see reports before they are ready, the docs are interested too (maybe because of revalidation)."*

However, there were many misgivings. Some who had more of a focus on improvement at local team or service level were critical:

> *"The FFT is time limited… designed by externals and we cannot use it as benchmarking (at team level). Our patient satisfaction survey can allow us to tailor it to individual services, explore what's happening and try and make improvements."*

Another issue is the logistics, with many feeling that the FFT has "become a monster". The roll out of the FFT is causing real difficulties, where Trusts have thousands of people using services and providing feedback. We heard examples of other patient activities being placed on hold: "We did have a successful tracker survey with the involvement of people on CPA, about 1,000 people, but that has been stopped."

The third main problem is the way in which FFT response rates are being linked to payments; in some cases corporate efforts have become geared to numbers of surveys filled in rather than what to do about the data (see also section 3.3).

2.5 Data analysis and insight

The most common message we heard was that patient experience teams want space and time to make sense and make use of the data they do have, rather than being on a constant 'hamster wheel' of data gathering and reporting. Many pleaded to national agencies, commissioners and even their own Trusts to help create that space.

With more data gathered comes a commensurate need to analyse it. Several felt this was creating rods for their own backs. And, in some Trusts, analysis of qualitative data and narrative work is at risk of falling by the wayside. A lack of capacity to do the work cropped up repeatedly:

> *"Lack of resources, everyone wants something. I can't do bespoke reports. Need a bigger team. I'm not asking for 200 people. It is never-ending."*

Analytical expertise is crucial so that teams can be "smarter, clever, use information meaningfully". Some get help from corporate teams, or from within their own team. But many are struggling: "It's a science. I don't know what we are looking at, I've got no analyst for the quantitative stuff." Others wanted qualitative expertise and the ability to understand context: "I can look at figures, but I want someone who can deal with the comments."

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[3] Research interviews were held in February and March 2015. It is noted that FFT guidelines were subsequently amended to remove the national target response rate requirement of 15% however local targets may still exist.

2. The data journey

Several organisations are making efforts to analyse data properly, and bringing in "different perspectives to eyeball the data", as one person put it. Some Trusts are encouraging patients to join the team that does this.

We heard several worrying examples of where inexperienced people are making (possibly erroneous) judgements about data based on their own feelings or assumptions about (a) what the data signifies, and (b) whether it is feasible (in their eyes) to do something about it. This institutional filtering can be exacerbated by a frustration that some data is telling the organisation what it already knows: "We know what's wrong. It's appointment times, staff attitudes and communication. It's been the same for 3-4 years. We can't change it and there is now a sort of complacency."

2.6 Key Messages

Trusts face huge challenges in gathering data, from different client groups who use services in different ways, across different settings, through different people (staff, volunteers) and different formats (paper-based, electronic). Many are rising to the challenge well, but many are now struggling to cope.

There are particular challenges in bringing the data together in order to make sense of it – coordinating activities, time to analyse qualitative data and general analytical capacity. Teams are stretched.

There are mixed feelings about the FFT. While it has helped raise the profile of patient experience work, in some cases it now seems to threaten it. Patient experience teams are so busy catering to the demands of the FFT in terms of data gathering, other important work may be lost, or at best shifted downwards in terms of prioritisation.

Case Study

A key aim of The Christie's Membership Strategy 2013/2016 is to develop and offer opportunities for our members to participate in the Trust. In 2014 our membership office developed a 'patient experience databank' within the membership database and offered members the opportunity to identify themselves as representing patients and carers and willing to take part in engagement activities. These members are now regularly invited to take part in patient experience focus groups to give us first hand feedback about our existing services and input into the ways in which we may wish to develop our services in the future. Focus group topics discussed so far include our website and patient entertainment system, equality and diversity, clinical trials, and complaints responses.

Involvement in improving complaint responses

Making a complaint is never easy and it is important that we have an effective and sympathetic process for dealing with complaints. Those who complain should feel that they have been listened to and that learning has taken place.

The patient experience focus group was asked to review a few randomly selected complaint responses and provide an independent and honest opinion on the quality of the response. The members of the focus group completed a pro-forma with prompts for each response they reviewed.

Their observations included:

- Most reviewers felt that lessons learned and what steps had been taken to improve were not always clearly stated.

- The language used should be less technical and not use medical terminology

Staff involved in the complaints process discussed the observations made by the focus group and developed actions which would improve the quality of our complaint responses. The actions were approved by the Patient Experience Committee, who oversee initiatives relating to improving the experience of our patients and families.

The actions were

To ensure that learning from complaints is clear, an action plan for delivering the agreed outcomes would be attached to the complaint response;

A list of complainant "likes and dislikes" in terms of complaint responses would be produced to assist those writing response letters;

Feedback and learning points from the focus group would be included in complaints training;

The focus group would be asked to review responses in a year's time.

3. Data for assurance and accountability

This section looks at how data and intelligence is reported in order to provide assurance that the Trust is meeting the needs of patients. In particular, it looks at efforts being made to improve reporting processes, challenges to this, and how governance efforts can be better connected to improvement.

3.1 Reporting on patients' experiences

Overall, we sensed that reporting on patient experience data is getting better. Many patient experience teams have been working to improve how they inform quality committees, boards and commissioners about how well the Trust is meeting the needs of patients. We heard lots of good examples of ways that teams were reporting regularly on progress (monthly or quarterly):

"Monthly board meetings include examples of improvement projects and often patient partners are included in conversations. We have very good reporting. The patient experience committee feeds into the risk committee and it's relatively easy to get your voice heard. Exec directors are present."

We heard examples of organisations producing different reports for different purposes or audiences, integrating reports (from different teams and divisions), embedding project reports into the overall report, or ensuring transparency (e.g. making accessible versions available on websites).

Many reports are aligned with Trust targets and several try to bring PALS, complaints data, narrative and qualitative comments together with quantitative data to provide more rounded information. Sometimes board meetings or committees will use patients' stories to try and ground conversations in the importance of patient experience work.

