What really matters to patients and their carers?

Six recurring themes of 'patient experience' and why staff need help and support to address them.

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Executive summary

- This report is an account of experiences of healthcare obtained from 130 interviews with patients and their carers across West Yorkshire (2017-2020) that reveal six commonly repeated themes irrespective of service specialty and Trust, about what matters most to them. Whilst patients and carers are overwhelmingly supportive of health services and the staff who work in them they report (usually with hesitation and regret) that care is repeatedly lacking in these areas.

- Given the close relationship between patient experience, quality and safety of care and the success of clinical outcomes, the report's purpose is to communicate these messages to health service leaders at all levels of influence and propose certain conditions and support required by clinical teams if they are to be able to address them.

- The six themes are that 'good services hold lives together'; 'goal setting and care plans are essential'; 'the patient journey must be consistent and clear'; 'certain patients feel particularly vulnerable and anxious'; 'trust and approachability means everything'; 'navigating health systems is daunting'.

- An evidence scan supports our findings that these themes are important and persistent and that there is a need to develop more compassionate care, better communication and trust, and increased recognition of individual patient need.

- The evidence also recognises that whilst frontline clinical teams are best placed to respond to these needs they face a number of cultural and organisational barriers that can prevent them from doing so and this can lead to burnout and low morale.

- Practical recommendations are made for a 'relationship-building' approach to improving patient/carer experience that recognises that support for the caregiver is as crucial as listening to and collecting feedback from patients.

- This approach includes independent facilitators, senior role modelling, and permission and support for teams to develop their own improvement interventions to suit their contexts.

Introduction

The purpose of this report is to share insights gained from conversations with 130 patients and their families/carers in West Yorkshire. We have identified six recurring themes that tell us what matters to patients, what is consistently lacking, and therefore what we think needs addressing. To deepen our understanding, we also include a summary of a scan of existing evidence that helps understand i) how our themes are evident in the wider literature, ii) why staff cannot always support these essential components of care, and iii) embryonic proposals for enhancing support for staff.

The report should provide much-needed guidance and support for teams wanting to enact improvement for themselves and those they care for. However, it is also targeted towards senior decision-makers in health and social care who can consider the conditions and support they need to provide for their clinical teams if real progress is to be made.

The perspectives of 130 patients in West Yorkshire:

Listening to the patient voice is a growing priority across the NHS not only to inform service improvement but to monitor performance and provide assurance. In response to this, the Yorkshire and Humber Improvement Academy supports a programme of regional support for staff from any healthcare service setting to use patient experience feedback effectively. An evidence-based tool called the Patient Experience Toolkit (PET) is central to our approach[1]. This was developed by the Yorkshire Quality and Safety Research Team in partnership with us, the Improvement Academy[a]. PET is designed to help clinicians understand what currently works well for their patients as well as areas of service where patients' needs are not always being met, by working through six sequential steps: i) bringing together a team, ii) gathering feedback through conversations, iii) making sense of feedback through thematic analysis, iv) presenting these themes to clinical teams and allowing time for reflection and discussion before v) prioritising and supporting improvement initiatives and vi) review. The format used in Step ii is a conversational interview approach based on four open questions: a) Overall how has your experience of care been?; b) Is there anything you would like to have happened differently?; c) What is most important to you when you are receiving healthcare? d) Any other comments? Interviews are carried out by trained volunteers from participating Trusts acting as a 'patient representative', alongside and supported by improvement specialists. In Step iii, a theming exercise is undertaken to draw out key insights about what really matters to patients.

Over a 3 year period (2017-2020), we have used the PET approach with seven different NHS Trusts; Leeds Community Healthcare NHS Trust, Bradford District Care NHS Foundation Trust, Airedale NHS Foundation Trust, Bradford Teaching Hospitals NHS

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[a] (funded through the NIHR *Health Services & Delivery Research Programme*).

