IMPROVING THE USEFULNESS AND USE OF PATIENT EXPERIENCE FEEDBACK

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ABSTRACT

Patient experience is recognised as a pillar of healthcare quality equal to safety and effectiveness (1)(2). In the UK National Health Service (NHS), this paradigm has supported robust feedback collection, leading to a repository of nationally-collected patient experience data (3)(4). However, such data has not been effectively used to drive local quality improvements (4)(5)(6).

This work addresses the question, *how can the usefulness and use of patient experience feedback be improved*?

In order to contribute a clear body of knowledge in response, this work ascertains the root causes of limited data use; tests how novel analytic techniques can enhance data utility; and explores how experience data can be used in conjunction with other data to improve organisational responsiveness to patient feedback.

First, this work systematically appraises the evidence relied upon to design patient surveys. This confirms a deficit of patient input into the evidence base, and subsequently insufficient information about how patients' priorities differ. Population segmentation techniques are then employed to identify patient groups and their varying concerns, and present feedback in a disaggregated way that facilitates targeted improvement. Furthermore, interviews with NHS staff elucidate what adaptations they feel are necessary in order to embed national patient survey results within their local improvement strategies.

This work then leverages existing data to generate a new patient experience composite score that challenges current national benchmarking metrics. The composite score is used to cluster acute NHS organisations, revealing organisational patterns in patient experience. Furthermore, multi-linear regression analysis delineates which organisational factors predict positive patient experience, intimating the importance of cultural variables. A translational research case study then captures the process towards achieving the organisational culture necessary to act on patient experience data.

Individually, these findings convey a series of policy recommendations, while cumulatively they showcase the possibilities for a more patient-centric health service.

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LIST OF ACRONYMS & TERMS

AHRQ	Agency for Healthcare Research and Quality
A&E	Accident & Emergency
AIPS	NHS Adult Inpatient Survey
AMI	Acute myocardial infarction
ANOVA	Analysis of variance
API	Autonomy Preference Index
CCU	Critical care unit
CHP	Centre for Health Policy
CI	Confidence interval
CQC	Care Quality Commission
DBS	Disclosure and Barring Service
DH	Department of Health (UK)
EBME	Electro-Biomedical Engineering
ERIC	Estates Returns Information Collection
FFT	Friends and Family Test
FM	Facilities management
GP	General practitioner
HCAHPS	Hospital Consumer Assessment of Healthcare Providers and Systems
HES	Hospital Episode Statistics
HSCIC	Health and Social Care Information Centre
ICD-10	International Classification of Diseases 10th revision
ICHT	Imperial College Healthcare NHS Trust
ICT	Information communications technology
IHI	Institute for Healthcare Innovation
IOM	Institute of Medicine
JRCO	Joint Research Compliance Office
KPI	Key performance indicator
LMICs	Low and middle income countries
MDT	Multi-disciplinary teams
MaPSaF	Manchester Patient Safety Framework
MeSH	Medical Subject Headings
NCPES	National Cancer Patient Experience Survey (UK)
NHS	National Health Service (UK)
NICE	National Institute of Clinical Excellence (UK)
NPSP	National Patient Survey Programme (UK)
NRLS	National Reporting and Learning System (UK)
NSS	National Staff Survey (UK)
OECD	Organisation for Economic Co-operation and Development
PCA	Principle component analysis
PFI	Private finance initiative
PIE	Picker Institute Europe
PPE	Picker Patient Experience Questionnaire
PPM	People performance and management
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PREMs	Patient reported experience measures

PROMs	Patient reported outcome measures
SAQ	Safety Attitudes Questionnaire
SD	Standard deviation
SHA	Strategic Health Authority
SPSS	IBM product name for data mining and statistical analysis
STIES	Health Strategic Executive Information System
UK	United Kingdom
US	United States
USA	United States of America
WaPEF	Warwick Patient Experience Framework
WHO	World Health Organisation
WTE	Whole time equivalent
Trust	The legal entity of a whole NHS organisation, inclusive of all of the organisations' hospitals and services

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STATEMENT OF ORIGINALITY

All the work presented in this thesis is my own and it is the work upon which I expect to be examined.

EXACT DETAILS OF CONTRIBUTIONS

I carried out all of the work in this thesis, however, in the process of completing all of the studies, other individuals were involved. The details are outlined below. The whole thesis was overseen by Professor the Lord Ara Darzi (AD) and Mr Erik Mayer (EM).

CHAPTER 1: Concept developed by Kelsey Flott (KF) and EM. For the following reference that was incorporated into Chapter 1, Chris Graham (CG) and AD contributed expert insight.

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CHAPTER 2: Study concept and design by KF with support from Imperial College Library.

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Sizmur (SS) provided data from which to select organisations. Dominic Shaw (DS) helped conduct interviews. DS's roles included sitting in two interviews and asking specific questions about improvements in patient experience. Sarah Gancarczyk (SG) helped conduct interviews, (including sitting in ten interviews and asking questions about improvements in patient experience), analyse data and write the following manuscript developed based on this chapter. LD, DS and SG all supported topic guide development. AD and EM also contributed to the manuscript:

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PUBLICATIONS, PRESENTATIONS & FUNDING

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CHAPTER 1:

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CHAPTER 3:

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Other relevant publications:

- Khanbhai M, Flott K, Darzi A, Mayer E. Evaluating the effectiveness of real-time patient experience feedback: a systematic review. Journal of Medical Internet Research. *In review*.
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- Graham C, Flott K, King J, Gibbons E, Jenkinson C, Fitzpatrick R. Strategies and challenges for monitoring patient experience at the local level. International Journal of Healthcare Management. 2015 Mar 10;8(1):1–3.

Other relevant presentations:

- Flott K, ISQua, Evaluation framework for patient safety incident reporting systems, oral presentation, 2016.
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- Flott K, Mayer E, Islamabad Patient Safety Conference, video presentation, 2017.

CHAPTER 1

NARRATIVE LITERATURE REVIEW

1.1 EVOLUTION OF PATIENT EXPERIENCE AS A COMPONENT OF QUALITY IN HEALTHCARE

Since the late 20th century, patient experience has emerged as a prominent concept in healthcare policy discourse and has become recognised as a defining element of quality (7)(8)(2). International prioritisation of patient experience has been indicative of a healthcare paradigm shift away from solely focusing on clinical outcomes, towards holistically evaluating entire care pathways (9). Despite this progress, and the repository of patient experience feedback it has facilitated, the trend has not gone far enough.

Extensive evidence demonstrates that patient experience feedback, particularly patient survey data, is collected and analysed, but often remains dormant, underused in local quality improvements (5)(4)(10)(5)(4)(8)(11)(12)(13). Patient voices are going unheeded in quality improvement strategies (7)(5)(4)(1). In response, improving the usefulness and use of patient experience feedback is becoming an increasing priority across health systems (10)(14).

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Patient experience is rooted in a complex history of healthcare quality. Summarising the evolution of healthcare quality, the terms that define it and the policies that influence it, gives context to the need to improve the usefulness and use of patient experience feedback.

Quality in healthcare has long been synonymous with positive outcomes, but over time its definition has acquired different components. It has grown into a multifactorial construct, associated with a range of professional standards and strategies designed to achieve it (15).

1.1.1 Defining quality across health systems

The contemporary definition of quality uses three domains: clinical effectiveness, patient safety and patient experience (Figure 1) (2). This work will primarily focus on acute care in the English National Health Service (NHS), where this definition is enshrined in policy (16). These three components also feature widely in international frameworks for defining quality like those upheld by the Agency for Healthcare Research and Quality (AHRQ) and Institute of Healthcare Innovation (IHI)(17).

Figure 1. The three components of quality in healthcare

The complexity of these three components, and the various ways to operationalize them, gives the illusion that quality could mean different things in different health systems. From a policy perspective, this is partially accurate as the roles and goals of health services across the world are not uniform (18). Health systems can be theoretically divided using parsimonious typologies like the classification of systems by financing structures: either private, social insurance or public (19). These three healthcare system types have fundamentally different incentives which might influence what components of quality are prioritised (19).

Despite these differences, however, there are conceptual parameters around how a system *can* be financed or otherwise structured, that apply universally (20)(21). More importantly, health systems face a list of common challenges (22). The conceptual parameters around policy structures, and the commonality of health challenges, means there is often a practical convergence of system types, even system goals (20). Awareness of such convergence is necessary to explain that, while differences in systems influence approaches to conceptualising quality, the importance of effectiveness, safety and patient experience are universal (22).

1.1.2 The evolution of the definition of quality in healthcare

Over time the definition of quality has not been static. The evolution of health systems and advancement of humanitarian paradigms have coincided with the gradual integration of the three domains into the contemporary definition (23). In the definition's infancy, quality was simply the delivery of effective healthcare. The remit of health systems, at least in Europe and North America, evolved from the charitable sector, taking responsibility for the poor and treating the unwell (24). In the NHS specifically, this was seen as a moral responsibility, but also as a means towards enhanced sanitation and a fitter workforce (25). As healthcare advanced, quality also began to refer to things like scientific innovation and catalysts for new treatments and cures, often without the protection of safety regulation (26). Records demonstrate that efforts towards surgical innovation in the early 20th century, for instance, were not always conducted with safety checklists or protocols for checking instruments (26). However, even when the concept of healthcare quality was relatively embryonic, it was common to keep administrative records of the effectiveness of patients' procedures and treatments (27). Since 1987, Hospital Episode Statistics (HES), a data warehouse including records of patient attendances and admissions for inpatient, outpatient and emergency care, has been gathered for all NHS hospitals, and can be used to measure indicators of clinical effectiveness (27).

With the growing capacity of health services, quality became known as something more than effectiveness. This expanded definition started to include patient safety. However, patient safety appeared only as blips on the radar before the 1960s (28). A timeline of the integration of safety into quality has been produced by the Health Foundation (28). This timeline reveals that contemporary mandatory safety procedures were born as controversial suggestions, like the proposal to introduce hand washing in obstetrics in 1847 (which did reduce mortality from 18% to 1%) (29). Florence Nightingale also made a controversial suggestion in 1855 when she posited the role of cold temperatures and poor sanitation as being greater than that of battle injuries in killing soldiers (28). More of these suggestions, combined with the advancing institution of health services and mounting evidence of organisational failures, initiated a shift towards understanding safety as a component of quality. In the NHS, this led to the first “NHS inspectorate” in the 1960s, followed by the introduction of an ombudsman and complaints system (29). Similarly in 1966, the US Joint Commission established “optimal achievement standards” to hold US organisations accountable for their safety (29). After this paradigm became embedded in many health systems internationally, the 1990s and early 2000s saw a watershed for safety as a component of quality with three key publications: *Human Error* explaining the “Swiss cheese model” of how multiple gaps and problems result in error; *To Err is Human* explaining that safety issues contribute to harm to patients; and *An Organisation with a Memory,* demonstrating the patterned and avoidable nature of harm (30)(31)(32).

Following the gradual recognition of each quality domain, records reveal a respective increase in efforts to gather data to measure them. The NHS in particular saw the beginning of systematic patient safety data collection through the National Reporting and Learning System (NRLS) in 2001 and adverse event reporting through the Health Strategic Executive Information System (STIES) in 2009 (33). It is also important to recognise the role of confidential enquiries into safety, such as the National Confidential Enquiry into Patient Outcome and Death, in building a precedent for the collection of safety data as a means to improve quality (34). The adage “make zero harm a reality” became enshrined in quality, and the hallmark of policy documents like the Berwick Report in response to the high-profile safety breaches at Mid Staffordshire NHS Foundation Trust (35). Similar principles are now integral to providers’ individual objectives for achieving organisational success (36).

In addition to clinical effectiveness and safety, a variety of other topics have entered and exited the accepted definition of quality. Some such as efficiency and equitability still remain in frameworks such as the AHRQ components of quality in healthcare (17). Furthermore, thanks to Donebedian’s seminal work, quality is often considered less in terms of how it is defined, but more in terms of how it is evaluated across the structures, processes and outcomes of care (37). While the three-pronged definition of quality receives broad intellectual agreement, the concept will likely remain fluid and responsive to the evolving nature of health systems.

1.1.3 Inclusion of patient experience into the definition of quality

The third domain that completes the quality triangle presented above (Figure 1) is patient experience. The integration of experience into quality could be the result of a more enlightened service delivery model, or it could be the effect of a disease burden that is shifting towards the need for continual care rather than single cures (38)(39). Regardless, it has become a mainstay of quality, and its evaluation is deemed to be as important as that of effectiveness and safety (2).

Early interest in "patient satisfaction"

As early as the 1970s, it became clear that the concept of healthcare quality could not be distilled to mortality rates (either as a result of effectiveness or safety), and epidemiologist Richard Doll suggested quality could also be related to how patients interpret their care (23). The term used to capture this idea, the predecessor term to patient experience, was "patient satisfaction"(40). Early justifications for the importance of "patient satisfaction" came from evidence suggesting that satisfied patients were more likely to seek appropriate care when they needed it, and more likely to maintain a relationship with one provider over time (41)(42). This offered the benefits of brand-loyalty to fee-for-service organisations, but it also brought cost-savings for publically funded services in terms of reduced emergency visits and enhanced medication compliance (43). Over time, the concept of "patient satisfaction" has matured radically. This history, however, is relevant as it explains that the initial idea to include this concept as a component of quality was rooted in a practical attempt to help patients adhere to their care pathway.