Several people we talked to said they try to make the data relevant and useful at the right level of the organisation so that it can lead to action. This means linking to divisions and teams: "The quarterly report in more detail goes to Service Business Units. Teams look at it, base their actions on it, put up posters and report back on actions… you said, we did." Another said: "Every service gets

a pie chart with strengths and weaknesses." But progress in this area is patchy (see below):

"This work has teeth. The board's role is crucial" said one interviewee. And it is clear that corporate systems and cultures have an impact on how patient experience work is valued: "Patient experience is part of performance monitoring, CQINs on it are linked to money, there's top-down encouragement, and it's high on the agenda."

3.2 Challenges

While many seemed proud of their reporting processes, there is a degree of frustration with a good number of the interviewees desperate to write fewer reports. People referred to reporting as "feeding the beast" or "the machine". The following example is worth quoting in full:

"There's so much bureaucracy, then we've got business teams, transformation teams, project teams, so many people, and I'm just thinking, what are we doing with all this? What difference does it make… governance, risk register this, evidence of that, inspections. This is why staff are spending too much time doing all this and they want to spend more time with patients. It's about embedding quality and patient experience…".

When the nature of reporting was onerous (duplication of effort for different purposes or committees) or where content of reports was not seen as useful, this frustration was exacerbated: "The emphasis on response rates (i.e. measuring success based on how many people have filled in surveys) has taken us away from what's important and risked our working relationships work with staff."

Another common challenge was not having sufficiently local, detailed ('granular') data upon which to base judgements or action. This is particularly important, given the increasing

emphasis that patient experience teams, and organisations as a whole, are placing on improvement work (see section 4).

Sometimes, reports to boards are skewed in that they report thoroughly on the quantitative elements of the FFT, but are unable to cover other intelligence in as much detail (e.g. qualitative data, PALS, complaints) for reasons explained previously (capacity, etc.). Boards may not always get a full picture of the experiences of patients.

When corporate cultures are not conducive to openness, there may be deeper issues. We heard one worrying example of gaming where a Trust had omitted blank responses to the FFT in order to put up satisfaction rates. In this organisation, "There's quite a bit of gatekeeping, so some of the concerns are not always heard at the right places. People 'in between' services and board don't want to share bad news. So on the one hand there's panic about the data, then we swing. On the other there's a bit of dampening going on, covering up."

3.3 Making the connections – governance and improvement

Checking up on quality is one thing. Making sure that this leads to action is another. In many Trusts this connection between governance and improvement is being fostered.

Creating the space for dialogue about data is one key aspect of this important corporate task. Organisations are beginning to find the nexus at which to have critical conversations – at the right level, and between the right people. These may be formal committees, or informal stakeholder groups. And they involve patients, staff and senior leaders. The following examples give a sense of the activity going on:

"We have a service experience group (one for adults, one for younger people). We try to involve all stakeholders and keep them up to date and explore issues every 4-6 weeks."

"Our patient experience committee is an example of good practice. It's informal and opt-in, led by a palliative care consultant and senior nurse. There's senior commitment, it's beyond the call of duty, not driven by Trust

objectives. There's lots of passion around the table."

"We have a good patient experience and PPI committee, chaired by an enthusiastic Chief Medical Officer."

"Our Patient Insight Forum brings together people involved in other work. It's valued by staff and patients and serves as a co-design group."

Patient experience managers are acutely aware of the need to take action, many producing local reports for business units, divisions or teams. Several people reported good working relationships at this level and gather feedback on actions taking place. But local action across and between Trusts seems inconsistent: "Teams get heat maps and should explore in more depth. It's patchy though. Some do, some don't. Good ones don't need chasing up, but I have to constantly remind others."

A questioning culture lies behind success. 'So, what does the data mean?' and 'so what do we do about it?' are the key questions. Many people said that the asking of these sorts of questions is fuelling a significant shift in corporate and team cultures: "We report through each division so that each clinical team has a Quality Forum reporting mechanism." The chair's priority is then to ask 'so what next?'. However this is not always the case, and we heard one or two worrying examples of 'punitive' cultures where monitoring mode took precedence, and where improving patients' experiences is more rhetoric than reality.

At the root of this questioning culture lies a desire amongst patient experience managers to go further than the target-driven focus: "There is too much (data). People are looking at a blur of colours in reports. We've lost a bit of focus." More meaningful measures are being sought by several organisations, including what actions have been taken in response to data and whether the organisation is getting better.

3. Data for assurance and accountability

3.4 Key Messages

Reporting of patient experience data seems to be improving, in terms of what is being reported and how. However, many patient experience teams say they feel burdened by onerous reporting requirements.

Some boards and commissioners may not be getting a full picture of patients' experiences, owing to several factors. These include lack of granularity of data, focus on FFT scores (to the detriment of qualitative data or other sources, such as complaints and PALS).

Several Trusts are beginning to move beyond requirements to measure against rigid targets, and are thinking more about what the data is telling them, how it can be – and is – used for improvement, and how to align governance and improvement work. 'Intermediary' fora (patient experience committees, stakeholder groups, etc.) have a huge role to play in making the connection between governance and improvement.

The Introduction of the Quality Team

In October 2014 The Tavistock and Portman NHS Foundation Trust introduced the new Quality Team. Its remit is to help streamline how we make sense of both clinical outcomes and patient experience data. It ensures that processes and procedures are in place to ensure that we meet locally and nationally agreed targets. The Team will also link to our quality improvement work, through awareness raising activities and training events and highlight the work we need to do to achieve our CQUIN (Commissioning for Quality Indicators) and Key Performance Indicators.

The team comprises the Data Collection Manager, CAMHS (Child and Adolescent Mental Health) and Adult Services Data Collection Officers who train and support clinicians, Quality Officer and PPI Manager and Officer.

The team – that includes data collection managers, representatives from each division and the PPI Manager – meets regularly to monitor progress on targets. It also meets monthly with department managers to go through the department's quality performance dashboard and any locally agreed targets. Action plans are put in place so that improvements can be made in time to achieve the targets for quarterly reporting.