Foundation Trust; Mid Yorkshire Hospitals NHS Trust; Leeds Teaching Hospitals NHS Trust, and Harrogate and District NHS Foundation Trust. We have spoken to 130 patients and/or their carers who were utilising 11 different service types in 13 settings; maternity, elderly rehabilitation, urgent and emergency care, stroke rehabilitation, rheumatology, amputee rehabilitation, medical, surgical, acute psychiatric in-patient, palliative care, and children's community nursing. In each of these services, feedback has been used to inform improvements to their individual services. However, through the process of supporting all these individual projects, we noticed recurrent patterns were emerging. As a result we carried out a 'meta-analysis' of all the themes across the 13 services and this revealed **six generalised themes.** The recurrence of these across all service areas was stark, irrespective of specialty or geographical location and this observation was the impetus for this report.

Six generalised themes

Before we explain each theme in turn, it is worth appreciating the high regard in which NHS staff are held by the patients we spoke to across all seven NHS Trusts. Sentiment towards staff is overwhelmingly positive and the feedback we collected was a cause for celebration because of the ways that staff could make their patients feel better, and the support they provided in times of need. Comments such as '*the team is a lifeline*' and '*from the bottom of my heart, I can't think of anything they could do better*' are illustrative of patients and carers' sentiments.

1 Good services hold lives together

Whilst each service provides a unique clinical role for patients, in every setting patients recounted often life-changing impacts that the service has had on them - staff are 'lifelines' to these patients helping them feel safe and supported during one-off events (e.g. Accident and Emergency attendances), longer term stays (e.g. stroke rehabilitation or palliative care) or ongoing treatments (e.g. amputee and other outpatient clinics). Crucially staff are giving patients and their families/carers hope during immensely challenging times and this is enormously appreciated by almost everybody.

This theme is really the foundation for understanding all of the others that follow. Because of the enormous emotional need that patients and families frequently present with, a clinical team or an individual that responds directly to these needs is appreciated beyond words. Conversely, because these needs are not responded to consistently across the whole patient journey of care, the issues covered in the following themes are felt acutely by most patients and families at certain points.

Figure 1: Six recurring themes

Overwhelming cause for staff to celebrate the vast amounts of complimentary feedback received from patients expressing their positive experience of healthcare.

Good services hold lives together

➢ Life changing impacts were recounted in the different services through listening, reassuring, clear explanations, knowledgeable staff with patients' best interests at heart.

➢ Patients view services as a lifeline.

➢ 'Human service which is authentic and genuine'.

➢ As well as appreciating their expertise 'instils confidence and patients' trust'.

➢ Time to chat is really valued – not always time.

➢ Patients want to use their time in a meaningful way, being given hope is essential.

Goal setting and care plans are essential

➢ Patients want and need to be involved in their goal setting & rehabilitation.

➢ Helpful to have a sense of what stage they are at and what they are aiming for as care plans not consistently used throughout services.

➢ Relatives as well as patients want to know/understand the care and treatment plan, time scales of treatment, implications on health.

➢ Feedback on progress is key and patients appreciate when staff are honest.

➢ Pain relief and comfort is an over-riding goal for patients and a central concern.

➢ Seeing progress is a key motivator. Being involved in this means a lot to patients and their families.

The patient journey must be consistent & clear

➢ Starting the process – initial introductions to the clinic and overall process is extremely important because they usually do not know what to expect.

➢ New patients are often nervous.

➢ Continuity of care – concerned staff across the patient journey know about them and their care needs. Inconsistency can lead to a lack of confidence in the service - making things stressful.

➢ Patients worry when spouses/other family members are excluded.

Certain patients feel particularly vulnerable & anxious

➢ Staff attitudes towards these patients are key.

➢ A dementia friendly environment – understanding factors that lead to confusion. Noisy ward environments exacerbate anxiety.

➢ Loss of control – relying on other services – 'who will let my doctor know?'

➢ Families also feel anxious and want to be involved.

➢ Patients need honest, clear and regular information.

➢ Cancer patients – pain & effects of chemo make it hard to remember/ understand what's going on.

➢ Many are unable to ask for reassurance and remain anxious.

Trust and approachability mean everything

➢ Asking for help from staff can be hard. Patients can feel guilty, like an inconvenience e.g. 'you are not my patient' 'don't want to pester busy staff'.

➢ Patients acutely aware of how busy staff are and concerned for them, their welfare – busyness is a barrier to communication.