Progressing from "patient satisfaction" to "patient experience"

Following Doll's interest in collecting feedback on patient satisfaction, early research on what matters most to patients discovered that patients overwhelmingly rated their satisfaction positively; however, when asked to rate the components of their care individually, they were more likely to reveal concerns (44). This phenomenon of highly positive overall ratings became a demonstrated trend that patients, regardless of medical needs, personal or social characteristics, were generally reluctant to be outwardly critical of their overall care satisfaction especially on closed-ended survey questions (44)(45)(46)(47). Studies then began to collect data on the components of satisfaction and assess their correlation to overall satisfaction (48). This revealed that satisfaction was a multidimensional concept and could not be measured with a single question (49)(50)(51). Such evidence provided the initial reasoning for looking beyond simple satisfaction measures, and into the multitude of experiences that precipitate them. This paved the way to wider use of the term “patient experience,” aimed at capturing what happened during patients’ care rather than simply satisfaction with the overall result (40)(49).

For the purposes of this work, and within the context of quality, patient experience is defined as follows:

“The sum of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care” (52).

The most pronounced justification for patient experience as a component of quality, and the one that has been consistently used to verify its legitimacy with clinicians, is its link to outcomes and safety (53). The link between patient experience and the other quality domains has been robustly demonstrated in multiple studies (1)(54)(55)(56)(57). For instance, Doyle et al. conducted a systematic review into the links between the three domains, establishing a positive correlation between them (1). Furthermore, patient experience has been linked to patient-perceived safety, with findings suggesting that patients who report poor experiences of care also tend to report perceived areas of malpractice (57). Other studies have also demonstrated that positive experience correlates to better treatment adherence and community uptake of services, which are central tenets of managing long-term conditions (55)(58)(59). Considering the increase in long-term conditions like diabetes and cancer, evaluating quality with reference to experience is pivotal to sustaining patients’ engagement with on-going treatment regimens (60).

1.1.4 The evolution of patient feedback collections

In its earliest form patient feedback from closed-ended surveys primarily referred to single-metric “patient satisfaction” surveys (23). Cleary and colleagues argued that these did not provide the adequate level of detail to inform quality improvement; these measures supported the status quo and contributed little insight into *why* a patient was satisfied or not (45). As described in a King’s Fund report in 2009, the reluctance of patients to provide critical appraisals of satisfaction, and the subsequent lack of data utility generated from satisfaction questions, inspired the healthcare sector's refinement of the concept to "patient experience" in measurements as well as dialogue (61). This emphasized the importance of itemising different aspects of patients' interactions with the health service, and new feedback collection captured how patients felt about each of these interactions (62)(50).

The systematic measurement of all components of experience emerged from patient complaints systems (63). As early as the 1990s hospitals in the US accredited by the Joint Commission had to operate a complaints system (63). In the UK, the 1983 NHS Management Inquiry was a watershed for collecting information on poor experience, as it recommended appointment of local managers to collect feedback on patient and community members' experience of local services (62). This was the catalyst for the development of patient-reported experience measures, or PREMs. PREMs mirror their clinical counterparts, patient-reported outcome measures, which have existed for longer and use a series of self-complete survey questions to assess patient perspectives of effectiveness (64). PREMs' key difference is that they measure a different domain of quality, patient experience (61).

Prominent PREMs in the NHS

PREMs are based on the components of patient experience and help decipher how patients perceive elements of care such as information, staffing levels and service integration, and can, in theory, pinpoint areas for improvement (65). In the NHS, the National Patient Survey Programme (NPSP), a series of PREMs administered across service settings at every NHS hospital in England, was introduced to gather systematic feedback from patients across the NHS. The largest survey in this programme, the NHS Adult Inpatient Survey (AIPS) has gathered patient-reported experience feedback each year consecutively since 2002. The NPSP also includes the Community Mental Health Survey annually and the Maternity, Outpatients, Children's, Ambulance and A&E surveys on a rolling basis.

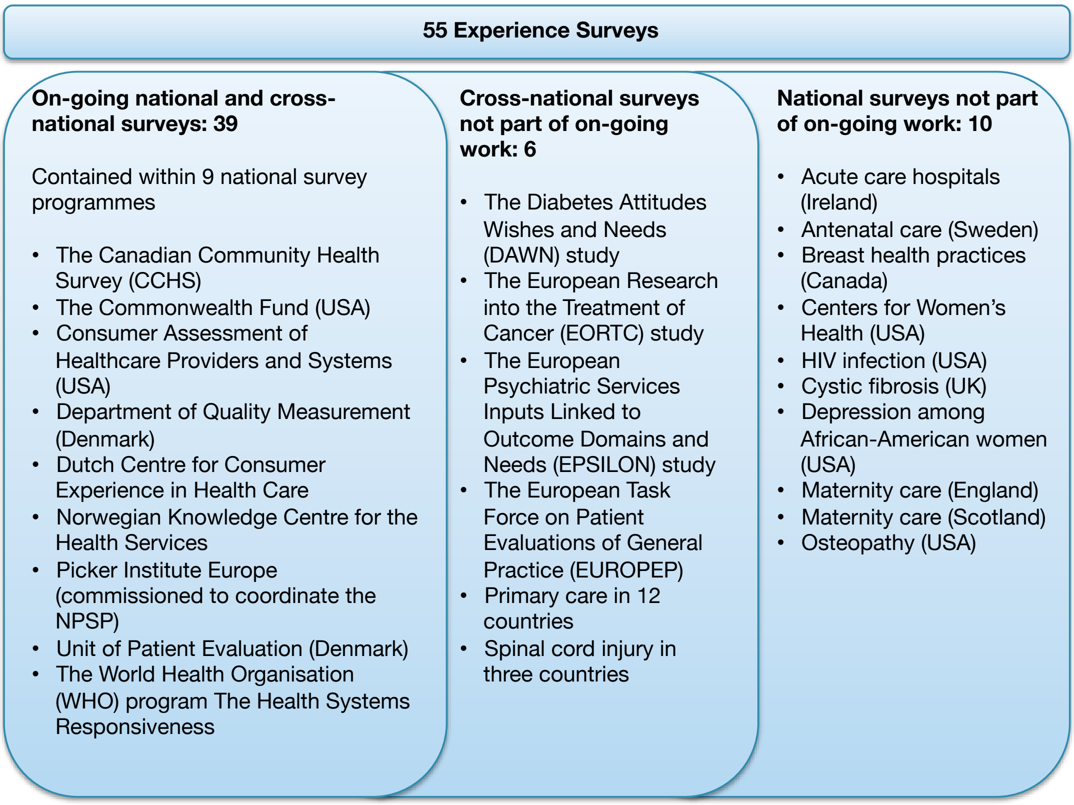
AIPS was first administered in 2002 as a way to systematically gather the views of inpatients about the care they received. It was instituted as part of a wider government initiative to enhance the level of substantive input acute patients have into their NHS care.

Most recently, in 2016 AIPS sampled 1250 patients who had spent at least one night in hospital and were discharged in July 2016 from all 149 NHS acute organisations in England. The survey received 77,850 responses, equating to a response rate of 44%. AIPS has nearly exclusively been administered via post, over a fieldwork period between August 2016 and January 2017 (66).

New approaches to gathering PREMs in the NHS have emerged, such as the Friends and Family Test (FFT) and the additional experience survey questions and free text questions that accompany it, a host of disease specific surveys like the National Cancer Patient Experience Survey (NCPES) and a surge of online outlets for patient feedback (62)(67). The national feedback collections like NPSP, FFT and NCPES surveys are a few pieces of the feedback puzzle that providers can use for quality improvement. Staff also interpret and integrate feedback from a multitude of sources such as bespoke surveys, online platforms, complaints, social media outlets and audits (10)(62).

1.1.5 Patient feedback collections across health systems

Systematic measurement of patient experience through closed-ended surveys is not unique to the NHS; while this research will focus on acute services in the NHS, it is necessary to understand the international context around patient experience surveys. One OECD study conducted by the Norwegian Knowledge Centre took an inventory of the patient experience feedback collections around the world. The study found 55 either national or cross-national patient experience surveys from different care settings and with varying modes of survey administration (3). Forty-two were national and 13 were cross-national (meaning the survey spanned multiple countries). There were 9 programmes of work, like the NPSP, which accounted for 39 of the surveys (3)(68)(69). The breakdown of findings is listed in Figure 2 and the characteristics of the cross-national surveys are listed in Table 1.



55 Experience Surveys

On-going national and cross-national surveys: 39

Contained within 9 national survey programmes

- The Canadian Community Health Survey (CCHS)
- The Commonwealth Fund (USA)
- Consumer Assessment of Healthcare Providers and Systems (USA)
- Department of Quality Measurement (Denmark)
- Dutch Centre for Consumer Experience in Health Care
- Norwegian Knowledge Centre for the Health Services
- Picker Institute Europe (commissioned to coordinate the NPSP)
- Unit of Patient Evaluation (Denmark)
- The World Health Organisation (WHO) program The Health Systems Responsiveness

Cross-national surveys not part of on-going work: 6

- The Diabetes Attitudes Wishes and Needs (DAWN) study
- The European Research into the Treatment of Cancer (EORTC) study
- The European Psychiatric Services Inputs Linked to Outcome Domains and Needs (EPSILON) study
- The European Task Force on Patient Evaluations of General Practice (EUROPEP)
- Primary care in 12 countries
- Spinal cord injury in three countries

National surveys not part of on-going work: 10

- Acute care hospitals (Ireland)
- Antenatal care (Sweden)
- Breast health practices (Canada)
- Centers for Women's Health (USA)
- HIV infection (USA)
- Cystic fibrosis (UK)
- Depression among African-American women (USA)
- Maternity care (England)
- Maternity care (Scotland)
- Osteopathy (USA)

Figure 2. Patient experience surveys conducted nationally and cross-nationally

Table 1. Cross-national surveys of patient experiences

Source: Garratt AM, Solheim E, Danielson K. National and cross-national surveys of patient experiences: a structured review [Internet]. Norway: Kunnskapssenteret: Norwegian Knowledge Centre for the Health Services (from 2016 is a part of the Norwegian Institute of Public Health); 2008, p.24. Available from: http://www.oecd.org/els/health-systems/39493930.pdf **(3)** Reproduced with permission from Garratt AM and Norwegian Institute of Public Health.

Author and organisations	Objectives	Countries	Setting and population	Sample size (response rate % when known)	Questionnaire
Becker et al (2000), The EPSILON study	To produce standardised European versions of five instruments in key areas of mental health service in five languages, and to compare data from five centres	Denmark, England, Italy, Netherlands, Spain	Adults aged 18-65 with schizophrenia, ICD-10 diagnosis F20	404 (6342, excluding Denmark)	Verona Service Satisfaction Scale – European version
Schoen et al (2000), The Commonwealth Fund	To assess and contrast the health care experiences of the US elderly with their counterparts in other industrialised countries	Australia, Canada, New Zealand, United Kingdom and United States	Men and women aged 65 and over who were non-institutionalised	3515	57 items
Üstün et al (2001), Letkovicova et al (2005), The World Health Organisation	To develop various methods of comparable data collection on health and health system responsiveness	60 countries	Adults aged 18 and over from private households having been in contact with the health care system last 12 months prior to interview; Institutionalised individuals were excluded	Long-form face to face (93), brief face to face (59), postal (48), telephone (25-55)	WHO responsiveness modules
Coulter and Cleary (2001), Jenkinson et al (2002), Picker Institute Europe	To describe the nature and frequency of problems reported by hospital patients in the United Kingdom, Germany, Sweden, Switzerland and the USA, and to develop and test a core set of questions to measure patients' experiences of in-patient care	Germany, Sweden, Switzerland, UK, USA	Adult inpatient acute health care	Unknown N (46-74)	Picker Institute Adult In-patient Survey and the 15-item Picker Patient Experience Questionnaire (PPE-15)
Schoen et al (2002), The Commonwealth Fund	Cross-sectional cross-national survey to compare health care system views and experiences	Australia, Canada, New Zealand, UK, USA	Non-institutionalised adults	7213	64 items
Schoen et al (2004), The Commonwealth Fund	Comparison of primary and ambulatory care experiences to inform policy	Australia, Canada, New Zealand, UK	Adults aged 18 and over	8672	
Kerssens et al (2004)	Comparison of patient satisfaction across countries and make comparisons with WHO performance measures	12 countries: Belarus, Denmark, Finland, Greece, Ireland, Israel, Italy, Netherlands, Norway, Portugal, UK, Ukraine	Adult general practice patients including: elderly, chronic obstructive pulmonary disease, diabetes, disabled, inflammatory bowel disease, rheumatism	5133	Quality of Care Through the Patients' Eyes (QUOTE)

Wensing et al (2004), European Task Force on Patient Evaluations of General Practice Care (EUROPEP)	To examine associations between patient satisfaction and characteristics of health systems	17 countries: Austria Belgium, Denmark, Finland, France, Germany, Iceland, Israel, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, Turkey, UK	Adult general practice patients from 36 practices per country	25052 (67-89)	EUROPEP instrument
Schoen et al (2005), The Commonwealth Fund	Comparative study of sicker patients examining issues of access to care, care co-ordination, chronic disease care and safety risks	Australia, Canada, Germany, New Zealand, United Kingdom, United States	Adults aged 18 and over	6958	93 items
Coulter and Jenkinson (2005), Picker Institute Europe	To learn more about European people's views on the responsiveness of their country's health system and healthcare providers	8 countries: Germany, Italy, Poland, Slovenia, Spain, Sweden, Switzerland, UK	Public aged 16 and over Those who did not have any care, treatment or tests within previous 12 months were excluded	8119 (13-60)	
Peyrot et al (2006), Diabetes Attitudes Wishes and Needs (DAWN) study	To assess country- and individual level patterns in patient and provider perceptions of diabetes care	13 countries: Australia, Denmark, France, Germany, India, Japan, Netherlands, Norway, Poland, Spain, Sweden, United Kingdom, USA	500 adult patients with diabetes mellitus from each region (Scandinavian countries grouped together)	5104 (92.8)	Ease of access, financial barriers, quality of team collaboration, patient-provider collaboration
Donnelly et al (2007)	To describe the utilization, accessibility and satisfaction of primary and preventive health care services to individuals with long-term spinal cord injuries	Canada, UK, USA	Adult spinal cord patients aged 15-55	373	The Health Care Questionnaire
Bredart et al (2007), European Organisation for Research and Treatment of Cancer (EORTC)	To identify variables associated with patient satisfaction	France, Germany, Italy, Spain, Sweden, Taiwan	Adult cancer patients hospitalised for > 3 days for medical oncology or surgery	762 (84.91)	EORTC IN-PATSAT32

Problematically, however, patient experience feedback collection appears to be vastly under-represented in developing health systems (3)(70). This could represent a lag in development in terms of the focus on quality in these countries, or a lack of publically available information about how patient experience is conceptualised and evaluated. The World Health Organization (WHO) has produced guidance on cross-cultural translation and validation of PREMs tools, however, so it remains surprising that PREMs programmes are not more widely established outside of North America and Europe (70). This might be a result of experience being deprioritised as an aspect of quality and understood to be secondary to effectiveness. This trend is especially pronounced in low and middle income countries (LMICs) where the burden of disease and the cost of service provision can undermine the importance of patient experience. Historically, this hierarchy of needs has been reasonable, however, there is an emerging opportunity through frugal innovation to investigate patient perceptions of care universally (71).