The team works closely with Clinical Governance, helping to promote any developments within quality and providing training on any procedural changes. The team is responsible for training all staff on outcome monitoring and the use of software for monitoring and recording outcome monitoring. More recently the team has been helping support staff as the Trust moves to a new electronic patient administration system. This help us to streamline our data collection and reporting, providing us with a paperless system with clinicians directly entering patient clinical and patient experience data. The team also works closely with the Trust's informatics department, helping ensure accurate data reports are built to support data collection.

The team is involved in a number of innovative projects: promoting quality standards; helping to build an awareness of physical health in relation to mental health service provision; engaging locals in community projects; involving service users in the development of our services; collaborating with neighbouring services.

Alongside the introduction of the Quality Team, a senior committee has been established, the Data Analysis and Reporting Committee (DARC). This will provide assurance to the Trust's Quality Lead and Trust Board, looking at clinical and patient experience data in line with the Trust's overall strategic plans and enabling the Trust to benchmark services both internally and externally.

We are excited about the team's development and plans for new and creative ways of engaging Trust staff in quality and data, moving away from data collection and reporting being something enforced as part of the funding process, to becoming more clinically relevant and meaningful. This will involve balancing Trust wide data collection alongside making sense of patient experience data and help us to look at data in more meaningful ways so that we meet services' and patients' needs.

4. Data for improvement

This section looks at how data and intelligence is used to help improve the quality of services, in particular how it can be made meaningful and available at the right level, and how staff can be involved.

4.1 How data is being used to improve services

We heard numerous examples of where patient experience data is being used to improve services at ward/team, corporate or (less frequently) partnership level:

> *"The FFT is a good marker. We can use it as a sense test to identify where wards are beginning to struggle and the markers dip. We have good clinical engagement and people are interested in using this."*

However, there seems to be significant variation in the quality of patient experience work across organisations and within them. It was difficult to perceive a pattern as to whether some sorts of Trusts or teams were, in general, better than others. Sheer size may be one factor. Sometimes organisations that had multiple or community-based sites, faced particular difficulties in embedding the work:

> *"It varies across business units. In-patients is good, community not so good, and with older people it's dreadful, they are not engaged at all. They make the assumption that they can't get the views of people with dementia, say. But we are doing it with learning disabilities, so why not? They are making assumptions and they're busy, so it is convenient to say they can't."*

Many activities are small scale and practical (more blankets on A&E wards). We were told about improvements in processes. For example, for people with mobility problems waiting in outpatient departments (with resultant improvements in satisfaction): new services offered (improving patients' access to physical activities); structural changes (e.g. waiting room design) or gathering and using data from seldom heard groups (e.g. investigating complaints from Afro-Caribbean communities).

A more systematic approach to using data was becoming evident in some Trusts, linked to a wider organisational culture that supports quality improvement approaches. We heard about projects based on the Plan Do Study Act (PDSA) cycle, dedicated co-design workshops, teams doing their own patient experience work, as well as about corporate projects (re-designing urgent care services).

Within the many models we saw, a few stood out as showing the merits of a more 'improvement-focused' way of working. As one person put it:

> *"The issue is how to support patient experience managers to be liberated to do the work they love – with people, relationships, improvement, rather than feeding the beast (i.e. gathering and reporting on data)."*

For some, reframing the task as patient experience 'work' rather than 'using data' is important. One or two have taken a more proactive stance and created a project-based model. The following example is worth quoting at length:

> *"We get requests in from clinical teams to undertake improvement work with patients, carers and staff. The ward managers 'own' the projects and release staff to do it, and we determine the support they need. It requires support and the right mind-set. People underestimate the challenges of delivering a good patient experience project. Unless people are given the right resources and they have the flexible models, they will fall at the first hurdle. You have to have good interpersonal skills, be able to work properly with patients in order to reveal the stories and ensure people feel safe and ensure that they trust action will take place."*

However, for some, it seemed there is still a long way to go. A few questioned whether patient experience data was making the difference it should, with one person saying: "Often it (patient

experience) is the second thing."

4.2 Making data available and meaningful

There seem to be several challenges to using patient experience data for improvement. As already discussed, data needs to be made available at the right level:

> *"It's not filtering down to teams and individuals. I want District Nurses to know how they are doing in a team."*

It's also about timeliness:

> *"I want to give heads of services useful weekly, service-specific and actionable data. But this needs considerable investment."*

Several people told us that information, for example from the CQC, was not fed back at the right time. Reaching people across different sites and in different contexts is also a major challenge, particular where sites are spread across the community.

Having data available doesn't automatically lead to people using it. There seem to be different types of challenges. Firstly, staff need to see that people's experiences of services are important in the first place – of equal importance to other 'hard' measures of quality, such as outcomes and safety patient experience data as a concept. Some may not see the value in it: "Patient experience is not the thing…needs working on culturally."

In two Trusts, we heard about exciting work being done to strengthen the basis for valuing experience data. One respondent reported on research they were doing to demonstrate the link between experience and outcome data. Another told us how their Trust has a new team looking at bringing together and analysing outcomes and experience data.

Several teams described how they had to 'market' themselves and 'sell' patient experience data as useful. Words like 'positioning', 'framing' and 'influence' were used: "People (staff) need to know information is relevant to them. When I talk to them I make it relevant to their everyday life, how it feels to walk into a shop, you'd come again if…".

The second challenge seems to be to persuade people of the value of qualitative (as well as quantitative) data with some seeing a 'swing' towards the former over time: "People now value the softer intelligence, rather than it being something my team likes to do, people have also seen the difference it can make, it goes beyond bald percentages."

Another challenge is how to make the data 'actionable':

> *"If clinicians hear feedback they will very often be able to fix it. It is more motivating to think about 'what I can do' so let's start thinking about what we do with data."*

But there are many barriers and what is 'actionable' can become a subjective issue. For example, data may not appear to provide sufficient, or the right type of, information (e.g. about the causes of poor experiences): "Is it telling us something we can use? Does it allow us to think of solutions?".