➢ The importance of positive interactions cannot over-estimate the human touch.

➢ Recognising each patient is different and needs different approaches – knowing the person behind the patient puts patients at ease. Patients don't always know what to ask.

➢ Hospitalisation impacts emotional, psychological well-being.

➢ Little time to respond to patients' emotional needs.

Navigating health systems is daunting

➢ Worried about the future – some people do not have relatives or advocates to act on their behalf or support.

➢ Patients not always convinced of good communications between other departments.

➢ Information and signposting really appreciated.

➢ Patients would like to know or understand where they are in the process within health & social care.

2 Goal setting and care plans are essential

Very few patients had a care plan. If they did, they weren't aware of it or it was rarely completed in a partnership manner between a member of staff and the patient/carers. This was then linked to an almost universal feeling from patients of being uncertain as to what was happening, what to expect and whether progress was being made. It often left patients, families and carers feeling powerless, devaluing the patient-staff relationship. For many patients (e.g. in palliative care) the goal of pain relief and comfort was key to them, and was a good example of where a clear plan of action could benefit.

3 The Patient Journey must be consistent and clear

Every point through the patient journey matters. Initial introductions to any service are important when patients and their families will often have lots of questions and concerns related to their health, what staff already know about them, and how the service can help. Lack of clarity provokes anxiety and often patients do not know what they can expect - a situation that can lead to misunderstandings. Inconsistency in care from different staff can lead to a lack of confidence in the service making things stressful for the patient.

4 Certain patients feel particularly vulnerable and anxious

Some patients will feel a heightened sense of vulnerability and anxiety that is not always reflected in the way staff behave towards them. These could be patients with mental health issues, dementia, or other conditions/treatments that affect their cognition and/or memory (e.g. those recovering from a stroke or those experiencing side effects of chemotherapy or pain relief). With these groups, the provision of honest, clear, and regular information was often lacking and many would not feel able to ask for help or reassurance. e.g. '*I don't want to be a bother or pester staff when they are busy working*' was a comment heard countless times from patients receiving palliative care whose pain levels and medication often led to confusion. An understanding of the needs of patients with specific vulnerabilities and the factors that exacerbate anxiety e.g. noisy ward environments is key in helping patients feel calmer.

5 Trust & approachability means everything

Almost without exception, all patients (not just the most vulnerable) really struggle to ask for help from the people who are there to do just that. Sometimes they do not even know what to ask for. Patients express feeling guilty having to ask, feeling like an inconvenience, especially when met with comments such as '*you're not my patient*', a comment which may be true but is hard to hear.

There is no doubt patients are well aware of the pressure staff are under - they witness it first-hand and become concerned for staff welfare. Busyness has become a barrier to communication. Hospitalisation impacts patients' psychological health but there is often little time to respond to anxieties and provide the emotional support which this warrants. The importance of positive interactions and the human touch can therefore not be over-estimated: simple acts of human kindness were highly valued and seen as underpinning feelings of safety and trust. Listening, reassuring, providing clear and honest explanations and being given time to talk to staff were **the** most important elements of care for the patients we spoke to. Above all, patients valued being understood - if staff show they know the person behind the patient, this puts them at ease.

6 Navigating health systems is daunting

The NHS is a complex and gigantic system to navigate. Many patients have worries about the future and want to be reassured that they are receiving a safe and good quality service but where lines of communication breakdown between staff, services, wards, and departments confidence is undermined. Efforts made to provide information and signpost are therefore greatly appreciated. Follow-up calls to check a patient has what is needed are not expected but very thankfully received. Patients want to feel the different parts of the service are working coherently to help them but often they feel the opposite - a feeling that is more acute when vulnerable patients do not have relatives to advocate for them.