Nevertheless, evidence from the survey programmes listed above demonstrates that programmes in more developed health systems have been successful in obtaining patient feedback and promoting the value of patient experience (72). In light of this success in gathering feedback, the development of feedback tools, specifically the evidence upon which questionnaires are built, deserves further exploration to understand why their resulting data have not been useful to local providers.

1.2 EVIDENCE DEFINING PATIENT EXPERIENCE

Improving the usefulness of patient experience survey data as a tool to support quality improvement first requires understanding what matters to patients and making sure those preferences are reflected in questionnaires.

The overarching definition of patient experience provided above does not individually define the components of patient experience. The following section collates evidence from structured patient feedback to characterise the different components that make up patient experience and begins to interrogate this evidence base, which is commonly relied upon to develop feedback tools.

1.2.1 Background to defining the components of patient experience

In 1993 Margaret Gerteis and colleagues published *Through the Patients' Eyes,* original research presenting what matters most to patients (73). This work, informed by the Picker-Commonwealth Program for Patient-Centered Care which began in 1987, led to the construction of the Institute of Medicine (IOM) Patient Experience Framework which first outlined the components of patient experience (74). Later, the Warwick Patient Experience Framework (WaPEF), which broadly resembled that of the IOM framework, was developed using existing evidence of what matters to patients to inform the UK National Institute of Clinical Excellence (NICE) standards on patient experience (75). The topics outlined in the IOM framework and WaPEF are now mirrored in the NHS Patient Experience Framework (Table 2), which is widely regarded as a reference for what matters to patients and what should be asked about in feedback collections (76). Amongst other UK national feedback collections, surveys in the NPSP use this framework as a guide from which to develop questionnaires (76)(77)(78).

Table 2. NHS patient experience framework

Source: Reproduced from Department of Health. NHS Patient Experience Framework [Internet]. 2011. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215159/dh_132788.pdf **(79)**

	Principle of experience	Description
1	Respect for patient-centred values, preferences, and expressed needs	These include cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making
2	Information, communication, and education	On clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion
3	Coordination and integration of care	Across the health and social care system
4	Physical comfort	Including pain management, help with activities of daily living, and clean and comfortable surroundings
5	Emotional support	Alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances
6	Welcoming the involvement of family and friends	On whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers
7	Transition and continuity	As regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions
8	Access to care	With attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

These eight principles are deliberately broad; however, they risk being interpreted only as they pertain to the majority of patients. In reality, these eight principles could refer to different features of care to different patient groups (80). Furthermore, even these eight principles are not entirely exhaustive, as they neglect other quality domains like safety and effectiveness, which could be drivers of experience (79). This invites deeper investigation into what is already known about what patients consider to be the most salient aspects of patient experience, and how their prioritisation- and conceptualisation- of the eight principles differs by group.

1.2.2 Evidence defining the components of patient experience

Focusing on the acute inpatient setting in the NHS, in order to understand patient experience and its components, a structured search sought peer-reviewed articles from 1995 to 2017 using the following terms:

- “What” AND “inpatient*” AND “want”
- “What” AND “hospital patient*” AND “want”
- “What” AND "matters" AND “hospital patient*”

Furthermore, the references from particularly useful sources in this search were explored using a snowballing technique. This yielded ten more articles. Finally, the websites of major healthcare research organisations that focus on patient-centred care in the NHS were also scanned for any relevant research reports. This included reports listed in the research publication section of their websites. The following organisations’ sites were reviewed:

- NHS England
- The Health Foundation
- The King’s Fund
- The Nuffield Trust
- The Patients’ Association
- The Picker Institute Europe

Articles were initially included if they were about acute inpatient care and considered the patient perspective on experience. Articles were grouped according to their relevance to the eight principles from the NHS Patient Experience Framework. Some studies about what matters to patients were associated with all of the eight principles and have therefore been included separately above in the generic patient experience section. Table demonstrates the breakdown of literature.

It is important to note that restricting the search to hospital inpatients represented a practical decision to narrow the scope of literature reviewed in order to understand certain aspects of patient experience in hospitals. Including other settings of care, as well as more generic studies that span multiple settings, could have returned other useful insights especially from harder to hear from groups (81). While this provides useful evidence for the inpatient setting, it would be necessary to supplement this search in future research with information from other settings to identify any conflicting evidence.

Furthermore, this work focuses primarily on structured patient feedback where patients prioritised aspects of experience, rather than open-ended feedback. This again was intended to limit the scope of the review, however there is literature to suggest the danger of this limitation: although structured data from surveys can provide clear information, it is also criticised for being reductionist and not capable of revealing the nuances of patient experience (82). While this work focuses on patient survey data, it is important to recognise that this specification has consequences for how the aspects of patient experience were discussed in the literature reviewed.

Table . Literature organised according to the aspect of experience they discuss

	Aspect of Experience	Studies’ primary aspect of experience	Studies’ secondary aspect of experience
i	**Generic**		
		Coulter & Cleary, 2011	Not applicable
		Cleary et al., 1991	
		Cleary et al., 1992	
		Fitzpatrick, 2002	
		Doyle et al., 2010	
		Jenkinson et al., 2002	
		Robert et al., 2011	
1	**Respect for patient-centred values, preferences, and expressed needs**		
		Bowling et al., 2008	Van Staa, 2011
		Vydelingum, 2000	
		Doherty & Doherty, 2005	
		Bruce-Jones et al., 1996	
		Heyland et al., 2006	
		You et al., 2014	
		Stoner et al., 2007	
		Kerridge et al., 1998	
		Delbanco, 2001	
2	**Information, communication, and education**		
		Walczack, 2013	Delbanco, 2001
		Bensing et al., 2013	Heyland et al., 2006,
		Thorne, 2013	Vydelingum, 2000
		Mazzi, 2013	Kerridge et al., 1998
		Hamajima et al., 1996	Stoner et al., 2007
		Gudnadottir et al., 2013	Webb, 2007
		Smith & Liles, 2007	
3	**Coordination and integration of care**		
		Webb, 2007	
		King et al., 2013	
4	**Physical comfort**		
		Severinsson, 2013	Delvin & Appleby, 2010
		Bender et al., 2008	Webb, 2007
		Edwards et al., 2014	
5	**Emotional support**		
		Detsky, 2011	Bensig et al., 2013
			Edwards et al., 2014
			Van Staa, 2011
6	**Welcoming the involvement of family and friends**		
		Van Staa et al., 2011	Bruce-Jones et al., 1996
			Heyland et al., 2006
			You et al., 2014
7	**Transition and continuity**		
		Gould et al., 2013	King et al., 2013
8	**Access to care**		
		Burge et al., 2006	
		Freeman & Denham, 2008 Delvin & Appleby, 2010	

Generic patient experience evidence

The primacy of the eight topics within the NHS Patient Experience Framework's principles has been reiterated in many studies of what matters to patients across different countries and cultural contexts (44)(46)(83). Despite methodological difficulties in comparing questionnaires, Coulter & Cleary affirmed that in Germany, Sweden, Switzerland, the United Kingdom and the United States, information, education, coordination of care, respect for preferences, emotional support, physical comfort, family involvement and care continuity were consistently important (46).

A study that used statistical correlations to identify patient experience survey questions that correlate to overall experience corroborated previous evidence and added pain control, eating meals, cleanliness and staff numbers as key patient priorities (84). In a similar study, Cleary et al. found that reported health status and reported problems held the strongest association with predictors of patients' overall evaluation (45). These findings suggest that patient medical needs significantly correlate to patients' overall interpretation of experience, a fact not fully accounted for in the NHS Patient Experience Framework (76)(77).

Given that the evidence agrees with the importance of the eight NHS Patient Experience Framework principles, but suggests they might be over simplified, the following sections detail the evidence surrounding each of the eight aspects.

1. Respect for preferences and decision-making

This aspect of patient experience received considerable attention in the literature especially around decision-making (84)(85). Patients themselves considered it central to care quality and prioritised it when asked about problems they encountered in hospital (86).

Literature reveals that specific patient groups have different preferences regarding treatment selection, but their varying preferences are not widely understood by practitioners (87). Patient priorities for decision making also varied with respect to patients' culture and medical needs (88)(89). This variation is also true with regard to patient preferences for involvement. Using the Autonomy Preference Index (API), male, surgical, older and highly educated patients demonstrated a desire for more involvement than female, medical, younger and less educated patients respectively (90). Elderly and less educated patients were especially unlikely to be confident enough to be the main decision maker (90). This was especially apparent in end of life decision making; patients contemplating end of life care preferred the support of experts to facilitate the decision, with the exception of single patients who preferred to be the sole decision maker (91)(92)(93).

In relation to decision-making, the literature revealed a discrepancy between what patients prioritise and what clinicians think they prioritise. In one study, 99% of healthcare workers and only 80% patients thought patient views should be given highest priority in decision-making (94). The evidence also suggests that some patient preferences are not informed by up to date clinical information and education, indicating a critical link between this aspect of experience and patient education and information (95)(96).

2. Information, Communication & Education

Studies revealed that there is a significant diversity of patient opinions regarding optimal communication. For instance, many cancer patients focused on tone and collaborative nature of communication; end-of-life patients tended to value therapeutic relationships in communication; and patients in distress focused on showing empathy (97)(98)(99)(100). Cancer patients in hospital also expressed different needs in terms of diagnosis information: most preferred it to be delivered in written form and they wanted to be completely informed about the details of their diagnosis (101).

Studies demonstrated that patients were largely willing and interested in learning about their condition and the hospital environment (102). However, preferences for delivery of this information varied: people with more education preferred written to verbal or video publication, and retired and older patients wanted more information than employed and younger patients (103). Further research showed that patients consider the delivery of information, specifically information about medications and diagnoses, to be very important to their experience (104).

3. Coordination

Research surrounding coordination and integration of services from the patient perspective is in its infancy and has not been explored with specific attention to the needs of different patient groups (46). One study revealed that patients rated the three following statements as the most important to their experience of care coordination (105).

- "Taken together, my care and support help me live the life I want to the best of my ability."
- "The professionals involved with my care talk to each other. We all work as a team. I have one first point of contact."
- "They understand both me and my condition(s). I can go to them with questions at any time."

4. Physical comfort, Pain & Cleanliness

In addition to the relational aspects of care discussed above, some evidence also demonstrated patients' priorities for the physical aspects of care, and verifies that improvement of physical condition is one of the paramount influencers of experience (46)(106)(107). Studies acknowledge that articulating preferences about comfort and pain requires time and a level of expertise about diagnoses that results in different expressions of priorities from patients with different abilities and resources (80). Other studies found that physical comfort featured amongst patients' top priorities; however, again, staff did not realise this was the case (104)(108).

5. Emotional Support

Findings from qualitative research explained that patients are likely to emphasize the emotional aspects of their care when reflecting on experience (97). Many studies that indicated the importance of physical comfort also cited emotional support as a key feature (85)(108). One study found that although restoration to normal health was patients' overall priority, the emotional aspects such as kindness, hope and caring were integral facilitators to recovery (109)(110).

6. Involvement of friends and family

Despite its position as one of the main aspects of experience, involvement featured far less prominently in literature about patient priorities (46). One patient group, chronically ill adolescents, prioritised this topic and desired heightened family inclusion (89). Research about end of life care also demonstrated that most people wanted a degree of family and carer input into care decisions, especially when they had a spouse or important social contacts (91)(92)(93).

7. Transition

Patients expressed preferences for medication overviews prior to admission and before transition out of the hospital (105). However, patients were generally unaware of the other possible services that the pharmacy could provide, such as delivery and renewing medications (109). The limited number of findings around experience of transitions is possibly due to the fact that this narrative review was limited to the inpatient setting.