Another sort of staff objection we heard was that, even if the data was seen as 'valid', nothing could be done about it: "We know the challenges… not much we can do as they are outside our control." Again, the data can be ignored. Sometimes seeing the same data again and again adds to staff malaise: "We know what's wrong, they've been the same sorts of things for years…problem is we have no lead to make sure training is done." Another person said:

> *"Sometimes it is about others who we can't influence, facilities for example. It is our duty to provide information and make it a pleasant and welcoming environment, but it is managed by those who don't have the same priorities."*

We heard numerous examples where, once staff see the benefits of using patient experience data to improve things, it becomes a virtuous cycle: Patient feedback is also important:

> *"Patients see 'oh that was my comment' and seem to like it. It is motivating for us as PPI Team too to be able to report back on what has happened."*

4.3 Engaging with staff

Engaging with staff is crucial. We heard that staff seem more aware these days of the work going on around patient experience, but that involvement in the work is extremely patchy. Getting buy-in is a struggle:

"Staff don't understand the importance of getting to the 40% response (for CQINS) for getting millions of pounds."

It seemed striking that only a few respondents mentioned the staff FFT. Where they did so, it seemed that good work was going on. One Trust was looking at the contrast between positive staff FFT scores and poor patient scores. And also how this could be used to help recruit staff whose behaviours were more attuned to patients' experiences.

Another Trust includes staff in the development of its patient experience work: "We always begin with the staff contribution to improving (or not) the patient experience. We focus on staff roles and responsibilities and include methods that look at what staff think they are contributing and then compare with patient perspective."

A positive and reinforcing culture can mean improvements happen anyway: "We have a good culture, good staff responsiveness. We don't always need surveys. We need to hold difficult conversations with staff and understand where they are coming from."

The most common explanation for lack of staff engagement with the work was sheer pressure and busyness, and again patient experience teams are acutely aware of this. The following quotes illustrate the nature and extent of the problem:

"I sense severe pressure to meet other targets. My team try to sell patient experience as useful. We run programmes on this and help build capacity and lift morale."

"Staff are tired of new things. Head space… capacity."

"The turnover in staff and team leadership has been hard for nursing staff and difficult for me as I have to go out and talk to them about the importance of the work."

"Staff stress, we have a black alert and the CQC visit coming."

With service changes, staff may be particularly disheartened, and find the work to promote patient experience hard: "A site closes, morale is very low and getting feedback is low on people's priorities and less time is spent with users. It's my job to see that patient experience work doesn't tail off."

Some organisations are finding innovative ways to boost morale through patient experience work, for example national and local award schemes. Several people said that their job was to help raise morale, to 'celebrate' the good, as much as to improve things. At the very least, individual patient experience managers and their staff are learning to be careful in the current climate: "People can be disheartened – we try to stress positive. The FFT can be seen as bashing people." People described situations where "open discussions" with staff about what's going well and not so well in terms of patients' experiences had a great impact on subsequent work.

Many interviewees described particular "tough nuts to crack" as one put it. For one it was the emergency department: "The ethos is 'we save lives, we are busy'…it's a clique… ingrained behaviours, a little empire." For another it was specialist areas (e.g. liver transplant team) and for another it was cancer: "Where they (the teams or departments) focus on outcomes. It has very poor patient experience scores… it's hard to engage the docs (doctors)."

Local leadership is crucial. We heard many times about the personal passion of, for example, particular ward sisters, or where regular meetings took place on wards to decide what to do with data. Clinicians are often leading the work: "Lots of detailed patient experience feedback work going on at team or service level led by clinical specialists, for example with the breast nurse. Developing different ways to run service or

4. Data for improvement

developing hand-held booklets. Lots of projects arise from patient feedback and then team may decide to do something about it."

During discussions, it was clear that engagement with nurses and nursing teams was often easier than with medics. But we also heard of several successful examples of engagement with doctors. This success seems dependent on having doctors in influential positions (such as chairing quality forums or patient experience committees), believing in the work, providing peer support or having had themselves a life-changing experience as a patient. Sometimes all three!: "The chair of the older people's committee was a traditional consultant, and this was a bit of a revelation for him."

The aim is often to get doctors to see beyond the immediate clinical circumstances: "We are trying to say to clinicians that patients' wider quality of life is important too, not just what happens in the consultation room. We want to work with clinicians to open up dialogue, to bridge the patient experience with people's lives." However, there is a long way to go, judging from many of the interviews: "Certain consultants, can they change their spots? They can find it hard to accept criticism."

4.4 Key Messages

There is a lot of good work going on, in terms of using data to help improve the quality of services. But there are huge variations between and within Trusts and significant challenges to the work.

Critical success factors include making meaningful data available (at ward and team level), staff engagement (and linking with the staff FFT), local leadership, dialogue with patients, dedicated support (e.g. from patient experience or service improvement teams) and a positive corporate culture.

Many patient experience teams want to be free to feed into and do more improvement work. But, given other demands (data gathering and reporting requirements), the potential for this sort of work is not yet being realised.

Case Study

Central London Community Healthcare **NHS**
NHS Trust

Patient Experience, Patient Safety and Involvement – Bringing it all together

Central London Community Healthcare Trust (CLCH) is the main NHS community healthcare provider in Barnet, Hammersmith and Fulham, Kensington and Chelsea, and Westminster. We employ more than 3,000 health professionals and support staff to provide community and in-patient services to almost 1 million people across London. Our vision is Great Care Closer to Home and our mission is to give children a better start and adults greater independence.

We provide a number of services in the community, including: adult community nursing services, children and family services, specialist services to help manage long term conditions, rehabilitation and therapies, palliative care services, offender health services and NHS walk-in and urgent care centres.

We use a range of methods to collect feedback from patients including patient surveys, comment cards, patient stories, compliments, concerns and complaints. We sample a range of people in our care to undertake follow up telephone calls every month to give a Trust-wide overview. Each service uses PREMs (patient reported experience measures) surveys or comment cards to get their individual service feedback. Some areas have a kiosk, others use a mobile tablet device or paper surveys that patients can complete at their own pace.

We use the same questions across all formats and include the FFT question. In addition, we also ask about being treated with respect and dignity, being involved in decisions, and being given enough information. All of these are indicators that go towards an excellent overall experience of care.