Evidence Scan

i) Our themes are evident in wider literature

Our themes indicate what we found to be important to 130 patients. A scan of wider literature finds the same themes evident, helping to solidify some key concepts that we have highlighted in bold. We use this wider evidence to understand our first theme 'good services hold lives together' as the bedrock of understanding patient experience. As described by Black[2] health services and therefore health professionals, touch lives **'at times of most basic human need'** and 'when care and compassion are needed most'. The small acts of kindness that patients often receive from so many during these times leaves them and their families **indebted, and emotionally attached, to the service.** Such a relationship is evident at personal and population levels during the current Covid-19 pandemic: those (including the Prime Minister) who have been directly affected by severe illness report dedicated care that, often, they can hardly believe exists at such a compassionate and person-centred level, and the wider public are **overwhelmingly grateful** that such a service exists should they or their loved ones require it. This is evident in the public's response of gratitude towards NHS staff (e.g. 'Clap for Carers' and rainbow posters displayed in homes).

But it is also clear from our themes that with this often intense emotional need comes a very significant responsibility on the caregivers. Our themes and the wider evidence reveals that these needs are often left unmet, leading many patients and families to feel

let down at various and repeated points. As Raberus[3] describes in an analysis of complaints, what patients are concerned most about is not medical care but a lack of information and communication, and a feeling of **being ignored** and of **nonchalance**. This lack of consistent, quality communication is striking in our theme 'patient journey through care' - a lack of introductions and a discontinuity of care. It is also evident in the theme 'goal setting and care planning' - where patients and their families often **feel excluded** from the decisions made about them. The evidence overwhelmingly suggests that a partnership approach reaps rewards through responsiveness to need[2] and by pooling the knowledge that comes from patients/carers with that of Health Care Professionals[4,5] but despite this, our theme of trust and approachability revealed that **staff are largely not available** and perceived as **too busy to talk**.

The recurrent nature of these themes within our own work and wider evidence suggests that all patients will experience them to greater or lesser degrees. If those accessing health services do so with their hearts on their sleeve, at the times in their lives when they are most in need of compassion, then we know from our fifth theme that this applies to particularly vulnerable patients even more - **they do not have the resilience or capacity to speak up** and shout loudly, so their needs go unmet more often. Finally, as our patients told us, the more complex someone's journey and the longer they need to be on it, the more difficult it is to 'navigate different parts of the system'. As Willis[6] describes, there is an assumption that someone with knowledge of the system will guide patients through - it is evident that they do not. Patients quickly learn this and so they **worry and lose confidence** over time.

Knowledge and an appreciation that these themes matter enormously to patients is not new. Indeed, they are advocated consistently within models of person-centred care which, as summarised by the Health Foundation[7] is care that is: personalised, coordinated, enabling, and that patients are treated with dignity, compassion and respect. Evidence also supports what our themes and the wider evidence tell us - that person-centred care is not standard practice[7]. If we are therefore to move beyond the collection of feedback into improvement for patients, we must look at the reasons why person-centred care is difficult to achieve, and begin to address them. This is viewed as a moral obligation[6], but is also related to improving clinical outcomes and safety[8]. There is also growing evidence that being able to provide person-centred care is good for staff job satisfaction - pride and joy at work[9], and avoiding burnout[10].

ii) why staff cannot always support essential components of care

To date, several reasons have been posed to explain this. This list is not definitive but we believe it points to some fundamental challenges that need to be acknowledged further:

- the **'emotional labour'** that comes with attending to many people in their hour of need has been defined as a 'suppression of a feeling in order to sustain an outward appearance of safety' [11]. This is stressful and can lead to a coping mechanism of withdrawing emotionally, and relinquishing responsibility for a person's care away from an individual to the organisation as a whole[12].

- The intense emotional needs of patients also requires **high level communication skills** and ability to be compassionate and care, that can't be assumed to exist in all staff [13]. Where patients have additional cognitive needs (e.g. dementia), further knowledge and skills will be required[14].

- Organisationally, there is evidence that because of the way healthcare systems are structured, **staff perceive a lack of legitimacy** to respond to patients' nuanced needs [15]. As outlined in the Feedback Response Framework, staff usually believe at a personal level that patients' needs are paramount but are prevented by their position in the hierarchy, or by the organisation's competing demands, in responding effectively.

- Linked to this is simply a **lack of time** for staff to behave in these ways - pressure to see large numbers of patients quickly leads to what has been termed 'compressed medicine'[10] where limited time means that patient participation cannot be achieved and there is no time for knowledge to be shared and relationships to develop[16].

- The dominant drive for efficiency within health systems advocates **task focused care** approaches that are at odds with person-centred care[17].