8. Access

The dimension of access is more relevant to patients in health systems where access is driven by financial means; however, evidence revealed that access also related to wait times and proximity of services. Studies demonstrated that while not as important as other aspects, patients included proximity, care wait times and cleanliness in their decisions of where to receive hospital treatment (86)(106). Age, marital status, gender and hospital procedure did not impact patients' choice of hospital (111).

1.2.3 Discrepancies in defining patient experience

The above literature expands on the definition of patient experience and presents what types of things are considered patient priorities, but it also exposes discrepancies in published evidence. For instance Doyle's study indicates that privacy is a high priority for patients, however, having a private room is less of a priority for end of life patients (84)(93). Although both findings are unsurprising, they demonstrate the importance of contextualising patient priorities in terms of the patient groups to which they apply. In terms of the hospital environment, Van Staa's work indicates that environmental features are a low priority, while Webb's suggests it is central to most patients perception of care quality (89)(104). Decision-making preferences and involvement of family were considered of upmost importance in some studies, and significantly lower in others (46)(84)(89)(91).

One culprit for such discrepancies could be limited understanding of how patient priorities differ depending on patients' medical or demographic needs. This problem obscures the knowledge around what patients want from their care, impacts what is asked on patient experience questionnaires and makes improvement from subsequent data untenable (112). The lack of granularity apparent in many of these studies makes a case for a more patient-centric breakdown of what matters most to different patients. The confusion arising from discrepancies calls into question the appropriateness of these studies as a guide for patient feedback questionnaire development and the utility of data generated from such tools.

1.3 USEFULNESS OF PATIENT EXPERIENCE DATA LOCALLY

Improving the usefulness of patient experience feedback locally requires national feedback collections to supply providers with meaningful organisational intelligence (113). First, in order to develop questionnaires capable of this, shortcomings in the patients' input into the evidence base defining what matters to patients deserve considerable scrutiny.

1.3.1 The quality of evidence regarding what matters to patients

A growing body of evidence explains what attributes are necessary for a study to usefully contribute insights regarding what matters most to patients.

As the evidence above demonstrates, priorities for experience are not uniform across patient groups (87)(114)(115). Experiences of care are likely influenced by self-reported health status and reported problems (45)(77). In light of this, it is important to identify whether or not existing studies about what matters most to patients include information about the type of patients to which their results apply (116). Studies should at least provide a breakdown of results by the patient groups to indicate what matters most and for whom (117). The utility of patient feedback to derive meaningful conclusions about where improvement is needed is not possible without better consumer insights and a more granular, patient-driven view of what different types of patients' value in their care (112).

Furthermore, the gold standard of a study providing evidence on what matters to patients is the inclusion of direct, unbiased qualitative input from the target patients (117)(118)(119). To achieve this, study methodology should allow scope for patients to delineate what matters to them in an open-ended way. Many studies above confine patients to a set of pre-conceived aspects of experience and do not include an open-ended route to express priorities (120). This is particularly problematic for harder to reach patient groups whose needs might not be present in researchers' schema of possible priorities.

The gold standard, however, is not always obtainable, especially when the objective of the study is not solely to catalogue what matters to patients. For instance, some studies provide evidence on what matters to patients as a by-product of another research question. In order for any study, regardless of its primary aim, to contribute to the evidence base around what matters to patients, the study should derive findings about patient priorities from patients (i.e. in open or closed-ended surveys) rather than extracted from literature, as it is more likely to be accurate and comprehensive (121)(122).

Finally, studies that attempt to understand what aspects of patient experience matter *most,* by definition should have an explicit ranking system to order patient priorities. Rankings should ideally be provided by the patient rather than inferred from principle component analyses (PCA). The traditional method of finding out what questions on a survey account for the most variability in scores is a PCA. This technique attempts to define the smallest number of measures or variables to account for as much important information as possible. The most significant component in a PCA is thought to be the one that captures the most important information (123). This component also accounts for most of the variability in cases or subjects. However, when applied to national patient experience datasets, a PCA might explain the variability in scores, but it does not necessarily indicate which questions mattered most to a patient at the individual level.

The literature above reveals that another common way to decipher what matters most to patients is to use pre-existing datasets, inclusive of multiple experience metrics, and run correlation analyses between the individual metrics and an "overall patient experience" measure (45)(85). This yields the statistical association between any given metric, for instance one about emotional support or information, and the overall experience. Such logic implies that if a single question on an individual topic is highly positively correlated to the overall measure, it is highly important to patients. However, as discussed in relation to the movement away from “patient satisfaction”, evidence suggests that patients are reluctant to give poor ratings on single all-encompassing questions even when they experience multiple problems with their care experience (45)(46)(124). Seeing as overall measures are largely inflated and unlikely to elicit a critical appraisal of care, this type of analysis likely only serves to identify other aspects of experience that patients rate highly (44).

Enhancing the evidence base to ensure that patient feedback tools reflect patients’ own priorities, however, is only the first step to bolstering the utility of patient experience data. Investigating the survey methods used to collect feedback, the translation of feedback into metrics and the policies that govern national feedback programmes is also required (5).

1.3.2 Technical overview of survey development

The vast majority of patient experience feedback comes from surveys like the ones listed in Table 1. Patient experience surveys will be the primary source of patient experience feedback discussed throughout this work. At its most basic level, a survey is a set of questions asked to people in order to find out what they think or feel about a particular topic (125). The types of questions and approaches to developing them and administering them are plentiful, each with differing impacts on resulting data (125). This section moves chronologically through each step of the survey process to account for how the technical aspects of survey development, deployment and dissemination, impact data utility for quality improvement. While this section focuses on AIPS, the steps broadly reflect those used to develop other PREMs in the NHS like the NCPES.

Three key terms are important to define in order to understand survey development (Table 3).

Table 3. Key terms regarding questionnaire development (126)

Term	Definition	How to achieve it	How to test it
Reliability	The extent to which a measure yields the same number or score each time it is administered when the construct being measured has not changed	• Repeat administration of the same tool with the target group	• Correlation of responses • Correlations should be at least 0.70 $r = \frac{\Sigma d_x d_y}{\sqrt{(\Sigma dx^2 \Sigma dy^2)}}$
Content validity	This is the extent to which the instrument measures the appropriate content and represents the variety of attributes that make up the measured construct.	• A plan for content and item construction before the measure is developed • Focus groups • Stakeholder consultations	• Item response theory tests the relationship between individuals' responses to a test item and the their scores on an overall measure of the topic that item was designed to measure.
Construct validity	The degree to which a measure correlates with other measures to which it is similar and does not correlate with (diverges from) measures that are dissimilar	• Cognitive testing	• Cronbach's alpha test where *N* is the number of questions and c-bar is the average covariance of the items and v-bar is $\alpha = \frac{N \cdot \bar{c}}{\bar{v} + (N-1) \cdot \bar{c}}$

Survey topic selection

As discussed above, survey topics should ideally build on patient-centric literature about what matters to patients. It is again important to articulate that the components of experience which are most important to patients will vary depending on which patient group is the target population for the survey (89)(91).

Without a robust evidence base or research strategy behind topic selection, the feedback tool risks providing data that is not *content valid* (Table 3). Content validity is the extent to which the survey tool measures the appropriate content for the research and includes the necessary breadth of questions to capture the topic entirely (126). Achieving content validity requires extensive reviewing of related content and engaging with patients and stakeholders to recognise the most important topics prior to construction of individual questions (126). For example a survey on patient experience would need to include communication as a topic, as it features heavily in the relevant literature. This requires input from the target population to define what good communication is to them. In most cases this is conducted through focus groups (126). Through specific questioning in focus groups, patients have expressed that they have a worse experience of communication when the doctor talks in front of them as if they are not there. This finding has allowed NPSP researchers to create a targeted question, "*Did doctors talk in front of you as if you weren't there?* (127).

Problematically, however, research from the field of PROMs and PREMs demonstrates that most emerging patient survey tools have been developed by researchers and senior healthcare professionals, without sufficient participation from patients (64)(119)(120)(128). This is worrying considering that research has demonstrated that the perceptions of healthcare professionals and patients differ considerably in terms of what matters most to patients (63)(120)(129). If the data produced through patient experience surveys is not content valid, it will be less useful in the improvement process because it does not accurately reflect what patients need in order to have a better experience of care.

Question development

The next step is translating a topic idea into a valid question that measures the topic and elicits patients' understanding. When questions are not understood correctly, they detract from the value of the data they produce.

Cognitive testing is a process by which draft questions are tested with individuals from the target population to make sure that questions are understood uniformly and that they are interpreted as they are intended (126). This helps researchers assess whether their questions will achieve *construct validity* (Table 3), meaning that responses to questions are, "consistent with theoretical hypotheses" (126). If items on a survey are not construct valid, it impairs their use as quality improvement tools, as they are likely not indicators of the aspect of experience intended to be measured. Cognitive testing to pre-empt this is used across then NPSP and large-scale patient experience surveys (78). For instance, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) tool in America was created with extensive patient participation, and cognitive testing played an integral part in developing questions (130)(131).

In addition to content and construct validity, evidence from the field of survey research suggests that achieving baseline data utility and avoiding bias requires five rules. Firstly, each question must provide useful information to answering the object of the research. Any questions that yield data that are not useful to analysis are unnecessary and can needlessly obscure important results (125). Secondly, each question should measure one concept only (132). Questions like, *"Did you find the doctor friendly and informative? Yes/No"* produce data that might refer to "friendly" or "informative" or both, but there is no way of knowing if doctors need to improve on their relational skills or their information giving. Thirdly, questions should avoid jargon or complicated language. When patients have to make guesses about medical terms or acronyms, they are unlikely to answer the question accurately or at all (132). Fourthly, question sequencing needs to be logical. Differences in scores on similar questions have been found due to question ordering (132). One way NPSP surveys address this is by ordering the questionnaire in terms of the normal patient pathway, and using framing phrases like, *"thinking about when you were in A&E…."* to put respondents in the right frame of mind (127). Fifth and finally, tools need to avoid leading questions that embed assumptions or imply what response is desired (132).

In terms of patient experience specifically, evidence also highlights the importance of avoiding questions similar to simple "patient satisfaction" questions, as patients often feel a pressure to report a positive experience, or want to avoid shaming their hospital, or do not feel they can group all experiences into a single response (85). Asking about multiple, concrete aspects of experience allows the respondent to differentiate and appraise the experience in a more nuanced way (85).

Survey mode selection

Historically, the most common approach to administering national patient surveys has been via paper-based, anonymous questionnaires that are sent through the post (78). Criticisms of postal methodologies are plentiful and often valid. Postal surveys rely on providers having up-to-date patient address records, they make it difficult to provide language translation, they exclude highly mobile or transient populations and they are becoming increasingly obsolete as the Internet dominates communication (133)(134). These biases aside, postal methods have been shown to produce some of the highest response rates when compared to all other modalities. Even as online options become more accessible, postal surveys for patients tend to elicit more responses (135)(136).

Patient surveys can also be conducted via face-to-face interviews, over the telephone or online. Face-to-face interviews are rarely used in large-scale patient experience surveys because they are expensive in terms of interviewer time and transcription. Furthermore, the presence of the interviewer can create a social desirability bias whereby patients feel uncomfortable relaying personal, private or potentially sensitive information (128). However, studies demonstrate that this bias is not unique to interview studies and regardless, the presence of interviewers has been shown to elicit more critical responses (47). This modality can produce very useful data, as interviewers can ask more in-depth and follow-up questions, yielding contextual information that would otherwise be unavailable. Telephone surveys can also achieve this in some cases and avoid the bias to an extent; however, they require up to date telephone information and create a significant sampling bias, systematically excluding the type of patients who do not own phones (137). Where address information is not available, like the Ambulance Service, the NPSP used a telephone method, which in its first and only administration received a response rate of 55% (138). Finally, online surveys can provide useful information, especially as the population becomes more familiar with the Internet and accustomed to completing tasks online rather than via post. Online surveys also eliminate the need for manual data entry and can be programmed so that certain survey questions appear only if previous questions were answered a particular way (125). However, the alarming truth about online patient experience surveys is that they receive a significantly lower response rate across all demographic groups than postal surveys, a fact that requires considerably more research (133). A trial in 2008 was conducted with AIPS as a mixed-mode, giving people an option to complete it online. During this trial, uptake of the online option was below 1% of the sample by all demographic groups, and there was no significant difference in response rate to the survey when the online option was introduced (139). This finding requires significantly more investigation including re-running the trial, as online surveys continue to become more prevalent and potentially more familiar to respondents.

Data quality in surveys is an on-going topic of debate, however, and can be defined by more than overall response rates; in fact, strategies for securing data quality can be highly conflicting (132). On the one hand data quality can be measured in terms of "item response," a feature better acquired in face-to-face interviews. On the other hand, it can be measured in terms of the absence of bias, an accolade only achievable when there is no interviewer present who could create a social desirability bias (11)(128)(133). Subsequently, there is no perfect survey modality, but that does not mean there are not many very good modalities for particular research questions (38)(120). Fortunately, the architecture behind the NPSP development process is robust and grounded in rigorous protocols for designing, testing and administering questions (78). While no survey can eliminate the potential for bias, the NPSP postal method has been cited as reliable and NHS staff say the data it generates is reflective of already known problems (128)(6).