Feedback goes via our third party provider, Picker Europe UK, who provide analysis and reporting to us on a monthly basis. This ensures anonymity for the patient and a high quality of analysis. We then collate a monthly report for Divisions that includes other feedback and activity such as patient stories and 15 Steps Challenge visits. The 15 Steps Challenge is a toolkit with a series of questions and prompts to guide a visiting group through their first impressions of a ward or service. It is based on the experience of a mother who said "I can tell what kind of care my daughter is going to get within 15 steps of walking on to a ward."

Managers can use the data and themes from the feedback to report back to their teams and individual staff members. It is vital that patients see what we are doing with their feedback and any changes we have made as a result. This can be in the form of a poster in departments or a newsletter using 'You said we did'. We use direct patients' comments where patients have agreed to this. The feedback from patients is a useful way of seeing what is working well and for giving positive, motivating feedback to staff.

The challenge is always to make sense of the data in the context of the experience so as to make improvements. One of the metrics that we would like to improve is the number of patients who report that they feel involved in the decisions about their care. We get slightly lower scores on this, but there seemed no correlation between that score and overall satisfaction. Comments did not surface any specific issues around involvement or whether it was dependent on the type of care being received (i.e how involved would you need to be or feel if you were having a blood test?).
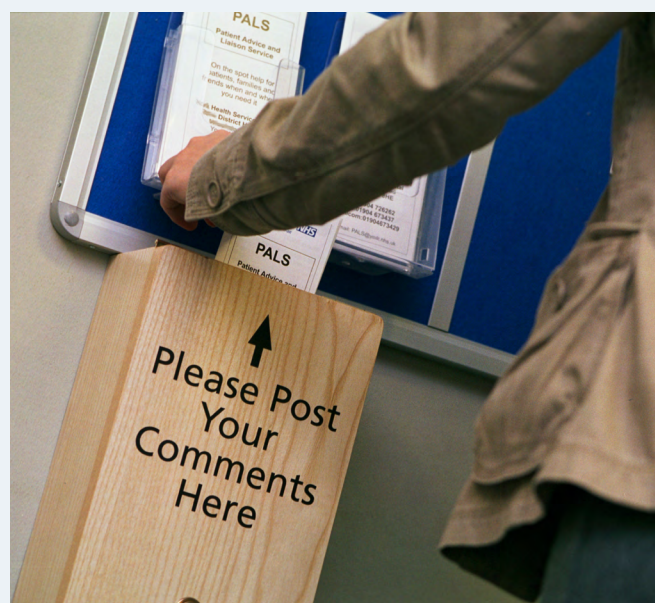
The Trust has also joined the national Sign up to Safety campaign. Issues around safety that also have an impact on patient experience include falls and pressure ulcers, and these are highlighted in our serious incident reporting.

To better understand safety and also the issues surrounding involvement, we invited all our Members and a random selection of patients to attend one of four local events. 69 people attended to discuss the issue, after watching a Trust video and hearing about Trust concerns. We then went on to ask 'What more could be done to improve safety if patients and clinicians work together?'.

After facilitated discussions, many ideas were generated across different themes (many of which were similar across each of the four events). These included:

- Communication (clinicians communicating with patients and carers, language barriers, other physical and psychological barriers, referrals, communication with our providers especially GPs, hospitals and social care)

- Holistic integrated care with other providers and social services (e.g. sign-posting to other services such as voluntary organisations and other providers, improving technology to reduce avoidable harm and human error and improving patient experience).

The themes from the events were shared at a 'Sign up to Safety' launch for staff. The Trust service improvement plan, developed in conjunction with The King's Fund, aims to engage the ambition of frontline staff by supporting their informed local knowledge about what improvements are now required, and how these can be achieved, supported and evaluated.

5. Patients and data

This section outlines how patients and carers are increasingly involved in work to improve patients' experiences. It also explores how this work is changing the nature of patient and public involvement.

5.1 Patients involved in improvement

Our remit was primarily on use of data, and on the whole, participants had responsibility for that area rather than patient and public involvement (PPI). However, a few also had PPI roles or had close connections with that function. And many were drawing patients into their own work.

"Patients are more than providers of data" as one person said. And in some Trusts professionals are not viewed as sole interpreters of the data, or as the only arbiters of what gets done with it. The role of patients seems to be becoming more important. In previous sections, we noted that some Trusts use volunteers (sometimes patients) to gather data via surveys.

A few are approaching patients in other ways to gather data, such as mystery shopping. One or two are also involving patients to help analyse it: "They can check our assumptions and interpretations. We talked to users and voluntary organisations to see where need (for a crisis house) was greatest."

We heard of many examples of patients and carers being involved in helping to use data, generate insights and work together with staff on solutions. Some of these moves come from the adoption of quality improvement methodologies that explicitly involve patients as part of 'co-design'. Those doing leading edge work on patient experience seek to include patients in generating insight and in co-design, and require patients to help, rather than raise issues to be tackled by others (professionals and organisations).

One Trust told us about their patient experience data bank where members are flagged for their level of interest and meet with staff to address priority issues every 6-8 weeks over 12 months. Another has 'peer experience listeners' who do special projects and go into more depth on issues (for example on why satisfaction with safety

had dropped). This programme "comes from on high. Team leaders know it will happen and are expected to report back on actions. Feedback from interviewers is swift so team leaders can implement improvements fast." Another Trust is bringing in client-specific patients to work on safety (pressure ulcers, falls, embolisms, urinary tract infections) and focusing on the question 'what more could be done if patients and staff worked closer together?'

We also heard about ward-based fora where discussions also had "semi-therapeutic purposes", Trusts working with people who had made complaints and several examples of where storytelling was being used "as a humanising piece". One Trust is working with families of loved ones who have died in order to ensure mistakes are not repeated.

Patients are sometimes accorded decision-making status (though this still seems a rarity). And there are still many challenges to bringing patients in to help with patient experience:

> *"The involvement manager has a panel of 150 people doing different things, on interview panels and within projects… But they are not really looking at data and action plans on my report as timelines are too tight."*

Much of the specific work mentioned around involving people in patient experience work was focused on addressing inclusion and diversity. There were specific pieces of work with interpreters (to generate patient story libraries), with community groups (around complaints) and with people from marginalised groups (such as older people and those with learning disabilities). But again, it should be noted that this was not a PPI research project and we are aware that we barely touched the surface on much of the wider involvement work that may be going on.