- Culturally there are engrained and accepted roles of **patients as passive adherents** to doctors plans and these are hard to shift [10].

iii) embryonic proposals for enhancing support for staff

The barriers to supporting the essential components of care outlined above are of a deep and systemic nature - relating to culture, levels of staff capacity and support, as well as the complexity and vulnerability of the patients that need care. Whilst these barriers cannot be easily solved there are some embryonic ideas posed that we must explore. First, there is no shortage of guidance on innovative techniques available from the field of patient and public engagement and co-design, on how to communicate with patients. Tools such as Experience Based Co-design[18] , and techniques of open questions, active listening and participative goal planning using a range of accessibility features (e.g. pictures, symbols, large print, braille) already exist[16]. What is now needed is an understanding of how staff can be supported to work with such techniques and principles in the mainstream. There may be some specific skills that also take time to foster and develop - training courses for empathy, reflective and listening skills are not straightforward but there is expertise available to support these[19].

In a National Institute for Health Research review of effective use of patient experience feedback in improvement[20], it has been proposed that strong, independent facilitation is needed if staff are to be able to overcome the barriers they face. This could be provided by someone who can help them reflect on the 'pebbles in their shoes'[10] that regularly prevent them from working in this way, and direct them to the help they will invariably need if they are to change things. This potentially creates legitimacy and empowerment for them where the current system does not already provide it.

This will only work if an organisation leads by example with the board becoming a genuine mirror image as role models of behaviour[9]. The same principle is found in the NHS Influence Model[21] which places leadership and culture change at its heart, and the concept of compassionate and inclusive leadership[22].

Summary and recommendations

We have identified six persistent and recurrent themes within patient experience feedback collected from very different healthcare settings, that tell us what is most essential to patients and their carers when they access healthcare services. These centre on compassion, communication, trust and a recognition of individual patient need. Whilst patients and carers are overwhelmingly supportive of the health service and of the staff who they rely on, our themes reveal that this support comes despite these essential components of care repeatedly going unmet. Our evidence scan points to the complex cultural and organisational reasons for this and identifies some embryonic proposals about how to address these. These all imply a need to shift the patient experience agenda from one that repeatedly asks patients for their feedback on services, to one that supports staff in what they need if they are to respond.

Based on our own themes, the wider evidence and our own extensive experience of supporting frontline clinical teams, we have built on the PET toolkit[1] to develop a *'relationship-building approach to improving patient/carer experience'*. In this approach the fostering of trust and shared goals between patients, carers and staff from all levels of an organisation is central.

This includes the following essential elements:

- Dedicated leadership of every frontline improvement initiative by one executive (e.g. chief nurse) who can 'unblock' organisational obstacles to frontline improvement.

- Solidarity and role modelling by senior members of the Trust to demonstrate a shared purpose centring on the essential components of care: listening, empathy, serving.

- Collection of qualitative experience feedback from staff as well as from patients.

- Involvement of lay volunteers in the collection and interpretation of patient feedback.

- Independent facilitation to help understand, reflect on, and respond to feedback.

- Protected time for reflection on patient experience feedback that provides the inspiration for improvement projects to be prioritised.

- Permission for teams to choose their own priority areas and adopt, test and develop interventions that are appropriate to context and owned by their team.

- Opportunities to forge new intra-organisational partnerships to tackle issues that extend outside the remit of one clinical team.

- Celebration and recognition of staff contributions and successes.

Our approach is grounded in the extensive peer-reviewed research programme from which PET arose[23-25], and that continues to be developed in practice with a range of healthcare Trusts across Yorkshire & Humber. We invite others to join in this improvement journey, believing it to be particularly relevant now in light of Covid-19, which has only intensified the challenges faced by frontline teams as they seek to provide care they are proud of.

The success with which healthcare organisations are able to support their staff teams to provide the essential components of care that we include in this report will continue to be revealed in metrics for staff and patient experience. Evidence suggests it will also be revealed in metrics for safe and quality care.

Get involved

If you would like to discuss any of the points made in this report, or you would like to get involved with developing our approach further, please contact the Improvement Academy. We would love to hear from you.

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