Survey response

In terms of how people actually respond to NPSP surveys and other national PREMs, however, Tourangeau and colleagues explain that there are four things that respondents do when they answer a question (137):

1. Comprehend the question
2. Recall the requested information from memory
3. Evaluate the link between the retrieved information and the question
4. Communicate the response

Completion of these four tasks is influenced by the administration mode. Postal surveys still require basic literary skills and could preclude comprehension for some people who have limited literacy or fluency in the survey language. Telephone surveys can address this problem, however, the need to convey an audible response, step 4, can be burdensome to some people (140). Interviewers can improve recall by using interpersonal tactics that spark memory without leading the respondents (133). The timing of surveys also plays a role in these four tasks. This is particularly true when considering patient experience surveys, as time to reflect on an experience, and the emotional distance between the experience and the survey has implications for responding (47). Waiting too long to administer a survey will increase the burden of recall and increase the risk of other influencers driving their evaluation of care (132). In the NPSP, patients receive their postal questionnaire about 7 to 18 weeks after their experience of care, which has been cited as unhelpful in terms of recall (78). Real time surveys like the FFT reduce the burden of recall, but do not necessarily allow for the reflection needed to evaluate their experience and provide an answer (141).

While this work relates primarily to close-end survey data from the NPSP, it is critical to note that other open-ended ways of surveying patients can improve communication of response. Specifically, Burt et al found that patients preferred to express concerns or critical feedback in face-to-face interviews, even when they had the opportunity to report the problems on closed-ended surveys (47).

1.3.3 Data presentation

Developing metrics from responses

Beyond how data is collected, there is also a question around how that data can be most usefully translated into metrics. Some arguments suggest that a single metric, which can benchmark organisations, would be the best placed to gain attention and drive action. This is, in part, some of the thinking behind the FFT (142). Despite the conceptual ease of a single metric, it does not go far to address where and how services should improve, and studies still find that questions asking about “overall experience” receive very high scores (143). In order to inform local, patient-centric quality improvement, survey tools need to include questions that account for the priorities of different patient groups and their associated medical and social needs and render relevant information for clinicians and managers (10)(118).

Often survey contractors within the NPSP, companies that help organisations run their survey and provide bespoke reports to individual organisations, convert survey responses on individual questions into metrics using a system called “problem scores”. This approach quantifies the level of concern expressed about certain aspects of patient experience (144). Problem scores are calculated by grouping responses as either positive or negative. Examples of positive responses would be “very effectively.” Negative responses would be any responses that are not distinctly positive, “somewhat effectively”, or “very ineffectively”. The percentage of total responses that are negative is then calculated. This percentage is referred to as the problem score. The problem score provides a description of how negative respondents were about certain aspects of the response: the higher the problem score, the bigger the problem (144). A question on AIPS provides a useful example:

Equation 1. Problem score

When you had important questions to ask a nurse, did you get answers that you could understand?

Yes, Always	12
Yes, Sometimes	6
No	2
I had no need to ask	2

Total scorable responses = 20

(Combined negative responses)/Total scorable responses = % Problem
(8)/20 = .40 → Problem score = 40%

This method of analysis has proven to be highly reliable and indicates the level of concern respondents' had, thereby identifying the areas where improvement might be most pressing (144). This approach, however, is not standard and the NPSP regulators, the Care Quality Commission (CQC), produce a standardised report for each organisation using an entirely different set of metrics (145). This is not particularly useful for local quality improvement, as analysing multiple reports on NPSP data and deriving meaningful improvements is a complicated task, subject to many misinterpretations (10).

Presentation of national patient experience data

The guidance for analysing the metrics provided on standard CQC reports of NPSP data also compromises the utility of data in terms of the way it is presented. The excerpt below illustrates the complexity of the guidance that local providers need to grasp in order for their data to be useful to them:

“The [colour] categories are based on an analysis technique called the 'expected range' which determines the range within which the trust's score could fall without differing significantly from the average, taking into account the number of respondents for each trust and the scores for all other trusts. If the trust's performance is outside of this range, it means that it performs significantly above/below what would be expected. If it is within this range, we say that its performance is ‘about the same’” (146)

Figure 3. Example of NPSP question scores for a single organisation as presented in a CQC report

In this example, the score for Q38 is at the low end of the expected range, but still very high on the scale, while the score for Q69 is nearing the “better” section but is still very far down the scale. It is unclear from the guidance and Figure 3 whether providers should focus on improving low scores or scores nearing the red.

Furthermore, NPSP data is presented in aggregate, meaning each clinician and service within an organisation only receives information about how the whole organisation is performing (147). Although many organisations use private survey contractors who can provide a further break down of their data, this is not provided as standard. While capable of identifying major trends, high-level reporting can be alienating to providers who are trying to engineer improvements relevant to specific services and to patients with complex needs and co-morbidities. Evidence suggests that organisations’ proclivity to implement quality improvements based on patient feedback is likely diminished when the data does not provide specifications around where problems are most pronounced (120). Most importantly, it fails to indicate how different patients experience care. Clinicians corroborate this problem and have cited a lack of specificity in reporting as a barrier to using the data for service improvement (6).

Problems with aggregate data reporting compel researchers to explore more useful approaches to survey data analysis and presentation, such as trialling techniques that are widely applied in other industries to ascertain more granular insights from feedback.

Disaggregating patient feedback

Patients' needs vary, as do providers' professional remits, however experience data continues to be reported generally (147)(148). Understanding patient preferences helps avoid what is termed "silent misdiagnosis" or the misunderstanding of patient needs and preferences, which result in unnecessary care, patients' inability to actively engage in their healthcare and conflict between patients and practitioners (149). Industries outside of healthcare are much more advanced in using consumer feedback to make sense of the different groups of people that exist within their consumer population and tailor services based on their preferences (149).

For example, Experian Mosaic, a cross-market classification system uses 850 million pieces of data about people's daily activities, age and postcode to group nearly 50 million adults into 66 consumer types, under 15 umbrella consumer categories (150). More specifically, the consumer science company, Dunnhumby, have used Tesco ClubCard data to classify customers based on what they buy, and when and where they buy it, to help Tesco better serve specific types of customers. As an early adopter of this data segmentation scheme, Tesco was able to increase its profits dramatically as the company was supplied with a continuous flow of data about the purchasing tendencies of different types of consumers. More importantly, this allowed Tesco to stock stores differently based on consumer needs and target their product advertising appropriately (151).

The field of patient experience feedback can learn from the success of other industries and apply investigative data mining to patient feedback. Identifying patient groups based on a thorough set of patient characteristics and their feedback could provide more useful insights about what different patients prioritise in terms of experience.

Understanding experience in terms of patient groups

Currently, the lack of understanding around patient groups compromises the ability of services to design improvement strategies geared towards their specific patients (120). Traditional parameters for grouping patient data into categories in the NHS are not flexible enough and rely on blunt categories such as basic demographics or disease type. While evidence suggests that more nuanced local knowledge exists around what matters to different patients, this is not meaningfully captured in survey data or presented in relation to service improvement (152).

In one national patient survey, NCPES, not only did ethnic minority patients report an overall worse experience, but they also reported lower scores for confidence in doctors and understanding of the information they were given (153). Furthermore in AIPS, women, gay/lesbian or bisexual patients, minority ethnic groups and those with certain chronic conditions reported lower levels of experience (154). One study by Pinder et al. demonstrated that ethnic minorities have particularly bad experiences when it comes to having trust and confidence in health professionals– this extends to doctor, nurses and specialists among other professionals (153). There was also evidence of variation in experience based on patients' medical characteristics. Patients with small intestine/rarer lower gastrointestinal, multiple myeloma and hepatobiliary cancers reported significantly lower experience of care than those with breast, melanoma and testicular cancer. These findings also indicated in-group variation for some of these demographics (155). Other studies of the NCPES data reiterate this same message and go further to present evidence that patients with mental health conditions and learning disabilities also report a worse experience of care (156).

This evidence, although based on simple grouping variables, provides an impetus to focus on care for underserved groups, but it also serves the problematic purpose of a scapegoat. Organisations are able to explain away poor scores because they have a patient population who generally report worse scores. A data-driven segmentation approach to profiling different patient groups could instigate quality improvements that account for the needs of marginalised patient groups who tend to report lower scores and whose voices can be diluted in current feedback collections.

1.3.4 The policies behind national patient feedback programmes

The sections above have explained how survey development, analysis and data presentation impact the usefulness of data; however, it is also necessary to contextualise the entire process within the NHS system around patient experience. This includes the regulators, third parties and established policies that uphold or undermine standards for data utility.

Regulators of national survey programmes

As a 2014 report by the King's Fund identifies, the paramount actors in the system around patient engagement are, in theory, the patients who provide feedback and the providers tasked with using it (157). However, most of the decisions that determine the usefulness of patient experience data are made by regulating bodies who mandate collection of patient experience feedback. While technically the NPSP is not a legal requirement for services to undertake, CQC inspectors require organisations to hold very specific data about patient experience. Collecting that data via the NPSP surveys is the most straightforward way to comply with the CQC rules (158).

The NPSP is commissioned by the CQC and coordinated by the NPSP Co-ordination Centre currently based at Picker Institute Europe. The CQC is responsible for the content of the surveys and the NPSP Coordination Centre develops and deploys the surveys on their behalf. Questions are decided by the NPSP Coordination Centre and the CQC based on existing patient experience frameworks with a focus on maintaining the ability to compare questions on each subsequent iteration of the survey (79). Patients are consulted during the development and re-development of all NPSP surveys, and the CQC publishes a report on this engagement (145). While patient engagement involves focus groups and interviews to test existing questions, it allows little scope for adding new concepts to existing surveys except in the case of new surveys like the Hear and Treat Ambulance Survey (159). As discussed above, this type of involvement might limit content validity as it only gathers patient input about topics already known to be important, rather than having truly patient-driven topics (119)(133). For the regulators, however, there is a balance to strike between maintaining comparability across years and being open to patient suggestions for new concepts.

Looking outside of the NPSP at national initiatives for more real time feedback, the Department of Health (DH), who requires the collection of FFT from every patient in certain services, is another regulator in the system surrounding patient experience feedback. The FFT is rooted less in methodological considerations and more in the volume of data it can accumulate. As a result, it is administered in different ways across provider organisations (141). Furthermore, the FFT question itself does not inquire *why* patients' experiences were positive or negative; however, providers themselves can supplement the FFT with additional questions digging deeper into patient experience (141). Finally, because the system measures success in terms of response rates, organisations have an incentive to boost response rates rather than include meaningful questions, or pursue feedback from the most hard to reach groups, therefore widening the scope for sampling bias. The FFT is arguably not very content valid, as the desire to recommend the service might not be a patient's highest priority, nor a particularly good indicator of what type of experience the patient had (141). The real time vehicle holds merit as an idea, but the system's execution of it has not been widely helpful for local improvement (160).

Third parties & procedures within national survey programmes

The system around patient experience feedback also includes the third parties involved in feedback collection, data storage and report presentation. In the NPSP, NHS providers can either conduct the survey "in house" which means sampling based on the 24 page sampling document provided by the NPSP Coordination Centre, Disclosure and Barring Service (DBS) checking each sampled patients to make sure they fit the criteria (i.e. ensuring the patient is still alive), printing surveys, posting them, posting reminders, inputting data and sending it to the Coordination Centre on time (161). This is a demanding and detailed project with enormous ethical risk if errors occur.

For this reason, the CQC maintains a list of approved survey contractors who can do this work for providers (162). Based on what package the provider purchases from the contractor, they are entitled to different types of analysis and data presentation. Quite crucially, this information is then owned by the CQC and the provider does not have access to their raw data, limiting the extent of local analysis that can be done (158).

Contractors often become closer to the needs of providers than the CQC or NPSP

Coordination Centre (162). However, not all contractors provide the same service, offer the same analysis or engage with providers on an equal basis. Many contractors publish their own reports aside from the CQC reports (called “contractor reports”), which might be useful, but can also present organisations with conflicting results when data is weighted or compared differently than it is in CQC reports (147). Further to this, even though contractor reports are released prior to CQC reports, both often come months after the patients were in care, making it very difficult to make timely improvements and measure them (144)(6). For example, patients sampled for AIPS were in hospital in July, and contractor reports are not released until February, and CQC reports as late as June (147).

The process for NPSP sampling is also questionable considering it takes place during a certain time of the year when beds are more available and hospital attendances are lower, and it may systematically exclude surgical lists that only occur during other times of the year (6). This creates a small data snapshot, not an overview of care. The sample for AIPS has only recently moved from 850 to 1250, still a very low proportion of some hospitals’ inpatients, but a much larger proportion of others (78). Nonetheless, sampling 850 or 1250 patients is administratively burdensome as discussed above, because sampling has to make sure only patients who fit the CQC’s sampling criteria (over 18, spent one night or more in hospital, not been admitted solely for mental health reasons, have not deceased since care) are included (161).

Finally, as a component of quality equal to safety and effectiveness, patient experience should not be measured in isolation to the other quality metrics; in order to ensure parity across the three domains, information about patient experience should be collected and integrated with effectiveness and safety metrics to comprehensively measure quality. This holistic measurement, however, has not extended in practice to how patient experience is collected and improvements are derived (10). Measures from patient experience feedback collections tend to be examined separately to other quality indicators (10). Moreover, it remains difficult to improve overall quality without understanding the interaction between its component parts (4).

These problems do not discredit the information patients relay in their feedback. Rather, they present considerations that organisations need to account for when interpreting data, and they raise questions over how the national system could supply providers with better data that could be more meaningfully translated into quality improvement information. The value of patient experience data for organisational quality improvement is currently not commensurate to the volume of data the system supplies. This misalignment is a symptom of the tension between survey programmes being set up to satisfy a national agenda rather than producing data useful to local quality improvement.