5. Patients and data

5.2 PPI and patient experience work

During interviews with Foundation Trusts, we asked specific questions about the link between patient experience work, Trust membership and PPI. Often patient experience work is being done within the Nursing and/or Quality Directorate, while Membership support is part of Corporate and/or Communications.

In some FTs, the link seems to be good:

"Membership is managed by a different team, but we have good links. There are user Governors and youth Governors on our youth forum…"

In others, it is not:

"I don't touch membership, but my Line Manager looks at inclusion and wants to vamp up relationships with Membership. We are aware that the database of Members is out of date and that we could do more."

People recognise other benefits of linking up. In some Trusts, governors are seen as particularly useful as they "have the ear of the Chair" and have been involved in specific pieces of experience work, but this was not the norm.

It is clear that more could be done in many Trusts to connect patient experience and membership work, and a few are struggling with ways to do this:

"Governors are managed by Performance Team, so there's no real link up or effort to use Governors and Members. We've been a shadow FT for 7 years. We've had issues (with patient experience) but FT governors don't know about them."

Some patient experience managers have roles that bring them into contact with other patient and public fora, external reference groups, local voluntary groups and HealthWatch (HW). But this is often the responsibility of others in their team, or in other areas of the organisation. One or two described initiatives on patient experience that explicitly involved HW:

"We have a quality and stakeholder group, that includes people from HW and other. We use it as a sense-check and bring in issues to explore. Podiatry appointments recently. Staff come there and discuss stuff."

However, on the whole, HW and the voluntary sector did not loom large in the work we heard about when it came to improvement and the patient experience. This may of course be an artefact of our research methodology (the sample and the topics we covered).

A few patient experience managers with whom we discussed PPI more generally told us that they were re-thinking the role of patients, seeking to utilise patient expertise more in the field of patient experience. This meant in some cases, eschewing 'patient reps' in favour of those patients with direct experience of services.

We are left wondering whether the link between patient experience and involvement work is changing and perhaps challenging the nature of activities within both areas.

5. Patients and data

5.3 Key Messages

Patients, users and carers have a significant role to play in making sense and making use of data – from gathering data to analysing it, from identifying issues to be tackled to helping do something about it.

Many Trusts are beginning to connect patient experience and patient and public involvement (PPI) work. But in several Trusts the work seems disconnected, partly because of separation of functions.

Few Foundation Trusts we talked to seem to be making the most of members and/or governors. This often seems due to lack of internal communication and separation of functions and responsibilities. Those that are linking up see members and governors as a particularly valuable resource.

Leicestershire Partnership **NHS**

NHS Trust

Improving Relationships in Order to Better Use Data

We are a very large NHS provider Trust serving a population of around one million people across Leicester, Leicestershire and Rutland and we have a budget in excess of £250 million. We also employ over 5,500 staff in a wide variety of roles.

We work with family doctors (GPs), local hospitals, social services and other local authority departments such as housing and education to provide mental health, learning disability and a range of specialist and community services. We also work with voluntary organisations and local community groups.

We have split our services into three clinical divisions (Adult Mental Health and Learning Disabilities, Community Health Services and Families, Young People and Children). We have had some concerns in relation to patient experience and have really focused on making positive changes to improve in these areas.

We have a really passionate senior management team with zero tolerance of sub-standard performance in terms of quality and safety. In the mental health and learning disability division there is a massive commitment amongst senior managers to be fully aware of how services are performing and impacting on staff and patient experience. We want to know what's wrong and why and how we can make it better.

Relationships with commissioners – Contractually, we have a number of KPIs (key performance indicators) from commissioners and we had two committees with different commissioners and Trust staff on them – one on 'technical performance' (e.g. waiting times, DNAs or Do Not Attenders) and one on 'quality and safety'. As a team, we were keen to bring together contractual performance and quality aspects so that we could better see the links and impacts of one on the other. We also have front line staff and people who use our services come to our monthly assurance committee so that we can hear first hand what it's really like for people, both the good and the bad. This enables us to quickly identify ways we can remove barriers for staff who are passionate about making improvements in their areas and also allows us to share best practice.

We've also spent a lot of time strengthening our relationships with commissioners, building a common sense of direction, being honest and open, so that there are no surprises. It makes difficult conversations about things that we are struggling with much easier and less confrontational as there is mutual respect. It's also led to getting investment for new or expanded services, such as an out of hours service for local mental health service users. Our feedback from people who use our services told us that the lack of such a service was a problem, and so we worked with our commissioners to develop a CQUIN. The data we had (feedback) enabled us to negotiate a more meaningful service. They're able to demonstrate that the investment has improved quality and we are providing a better service. Everyone is happy.

The relationships we have developed with our commissioners have also supported us in negotiating some 'breathing space' to agree how we improve our data capturing and analysis systems in order to generate more meaningful data. I am confident about this move, as it's in everyone's interest – patients, staff and commissioners – to get it right.

Leicestershire Partnership NHS

NHS Trust

Relationships with staff – As well as using lots of different ways to gather data – one mechanism is never enough – we've spent a lot of time building relationships with staff. They used to feel that this work was just another thing to sort. We spent a lot of time asking 'how can we make your day easier and help you provide the sort of service you want?' The staff want to do a good job and provide excellent care and they understand that if you get patient experience right, you don't get formal complaints that inevitably take a great deal of time to investigate and respond to. Staff are now being much more proactive about having meaningful conversations with patients, families and carers in order to address concerns at the right time and in the right way.

Our 3-4 month programme called 'Changing Experience for the Better' brought together staff to hold honest discussions on what it felt like to deliver services, what can be controlled or influenced. Staff felt listened to. The next stage brought patients and carers in, over a cup of tea and biscuits, to find out what it was like to use services. We thought it would be difficult for staff to hear, but it had quite an emotional impact. Both 'sides' said they had never had time to reflect like this and just listen. They enjoyed it and things changed.

For example, one service user described how he had felt vulnerable because nurses had not smiled at him when they came in to the ward. Now he understands that they were just busy. But the staff hadn't spotted the problem, nor the big impact of making such a small change. We also make sure we include space under our ten-item questionnaire to address 'were you made to feel welcome?'.

Big challenges remain. How to make relevant and timely data more available to teams and managers. They get high level, out of date, reports. We have now developed a system where by front line managers will get weekly data that enables them in a much more speedy manner to address issues, rather than waiting 4 – 5 weeks and it being quite difficult to rectify things.

Relationships with patients – As well as involving them in the 'Changing Experience for the Better' programme, we make an effort to involve patients in other ways. Through our community and voluntary sector forums, via patient and carer champions, ward forums and a patient and carer reference group, we get them to help interpret data and contribute towards solutions. We have developed a local crisis house. This only happened through strong involvement of local users and carers at each step of the way – identifying the need, having honest conversations about the data on where need was greatest, in design and in procurement.

What I have come to appreciate more than ever before, is the key strength you gain from proactively developing and nurturing relationships, not just developing once you have a problem. We have worked hard with all our different stakeholders to make sure that they feel part and parcel of the running of the services we provide and we view ourselves as the guardians of something very precious.

6. The climate – internal and external context

This section looks at the environment for patient experience work, and some of the challenging internal and external factors helping (or hindering) the effective use of data.

6.1 Internal support and leadership

With all the pressures that come with patient experience work, what can help? Most teams who were involved in working with staff on gathering or using data talked about providing dedicated support, for example running focus groups, generating patient stories, developing tools such as engagement guides, or providing training. And, good practice spreads if one part of the organisation is doing the work well.

However, it is about more than just tools and techniques. Patient experience managers are learning on the job about influencing skills:

"I have learned to deal with my own anger. I try to sit on the fence, check facts. I don't make assumptions. Relationships are key."

Another said:

"It's important that we don't attack people with the data. It's not finger pointing."

Success was often down to a local leader who sees the importance of the work: "It's that enthusiasm that rubs off on staff. She says she knows how important it is to ask, says how can we expect to change things unless we know how people feel? We need to clone her." The importance of good staff who role model came through time and time again. In a few cases, this sort of leadership seemed embedded across the organisation due to the overall culture, but this was not generally the case in our sample.

Many interviewees gave the sense that supporting improvement work was a stretch. Many teams seem so busy gathering, or reporting on, data that they do not have capacity to support improvement work properly. But there were striking exceptions. In one Trust, the patient experience team is not responsible for gathering national survey data or for overseeing the FFT. Using a project-based approach, this allows them freedom to work with teams on local patient experience and improvement projects:

"The structures and split of our teams helps. People feel liberated. We are not tick box, we connect. The flexible project process is key with follow up, the 'so what' question. We are not seen as the Cinderella; We've always had participatory approach since 2002-3; always more than surveys."

Whatever the specific arrangements of the patient experience team, the wider corporate culture is another key to success:

"We try to link corporate culture and values to using experience data and improvement work. We strive to be values-based. All staff know our values and themes. But importantly, that is linked to action. It gives us the four key areas that form the basis of how we analyse our complaints. So people are ready and able to do it. We translate abstract values to actionable work."

It may be easier in some sorts of Trusts than others. In some there seems to be an overall receptivity, linked to the passion of the staff.

Sometimes it is a key individual in a powerful position that makes the difference: "The divisional director who is forgiving in some ways, but down like a ton of bricks on other things (concerning individual patients' experiences)." Several interviewees pointed to senior leaders – either new or who had been there for some years – who had made patient experience a corporate priority and/or who had led the work with personal enthusiasm and thus made a huge difference.

It helps if the leadership for, and belief in, the work comes right from the top – the chair or chief executive: "We also have a chief exec who gets direct emails from patients and signs off complaints. Culture and leadership is integral." Sometimes though the "senior clout" (as one person put it) for the work was simply missing. One person pointed out that cultural change is coming from a different direction: "As we move towards patients and the public wanting to practice shared decision-making, so this affects

our culture. People are willing to have a different connection with power."

6.2 National policy context

There is no doubt that the national focus on people's experiences and safety, fuelled in large part by what happened in Mid Staffs, has helped create a climate for this work:

"People are more interested in the last 12-18 months, people want more stories. They understand the relevance of the work more, more engaged, less cynical. National drivers help."

At the same time, system pressures have made the work more difficult too:

"Operational and financial pressures are significant. Our great barrier is demoralised staff. How do we keep them engaged in human kindness? How do we provide people with the resilience to deliver? When a system is under pressure, they will work to the hard piece, the targets."

There is almost universal condemnation of rigid targets around the FFT. The following comment was fairly typical: "They set the FFT target that is wholly unachievable. We have lots of arguments about realistic figures. All they're bothered about is a figure they've set. They're not interested in improvement."

These targets feel like an added pressure, rather than a tool to support the work that now needs to be done – rethinking assurance processes and supporting improvement: "We have an engaged CCG (with patient experience) but that is against the tide of financial and operational pressures." One person regretted the loss of regional support around patient experience and PPI (from the Strategic Health Authorities).

Our questions did not specifically ask what people thought about national agencies, but in some cases people did mention NHS England. One or two wanted better regional support mechanisms. But where NHS England was mentioned, people generally called for a relaxation of targets, particularly around FFT response rates as a success measure.

With such variation in local patient experience work, a few interviewees called for more of a national framework. But what people meant by this seemed to differ. Some called for better metrics – ways to measure how well they were doing. Others called for more of a steer on how to do the work, or how to structure patient experience functions. Others wanted more awareness-raising – a "better brand" as someone called it – demonstration of benefits, celebration of the good work going on or better sharing of learning. A framework could, as one person put it, "give comfort, steer people and catalyse the work."

One or two mentioned the CQC as having given some teeth to the work: "We can use the CQC inspection to raise awareness of the need to get feedback and publicise surveys. I hope that doesn't disappear after the inspectors have been." The attention of an inspectorate though is not always a good thing in people's eyes: "Morale is a bit low, being on special measures, this has a bit of an impact."