1.4 USING NATIONAL PATIENT EXPERIENCE DATA

Since national patient surveys have been carried out in a consistent and regular way across NHS organisations, it has become possible to compare high-level performance and monitor change across a range of patient experience metrics. In the early 1990s experts in the United States postulated that once surveys were effectively developed, their data would be able to be used for quality improvement (163). While this projection has been thwarted by a series of data utility issues outlined in the last section, it is still imperative to investigate how patient feedback has actually been used, to what extent it has contributed to organisational quality improvement and how the use of existing data can be improved.

The impact of survey mode effects, the inescapable reality of bias and the evidence that some groups score systematically worse in terms of experience are all valid considerations when interpreting existing data from national patient experience surveys. They are caveats to the *absolute* reliability of data; they do not, however, detract from overall messages that patients deliver in their feedback. In other words, while it is critical to enhance the utility of data, it would be impermissible to use these caveats as a justification for not engaging with and using existing patient feedback.

1.4.1 Previous and current uses of national patient experience data

Although there is extensive literature published on how organisations and individual clinicians use PROMs data, there is very little published literature in academic databases about how they use PREMs or other patient experience feedback (164). Table 4 below presents 39 sources that provide information on the use of patient experience feedback. The primary focus of these studies is not on local quality improvement and they include very little mention of how patient experience feedback is being used in conjunction with other quality indicators. The analysis of these sources does, however, reveal how experience data has been used in national policy and academic contexts. Most notably, the literature reveals a host of internal and external barriers that prohibit data use at a local level.

Table 4. Literature on patient experience data used for improvement

Typical uses related to improvement		Explicit improvement uses		Barriers to use for improvement	
Inequalities reports **2**	Fitzpatrick et al., 2005 (165) Lievesley et al., 2009 (166)	**Guidance and information** **4**	Carter et al., 2009 (167) DH, 2009b (76)3) Groene et al., 2008 (168) Black & Jenkinson, 2009 (169)	**Clinicians** **6**	Cheraghi-Sohi et al., 2008 (170) Reeves et al., 2008 (6) Wensing et al., 2003 (8) Davies et al., 2008 (171) Asprey et al., 2013 (172) Reinders et al., 2011 (173)
NHS ratings **2**	PIE, 2005 (174) Richard et al., 2007 (175)	**Interventions from AIPS** **3**	Yates, 2009 (176) Ross, 2009 (177) Friedberg et al., 2011(178) Reeves et al., (2013) (179)6)	**Data** **5**	Davies & Cleary, 2005 (7) Greaves et al., 2013 (62)9) Wensing & Elwyn, 2003 (8) Cleary, 1999 (163) Wensing & Elwyn, 2002 (180)5)
Perceptions of staff **3**	Raleigh et al., 2009 (181) Audit Commission, 2001 (182) Campbell et al., 2008 (183))	**Interventions from qualitative data** **2**	Coulter et al., 2014 (5) Coulter, 2012 (184)	**Management & organisational capacity** **5**	Rozenblum et al., 2013 (185) Kazt-Navon et al., 2007 (186) Snyder & Aaronson, 2009 (187) Sargeant et al., 2008 (188) Luxford et al., 2011 (189)
Policy & National Reports **3**	DH 2001 (190) DH, 2009a (191) Nicholls et al., 2008(192)				
Statistical analyses **3**	DeCourcy et al., 2012 (4) Sizmur & Reading, 2009 (193) Doyle et al., 2010 (84)				
Total: 13		**Total: 9**		**Total: 16**	
39 total sources relevant to patient experience data use for improvement					

Typical uses of national patient experience data

In 2012 DeCourcy and colleagues conducted arguably the most comprehensive study on the use of patient reported feedback from national survey programmes, providing a systematic review of all the uses of the AIPS data since its introduction in the NHS (4). Their results suggest that AIPS data is most widely used by companies responsible for contracting the survey and running it, rather than providers or organisations interested in promoting quality improvement (4).

AIPS data has also been published as descriptive results in national reports, cited as supporting evidence in national policy documents, employed to explore healthcare inequalities and analysed to determine relative importance of varying aspects of experience (103)(165)(166)(190)(191)(192)(193). AIPS data has also been used to understand patient perceptions of staff availability and their professionalism (181)(181)(182). These are potentially valuable findings for service quality improvement; however, data use in these studies reveal a critical neglect to consider other quality domains as explanatory factors for experience scores. The literature suggests that interoperability of patient feedback is poor and that holistic improvement via linked data is either critically under-documented or insufficient (163). Evidence from AIPS has, however, also been employed to appraise patient-centricity within the NHS (173)(174).

Local uses of patient experience data for improvement

DeCourcy's findings explain that the stated purposes of AIPS data are intended to relate to regulation and local quality improvement (4). However ascertaining whether the latter has materialised is difficult considering such evidence is rarely available in the public domain (4).

Two documents were identified, however, that provided guidance for using patient experience feedback to improve quality locally, one for general practice and the other for acute care (75)(166). The acute care guidance identified how patient experience data can be under-valued and deemed anecdotal in comparison to safety and effectiveness data despite robust collection methods. To overcome this problem, it included a specific suggestion to link experience data to safety and effectiveness data (75). Considering patients' views in a systematic way could be a useful first step to integrating for clinical practice improvements (168). Furthermore, one local trial of using data for improvement found that while informing nurses about AIPS results does not necessarily generate action towards improvement, including discussion of the results in ward meetings can stimulate more action (178).

The NHS Institute for Improvement and Innovation website contains two examples of organisations using AIPS data for local quality improvement: one focusing on improving pain assessment and one tackling re-design of care records, both with very few published results (175)(176). Another study of patient feedback use demonstrated that survey data was rarely used to improve clinicians' interpersonal abilities despite the importance of those skills to patients (177).

Further examples that showcase the use of locally-collected patient experience feedback, rather than local use of nationally-collected AIPS feedback, were also helpful to understand how patient feedback could be used. A King's Fund report showcased some organisations that had used data for interpersonal skill enhancement: Oxleas NHS Foundation Trust, for instance, implemented experience Co-Design, a programme which presented staff with videos of patient interviews that highlighted a need for better patient to staff communication (183). Along with managements' support and investment in the programme, Oxleas saw an 80% decrease in complaints (183). Northumbria NHS Trust trialled a similar approach to improve patient experience using a bespoke questionnaire that produced rapid results at the department, ward and consultant levels (183). For the most part, feedback strategies like these have been shown to initiate more patient-centred cultures (167).

The success of these programs that used locally-collected information is indicative of the utility of granular and specific patient feedback. Findings related to nationally-collected feedback suggest that local use of data from these collections remains limited (19).

1.4.2 Barriers to using national patient experience data locally

The most prominent theme throughout the literature concerning local use of data from national feedback collections was not how patient experience data had been used, rather the extent of barriers preventing it (117)(169). In 2005 Davies and Cleary outlined three categories of barriers effecting data use: organisational factors, professional challenges and data characteristics (7). Specifically, the third category around data characteristics relates to lack of timely and granular results, staff's lack of expertise with survey data and uncertainty around how to derive effective interventions (6). A 2015 publication from InHealth Associates in association with the Point of Care Foundation explains that there is no single defined way for organisations to manage patient experience and there is wide variation in terms of the roles and responsibilities of those working with feedback (193). As a result, confusion and duplication of efforts is commonplace (193).

Staff-identified barriers towards using national patient experience feedback

In 2007 Reeves and Seccombe conducted in-depth staff interviews to understand the specifics behind the barriers to using NPSP data. Findings from this work articulated staff's concerns around using aggregate, organisation level data to engage clinicians within specialities, and their difficulty navigating the statistical underpinnings of results (6). Their work put forth staff-driven recommendations for improvement, such as increased resources and organisational prioritisation for patient experience. Nearly a decade later, however, the lag in data use still exists (5).

Many methods for gathering patient views are not implemented with regard to their intended application and are too often punitive and divisive rather than useful (179)(185). Subsequently, national targets and guidelines for patient feedback reporting often obstruct or undermine the local patient-centred objectives they were designed to promote (5). Even when data is not punitive, general survey methods often receive scrutiny from staff (171). For instance feedback collected from online forums provide a rich source of feedback; however, using such reports requires considerable effort to account for selection bias and patients' accessibility to online media, and therefore staff are often reluctant to use it for improvement (61). Even though survey content could be improved, often providers are not aware that many national collections are longitudinal, robust and rigorously tested with patients (111)(162).

Despite scepticism around existing patient experience data and feelings that it is ill-equipped to drive change, staff demonstrate a strong desire, in principle, to improve services via patient experience data (171)(184). Staff consider certain sources of patient feedback valuable, but have neither the time nor the expertise to use it (119)(171). On a technical level, gleaning information from experience data requires the same analytic capability as interpreting clinical data, but that resource is often unavailable for experience data (194). This evidence is bolstered by Gleeson's review of the use of PREMs data suggesting that statistical confidence and familiarity with quality improvement techniques is important to generate data use (6)(119). Data goes un-used when staff cannot make sense of the data or do not fully understand how it was collected (163).

This trend extends to qualitative data from national PREMs; free text from NPSP has also become underutilised because of the existing necessity for most organisations to sort through it manually or pay for external analysts. As Rozenblum and colleagues identify, this process is limited by human resource and the lack of a systematic way to extract the useful insights to facilitate quality improvement (184). It is reliant on individuals to articulate a coherent plan for data use, cascade information and judge what is and is not important to certain areas within the organisation (184).

While national survey programmes are adapting methods to facilitate better data use, these barriers hinder staff's ability to use national patient experience feedback for local improvement (188)(195). They perpetuate siloed approaches to patient experience data interpretation, creating a chasm between patient experience data and information for organisational quality improvement.

1.4.3 Overcoming barriers to using patient experience data locally

The Patient Feedback Response Framework developed by Sheard et al. explains the organisational prerequisites necessary to inaugurate change based on patient feedback (196). It demonstrates that data must hold "normative legitimacy," (which is defined as a "moral orientation being based on the ability to convince others of 'what ought to be' or 'what is the right thing to do") and "structural legitimacy," (meaning staff are equipped with power to make changes) (197). If these two conditions are met, the framework stipulates that the local organisation must also demonstrate "organisational readiness to change," defined by Weiner in 2009 as "collective, or shared resolve to pursue the courses of action involved in change implementation" (198). As demonstrated in the literature above, staff might feel the moral obligation or "normative legitimacy" to make changes, but they often do not have the structural ability to do so (196).

The conceptual message presented in this framework suggests that in order to improve the use of patient experience survey data, the data itself needs to be meaningful, accompanied by concrete levers to support change and the organisation itself must uphold the necessary ethos to promote patient-driven change (7)(196). This framework provides conceptual underpinning to the fact that many organisations have made well-defined attempts to use patient experience feedback from national surveys, but have found their efforts thwarted by a series of barriers relating to the nature of the data and the organisational context (193).

Previous sections establish the importance of improving the way patient survey data is collected and presented for local use. It is likely that the barriers to using patient experience data for quality improvement can be mediated if the stakeholders with influence over the NPSP are willing to depart from traditional survey approaches . This includes developing new survey collection methods, as well as improving upon how existing data is used to generate metrics to better use the swathes of patient experience data already existing in the NHS.

1.4.4 Improving single metrics to enhance data use

Different ways of developing metrics from patient experience data have implications for how providers assess the root cause of feedback, interpret quality and determine direction for improvement (193). As alluded to in the section above regarding developing metrics, the need for statistically robust, accurate and comprehensive measures of patient experience has to be reconciled with the equally valid need for a conceptually simple, digestible single benchmarking metric. The need for multiple indicators to drive local quality improvement can conflict with evidence that suggests limiting the number of metrics, and associated statistical complexities, that staff receive can enhance data use (199).

Two UK national collections demonstrate this tension: The NPSP is designed to generate methodologically robust data on multiple aspects of experience, but is criticised for the complexity of metrics it produces; the FFT on the other hand, is intended to yield a simple single benchmarking metric, but is then criticised for issuing unhelpful information due to its methodological shortcomings and inherent problems with single-question surveys (141). Ideally two sources as different as these would be complementary and mutually beneficial to local quality improvement. However, they are often presented in conflicting ways, both with misleadingly positive results and very little variation across organisations (84)(200). To add to the confusion between the metrics focused upon nationally, the NPSP questionnaires also contain their own single metric question that attempts to assess overall experience. The existing overall question on AIPS asks patients to rate how they felt about their overall experience from 1 to 10. This question is often used for national benchmarking.

Evidence around these existing single metrics reveals questionable logic for giving them preferential weight as quality indicators or tools to support quality improvement. Evidence suggests that responses to single metric questions are driven by subjective expectations rather than balanced reflections on care pathways (45). Similar to “patient satisfaction” questions, these overall questions do not indicate areas for improvement and they often measure loyalty to a particular service rather than an assessment of the care it provided (44)(123)(140). This type of metric can distort understanding of quality, as benchmarking organisations using the current overall metric could be overlooking specific problems that patients have identified. Evidence converges to suggest that patient experience is a multi-dimensional concept, and impossible to capture meaningfully with one single point of feedback (45)(74)(78)(201).

In terms of generating information useful to quality improvement, this type of single metric is particularly unhelpful. According to a review of AIPS scores from Picker Institute Europe and the King’s Fund, the current AIPS overall metric also paints a flat, relatively unchanging picture from which there is little potential for leaning (12). The report confirms little variation across organisations; this lack of variation does not encourage inquiry into which organisations are doing the best and how they are achieving it in order to improve (12).