6.3 Relationships with commissioners

The overriding message from teams to commissioners is for better relationships and some free reign: "We need breathing space. I've told them (CCG) to get off our back responding to queries, and we could sort it out. They seem amenable to that."

Partly due to reporting requirements, relationships between Trusts and commissioners is threatened. Some interviewees were outspoken:

"The CCG is a cacophony of confusion. Patient experience is just numbers and nothing else."

Several seemed quite angry with commissioners for their inflexibility or for their inability to have a dialogue.

Added to this, with patient experience data gathering demands increasing, some teams are at breaking point:

"That money (from the CQIN) goes into a Trust black hole. It's never used to buy survey solutions. I am too low ranking… We are

not the only Trust in this situation. What do you stop doing in order to invest in the infrastructure for patient experience?"

A few Trusts and CCGs though – with corporate support – are beginning to shift things:

"I took her out for a cup of tea, relationships are vital. We managed to negotiate a CQIN around Out of Hours services. The data showed dissatisfaction with that. We said, commission us to do something about it, attached to a CQIN for how well we do it."

One or two Trusts are working with CCGs in other ways too, for example, rationalising reporting mechanisms. They may also work together on improvement: "It works well (CCGs and Trust joint working) in the integrated care programme, particularly as we also have community services." However, joint working across the health economy is not always easy: "There is a tension between having to focus on our own priorities and the need to link up on the integration agenda. We can't do everything. The focus has to be on the internal, but we know there are lots of problems around pathways and discharge."

6.4 Key Messages

Patient experience work benefits hugely from senior and local (i.e. divisional, team) leadership – people who believe in the work and who can make it happen. Many Trusts have this in place, but corporate, divisional and team cultures seem extremely variable.

Relationships between patient experience teams and commissioners is variable. There is consensus that rigid targets and incentivisation schemes around patient experience work are unhelpful, particularly concerning measuring success through FFT response rates.

The national focus on people's experiences and safety has helped create a positive climate for patient experience work. But now national and system pressures – including rigidity of targets – make the work more difficult.

Discussion and next steps

Our research shows a huge amount of good patient experience work going on. More and more Trusts, teams and staff are **seeing the value** of gathering and making use of patient experience data.

There is a clear sense of **passion and commitment** for the work from everyone we spoke to. Patient experience teams are finding effective ways to gather data across a wide range of settings, systems for inputting and analysing data are available and reporting mechanisms are becoming more coherent and useful.

Patient experience teams are learning about what works and becoming more adept at making sense and making use of data in a complex and changing environment. Effective models are emerging, people are **seeing the benefits** of using data well and this is leading to wider ownership of the work.

The corporate culture, in many cases, is more conducive and **enthusiasm is spreading**. As Trusts try to connect governance and improvement work – asking the 'so what?' question about what the data signifies and what needs improving – so the spotlight is being shone on how make better use of the data.

Patient experience teams are working hard to make the data meaningful and accessible to staff, and to work with them (and service improvement teams and patients) on solutions. The result is **better services for patients**. But…

There are huge **variations between and within Trusts** as to how they make sense and make use of data, and significant challenges to the work.

Trusts and teams are struggling to gather, bring together and analyse more and more data. With onerous reporting requirements and rigidity of targets, many patient experience teams feel they are **feeding the bureaucratic beast**. With more time spent on servicing the FFT scores, boards and commissioners may not be getting a full picture of patients' experiences (owing to a lack of granularity of data and capacity to analyse qualitative data).

Moreover, teams are so busy gathering data (particularly for the FFT) and compiling reports, that less time is available for doing something with the data – **efforts to improve services are in danger of being squeezed out**.

The ability to **engage with staff** – so critical to the effective use of data for improvement – remains a tough nut to crack, and may get tougher due to increasing operational and system pressures. For patient experience work, this means that the **'positioning' of this work**, as helping both staff and patients, is more important than ever.

Patients and Members (of FTs) could have a significant role to play in making sense and making use of data – from gathering data to analysing it, from identifying issues to be tackled to helping do something about it. But the potential is not yet being realised fully.

The national focus on people's experiences and safety has helped create a positive climate for patient experience work. But now national and system pressures, including rigidity of targets, **make the work more difficult**. Relationships between patient experience teams and commissioners needs improving.

Despite the difficulties, patient experience teams seem to be clear about what needs doing, and with **the right sort of support**, have the passion and expertise to do so.

In order for this to happen, there needs to be a **wider shift** – a re-calibration of the work. National and local agencies (commissioners and providers) need to help create the climate for the effective use of data for improvement.

In turn, the national and local desire for 'checking' and benchmarking needs to be balanced with a recognition that Trusts need the **space, time and capacity** to make sense and make use of the data. We hope that our research helps to create that climate.

Discussion and next steps

We think the following steps might help:

Patient experience teams

Teams could move towards a more 'embedded model' for patient experience work, whereby local staff teams undertake their own patient experience work and patient experience teams provide support for implementation. This model seems to be working well in a few Trusts we talked to. More could be done to build relationships between patient experience teams, membership departments, communication and social media activities and patient and public involvement.

Staff engagement

Patient experience and staff engagement (and FFT activity) should be better aligned and connected. Organisations could do more to stress the value of patient experience work to busy staff, helping people to see that this better staff and patient experience can be mutually dependent. Support for patient experience teams could focus on developing influential relationships and staff engagement.

Corporate support

There should be better corporate support for analytical and insight activities. There could be sharing of learning around effective and efficient data reporting and governance approaches. Where it is not happening, stakeholder fora (with patients, staff and clinical leaders included) should be developed to catalyse efforts to improve, based on patient experience. Trusts should consider how they create space for patient experience teams to re-balance improvement work with data gathering and reporting requirements.

Commissioners and national agencies

Better metrics and a common national framework around patient experience should be developed. This should include consideration of actions taken as a result of data gathered and improvement measures. Ways should be found to relax current rigid reporting to factor in local context and incentivisation processes.

An electronic version of this report is available at **www.membra.co.uk/case-studies/ research-surveys**. There you can also find an abridged version summarising the key findings.

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