Given the practical utility of single metrics, however, it is important to note that they do not have to be built on only single questionnaire items as they are currently. Composite scores that take an average of many specific experience measures have proven to be reliable, valid and more reflective of patient’s actual experience than overall questions

(202). The utility of single metrics and their general ability to attract attention from policy makers and senior leaders, combined with the need for local providers to be able to extract meaning from their patient experience data, provides the impetus to explore construction of a composite metric from existing patient feedback like NPSP section scores.

NPSP surveys are broken down into section scores, giving an average score for all the questions contained within a specific section of the survey. Sections are topic-specific and cover everything from hospital admission to discharge. There are usually about ten sections on every NPSP survey and each section is comprised of enough questions to thoroughly measure the topic (126). Often, however, section scores are not considered with the same weight as the overall score. If combined into a composite metric, they might have the potential to support national benchmarking, while in their disaggregated form still provide the insight into local variation in experience scores necessary to support quality improvement.

1.4.5 Using experience survey data to understand acute provider organisations

Arguably, the reality of the national focus on single metrics and benchmarking reports has fuelled an enduring misuse of patient-reported experience data to simply rate and rank providers (146). This is a particularly unhelpful use of data for providers bearing the brunt of social inequalities. The patient needs and subsequent improvement priorities of such providers likely require substantially more resources than those of more affluent providers. For instance, the Homerton University NHS Foundation Trust operates within a deprived area of London with high rates of poverty and associated health consequences. Their staff report substantial obstacles to engaging patients often because they do not speak English and cannot be reached at fixed addresses to participate in surveys (151). This leaves the Homerton struggling to obtain high experience scores, and national benchmarking leaves the organisation at a loss for insight on how to make improvements relevant to their patients and feasible within their circumstances. This situation is not unique to Homerton, analysis of NCPES results reveal geographical disparities in performance, including trends that cannot be explained entirely by patient case mix (203). Similar to the idea of identifying patient groups based on their experience feedback, investigating providers' patient experience scores through the lens of organisational and geographic differences would introduce a more equitable, meaningful comparison system.

In the NHS specifically, the current typology for acute services provides very little information about their organisational differences. Rather than divide organisations by clinical, social, demographic or financial characteristics that might influence patient experience, NHS organisations are usually grouped in terms of relative size or broad service remit (i.e. large, small, teaching, specialist).

One novel use of patient experience feedback revolves around creating a data-driven typology of acute providers based on their patient experience feedback. A typology based on experience scores would create a more meaningful, patient-centred differentiation of providers than currently exists in the NHS. Secondly, it would elucidate what organisational characteristics are associated with positive patient experience. Thirdly, it would demonstrate which organisations have been able to achieve high experience scores despite an absence of those characteristics. Finally, grouping organisations on their patient experience scores will allow for better sharing of improvement plans that are relevant to organisations' characteristics and provide insight into what helps create a positive environment for patient experience.

1.4.6 Determining the predictors of positive patient experience

Given a wealth of organisational and patient data in the NHS, it is not only possible to group organisations based on their experience scores, it is also possible to explore what organisational characteristics actually predict the best patient experience.

Currently, digesting patient experience feedback in the NHS into actionable improvement tasks is difficult. As discussed above, data is often relayed at an aggregate organisation level rather than a service-specific level, or it is produced through ad hoc sources at an anecdotal patient level without information on how it can be extrapolated to the entire patient population (10). Further to that, there is often no way to link patient feedback to clinical outcomes or safety indicators, and there is still scepticism around how such initiatives will align with other goals like financial efficiency, meeting external targets and future commissioning decisions (204)(205). There is also an external emphasis placed on improving scores to specific questions, which can inspire “question chasing,” rather than root cause improvement. Tucker et al. explain that, “problem solving behaviours which focus solely on overcoming immediate obstacles prevent organisational learning” (196)(206).

Understanding how certain organisational and care pathway factors influence experience could provide insights on how characteristics could be amended to support better experience, an approach likely to be more helpful than “question-chasing.” Characteristics can be broken down into two groups: features that are within the organisations’ control and could be changed in order to support better patient experience and features that are permanent, around which quality improvement efforts would need manoeuvre.

Evidence already points to characteristics being correlated with patient experience. Insufficient budgets and restricted service availability, can translate to more frustration amongst patients (19)(207). Examples of care pathway features like wait times and route of admission, as well as organisational factors like staffing, hotel factors, mortality rates and staff experience, feature heavily in the literature as possible influencers of experience (1)(167)(202)(207)(208)(209). Furthermore, one study found that analysis of cancer experience feedback could help identify points along the cancer care pathway where it would be most fruitful to make improvements to care experience and treatment timeliness (210).

Systemic improvement of patient experience requires a much more sophisticated understanding of what drives patients’ perception of their experience than is currently available (119). There is often a perception of experience being driven by highly personal factors and expectations; although expectations have been shown to be important when determining general satisfaction, they do not have as great a bearing on more objective experience measures and are much less important predictors than broader societal factors (37)(211). Furthermore, in surveys like AIPS it is likely that the sample size is large enough and covers a diverse enough range of patients, that expectations of the groups do not bias results.

Patient experience has not been thoroughly explored within the context of the objective care pathway and organisational factors that might influence it. A more useful inquiry into what drives patient experience revolves less around criticising potential survey bias and patient expectation, and more around care pathway and organisational factors. Such an approach would help determine the explanatory power of a range of features on experience scores and map areas for improvement. Studies from diverse care settings demonstrate that when patient experience data is combined with other sources of quantitative information, it is better suited to driving improvement (212)(213). Exploring patient experience data in line with other organisational factors could also galvanise the interest of clinicians and overcome some of the barriers to trusting and using data (75).

1.4.7 Systemic improvements to patient experience data use

The value of understanding the relationship between organisational characteristics and patient experience scores also allows insight into characteristics pertinent to organisational culture and the context in which use of patient experience data would occur. Existing literature clearly states the importance organisational culture to promote the effective use of patient experience (8)(6). Such findings emphasize the role of strong leadership, reflection on results, meaningful engagement of patients and clarity of goals and performance in relation to improving the use of patient experience feedback (183)(186)(187)(188).

Studies of providers' proclivity to initiate and sustain improvement demonstrate that staff responsible for managing patient experience data have a strong interest in using it to drive quality improvement (8)(6). The Beryl Institute for Patient Experience in the United States advocates that certain facets of organisational culture could be enhanced to garner enthusiasm from staff and support an environment amenable to patient-centric change (7)(119)(178)(214).

As depicted in Patient Feedback Response Framework introduced earlier, organisational readiness is central to the ability to use patient feedback for change (196). Experts agree that the organisation must have the authority to make necessary changes, support from the national-level actors and, perhaps most importantly, a culture positive about enacting patient-centric change (214). Organisational readiness is not driven exclusively by availability of resource and financial backing; rather, it is inextricably linked to the other levels of the framework: staff's moral obligation, or "normative legitimacy," to use feedback and their "structural legitimacy" within an organisation to do so (196).

Sheard and colleagues demonstrate that staff's moral objective to use patient feedback for improvements does not automatically erect the necessary infrastructure or culture to implement changes (196). This disconnect between interest in patient voice and ability to act on it typically manifests itself in a demonstrated trend whereby organisations' leaders initiate feedback collections without appropriate plans to use it (184). Sheard and colleagues therefore argue that, in order to bolster staff's ability to use data there needs to be, "less concentration by senior management on the formal metrics and targets of individual wards and an increased fostering of a culture where interdisciplinary and inter-departmental working is encouraged and rewarded” (196). Such a departure from formal metrics is potentially overstated in the context of improving the use of experience data: previously presented evidence differentiates aspects of experience and demonstrates the importance of specific measures (60)(64)(84).

Rather than abandon the proven desire for, and utility of, specific patient experience data, this research argues that it is possible to pursue two parallel goals: enhancing the relevance of national patient experience metrics to individual services, while also promoting the necessary culture for local, patient-driven improvement to take hold.

Defining and measuring organisation culture

Organisational culture can be defined as, “the set of guiding beliefs, understanding, and ways of thinking that is shared by members of an organisation and is taught to new members,” but it is also related to how that culture is perceived (215). Within healthcare quality, it is also common to further specify this concept as “safety culture” or, “the product of individual and group values, attitudes, perceptions, competencies, and patterns of behaviour that determine the commitment to, and the style and proficiency of, an organization's health and safety management" (216). The components of safety culture can be defined as the following:

1. Commitment to overall continuous improvement
2. Priority given to safety
3. System errors and individual responsibility
4. Recording incidents and best practice
5. Evaluating incidents and best practice
6. Learning and effecting change
7. Communication about safety issues
8. Personnel management and safety issues
9. Staff education and training
10. Team working

While the ten components above relate to safety more than the other two dimensions of quality, they are conceptually useful in articulating the characteristics of an organisation culturally patient-centric (217).

Extensive evidence from the field of patient safety suggests that frontline staff struggle to generate action from quality indicators due to deficiencies in each of these areas (33)(218). In relation to patient experience feedback, Sheard and colleagues find that cultural attributes like poor cross-team working and communication about issues across organisations perpetuate siloed attempts to respond to patient feedback (196). Moreover, researchers at the Beryl Institute found that organisations cite positive leadership and culture as the most important drivers of positive patient experience (214). Their report also found that cultural aspects were cited as the underlying roadblock to improving patient experience (214). The cumulative evidence suggests that a culture of collaboration and clear communication is a central lever to improve how organisations respond to patient feedback (214).

In order to understand organisational readiness to make changes based on patient feedback, it is necessary to capture cultural attributes in a meaningful way. Given the complexity of organisational culture, and the subjectivity of its components, measuring it in a way that yields actionable data can be difficult (218). Some research positions the value to staff satisfaction metrics as a proxy for positive culture, as the relationship between staff satisfaction and all dimensions of quality has been extensively corroborated (153)(180)(214). More usefully, a variety of tools have been developed and validated to measure organisational culture (216)(219). One evidence-based tool for measuring culture has been developed to apply concrete metrics to each component of safety culture, the Safety Attitudes Questionnaire (SAQ). Tools like this present a potential vehicle for assessing culture within an organisation and identifying aspects of culture that might prohibit readiness to use patient experience data for improvement.

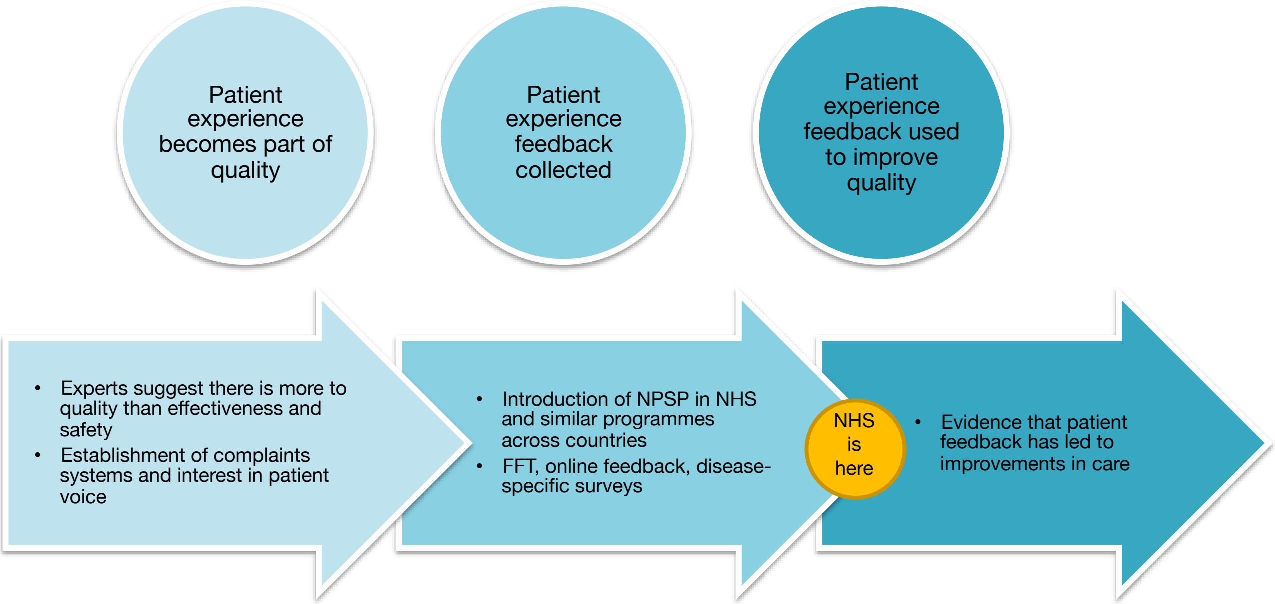
Culture as a lever for enhanced patient feedback use

Recent research has questioned the value to collecting more patient data without developing the organisational culture necessary to act on it, postulating the ethical implications of data underuse (5)(196)(220).

Based on such evidence, it is clear that a systemic approach to improving data use requires evaluating the context into which patient feedback flows, measuring readiness to act on that feedback and instilling cultural attitudes receptive to patient feedback.

1.5 THE PATIENT EXPERIENCE CONTINUUM

NHS policy has advanced along a continuum from valuing patient experience feedback to collecting it, and it is at a juncture where it should be leveraging it as a useful mechanism for patient-centred quality improvements.



Patient experience becomes part of quality

Patient experience feedback collected

Patient experience feedback used to improve quality

- Experts suggest there is more to quality than effectiveness and safety
- Establishment of complaints systems and interest in patient voice

- Introduction of NPSP in NHS and similar programmes across countries
- FFT, online feedback, disease-specific surveys

- Evidence that patient feedback has led to improvements in care

Figure 4. Patient experience continuum towards data use

Research in the area of patient experience feedback has been largely concentrated on how data should be collected rather than ways to improve its usefulness and use (196). Gathering patient voice is central to quality improvement and effective co-design, but the challenge has moved from feedback collection to effective feedback use (220). The process of sustainably improving the use of patient experience feedback requires more information. It demands investigation into the complexities of the data and why, after nearly two decades since the advent of national survey programmes in the NHS, data has not been able to influence local change (5)(4).

Advancing to the next point along the continuum is not about gathering more feedback from patients, but about exploring the data and the system around it to enhance its utility and instigate its use.

After years of robust implementation of surveys like AIPS, the results have not been used to drive improvements and the scores for most providers have remained virtually unchanged (5)(11)(12). While some scores have seen moderate improvements, these tend to be concentrated in areas where there have been corresponding large-scale national initiatives like around ward cleanliness (221). Otherwise, year on year variation within local organisations tends to be random rather than statistically meaningful (12). While patient feedback has improved communication, there is no substantive evidence of use to improve care management or services (222).

Healthcare staff have repeatedly voiced their interest in patient experience feedback and indicated that it is not that they do not value feedback, but that they face barriers to actually using survey data about experience (6)(163). Despite good organisational intentions to use it, the utility of feedback has been undermined by cumbersome and time-consuming survey processes as well as the frustration associated with how long it takes for change to be reflected in subsequent surveys (8). A lack of patient-centric culture and the inability to triangulate all sources of patient information have also been shown to delay feedback integration into improvement strategy (7). The gap between feedback collection and use represents a costly misuse of resources, as national surveys cost upwards of £640k per survey per year (193)(223).This is an expensive and inefficient under-use of information, but it is also unethical, and incongruent with the needs of policy makers, providers and patients (5).

Underuse of data is unacceptable from a quality assurance perspective, as the requirement to do analysis without proper resource risks key details being missed. It is frustrating from a clinical and operational perspective, as time and money are being invested with little return of insights to improve care. Even the National NHS Staff Survey demonstrated that only 20% of staff strongly agree that their organisation acts on patients' concerns (224). It is demoralising and dangerous from a patient perspective, as their input goes unheard, problems persist for others and they rarely hear about change implemented as a result of their suggestions. Ultimately, it is morally questionable, as patients have provided sensitive information, but their feedback fails to drive change. In evidence from patient involvement in research, patients have clarified that, while they appreciate being able to provide input, witnessing some degree of impact from their feedback is central to continuing their involvement (225).

This research recognises that the new era for patient feedback involves progressing from collection to action. The next step is harnessing this feedback to set priorities for delivering a better service.

1.6 RESEARCH FRAMEWORK

The framework below depicts how the six empirical chapters will address the most relevant evidence gaps identified in this narrative review and culminate in a foundation for embedding nationally collected patient experience data for local use.

In order to answer the question, *How can the usefulness and use of patient experience feedback be improved?*, the first three empirical chapters will focus on improving the usefulness of patient experience feedback, specifically data from structured surveys. **Chapter 2** will interrogate the extent to which the evidence that sits behind patient experience feedback tools is driven by patients' own input. **Chapter 3** will then test whether population segmentation techniques can be applied to patient experience data and then test those techniques on a defined patient cohort to identify how patient priorities for experience differ across groups. **Chapter 4** will solicit the views of NHS staff to determine how national patient surveys, and the system surrounding them, can supply staff with more useful data.

The following three chapters will focus on how to improve the actual use of patient experience feedback. **Chapter 5** will explore how existing data can be used to produce a simple composite metric from which to more intelligently benchmark organisations and identify areas for improvement locally. In **Chapter 6** clustering techniques will be applied to existing data to group providers based on their experience scores. Furthermore, patient experience data will be used in conjunction with a range of care pathway and organisational factors to reveal what features predict experience. Finally, in **Chapter 7**, the real life process towards systemic improvement of patient experience, and the organisational ability to respond to patients' feedback, using cultural levers will be explored in an NHS organisation.

In **Chapter 8**, the findings from these chapters will be collated into a set of recommendations for improving the usefulness and use of patient experience feedback in a local quality improvement context.

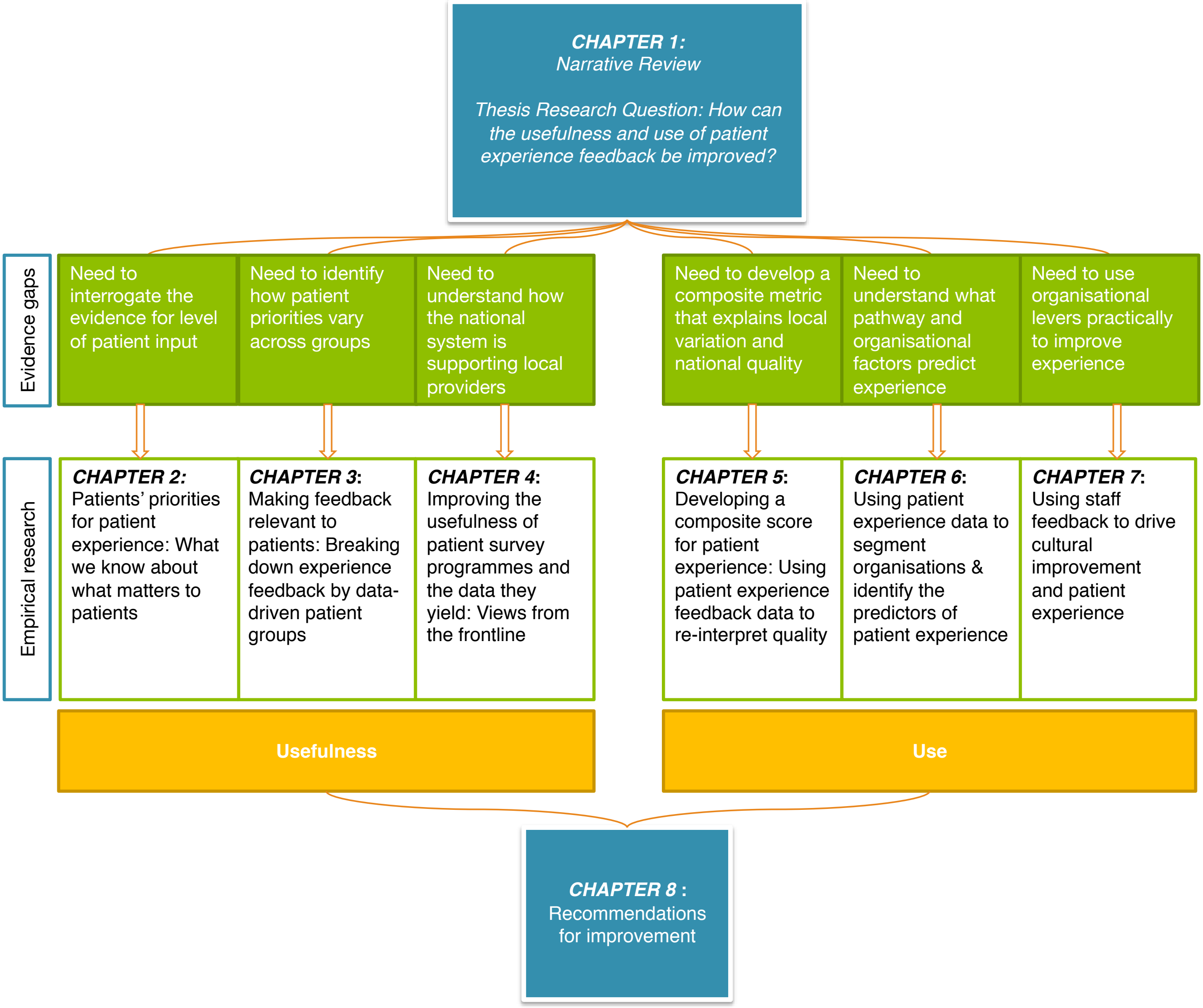


Figure 5. Research framework

CHAPTER 2

PATIENTS' PRIORITIES FOR PATIENT EXPERIENCE: WHAT WE KNOW ABOUT WHAT MATTERS TO PATIENTS

2.1 INTRODUCTION

Evidence from the field of PROMs suggests that underuse of patient experience feedback might be a result of how the tools used to collect feedback were developed in the first place (118). A systematic review found that only 25.9% of PROMs development included some form of patient involvement (118). According to this work, when patients were involved, they were only consulted about what topics the tool should measure 10.9% of the time (118). This demonstrates a severe lack of patient-centricity and an insight gap regarding what matters most to patients. While studies about how to make patient feedback most useful indicate that there is no single best survey methodology, it is still essential that any feedback collection tool be developed based on what is important to patients (119).

In terms of PREMs, the process for developing NPSP survey tools does not typically involve patients during the early phases of topic selection. While the process does involve patients at the point of question development, this involvement does not necessarily include the opportunity for patients to formulate questions, but rather allows them to comment on existing survey items (226). PREMs topic selection often relies upon literature about what matters to patients in place of original patient involvement (226). Evidence around what matters to patients is therefore one of the chief sources of information that survey developers reference when designing national patient experience feedback tools. Such evidence has also been used to develop patient experience frameworks like the WaPEF (74). Identifying literature about patient preferences in order to select survey topics lacks direct patient involvement, but it is a well-recognised step in survey development and ensuring content validity (124)(125)(127). Given that this literature is used to guide patient survey development, it is important in the context of this study to scrutinise the extent to which it includes patients' own input.

As revealed in the narrative review in **Chapter 1**, however, this evidence base contains numerous inconsistencies about what is actually important to patients, a feature of the literature that has not before been systematically evaluated (45)(83)(88)(90)(103)(227)(111). While variation in patient preferences is inevitable, it is important to establish whether inconsistencies are a product of diversity or a result of methodological shortcomings in the literature. Misunderstandings regarding what is important to patients can have serious policy implications. For example, after many of AIPS's earliest iterations, there was a trend of patients answering 'yes" to a question inquiring about whether patients stayed in mixed sex accommodation. This trend was assumed to be problematic and national investment was made to eliminate mixed sex accommodation in acute hospitals (112). Over time, the percentage of patients responding "yes" to the question declined. However, subsequent studies demonstrated that, on a whole, patients themselves did not consider mixed sex accommodation to be a problem, and the investment in eliminating it did not have an impact on their experience (112).

According to survey development literature, in order to contribute usefully to the evidence base surrounding what matters most to patients, studies should exhibit certain methodological characteristics (111). They should provide patients with an open-ended opportunity to express what matters most to them (116)(117)(118). They should allow patients themselves to rank what is most important to them in terms of experience and avoid rankings based on statistical inference (44)(45)(84)(120)(121)(123). Finally, they should disaggregate their findings by patient characteristics, or at least provide demographic context so their results can be extrapolated to the appropriate population (115)(116)(54).

An evidence base incorporating these qualities is increasingly relevant as policy makers in the NHS have demonstrated a clear enthusiasm for gathering patient feedback with the introduction of campaigns like the FFT, the guidance for which encourages additional experiential survey questions, and sustained support for the NPSP (141)(147). NHS commissioners' have also engaged with the idea of patient feedback and now require it of most funded services (8)(14). Political leaders at an international level are also attempting to integrate PREMs as a currency for cross-national comparisons of health services (228). These are all important movements toward patient-centric quality assessment, but will only work if measures within surveys accurately reflect what matters most to patients (117).

Evaluation of studies within this evidence base will provide insight into why some national PREMs are yielding patient experience data that is not useful or relevant to local quality improvement.

2.2 AIMS & OBJECTIVES

The aim of this study was to assess the quality of existing evidence surrounding patient priorities for experience in healthcare by exploring the characteristics of that evidence. This involved three objectives:

i. To identify all recent English language literature providing information about what matters most to acute inpatients in terms of patient experience
ii. To systematically score how well each study delivered information on what matters most to acute inpatients
iii. To identify where existing evidence fell short of being able to guide patient experience survey tool development

Analysis of findings contributes to a case for enhanced knowledge of what matters to different patient groups that is data-driven and patient-centric.

2.3 METHODS

2.3.1 Literature search strategy

The evidence base surrounding inpatient experience is vast, and other studies attempting to systematically identify similar literature have encountered many barriers to constructing a meaningful set of search terms (74). The strategy used in this study sought peer reviewed articles from the Web of Science multidisciplinary database in English from the years 2000-2015. To identify all relevant articles, a series of search terms was derived to capture each of the relevant concepts. A PRISMA flow chart for systematic reviews depicts this strategy (Figure 6) (229).

Terms used to conduct the search:

1. Inpatients: Inpatient*, patient* in hospital, hospital patient*, acute inpatient*, acute patient* (n = 250,573)
2. Prioritising: Rank, value, best, most important, matters, prioriti* (n = 6,897,127)
3. Experience: Experience, patient experience, patient satisfaction (n = 2,013,979)

- Combined using AND (n = 1,156)

The three concepts were searched for individually. The results from each of the three searches were then merged to identify papers containing all three concepts. Results were filtered by subject relevance. The following filters were used:

- "science technology" "social science" "healthcare science services"

Building on **Chapter 1**, the websites of major UK healthcare research organisations that focus on patient-centred care in the NHS were also scanned for any relevant research reports. This included reports they had listed in the research publication section of their websites. The following sites were reviewed:

- NHS England
- The Health Foundation
- The King's Fund
- The Nuffield Trust
- The Patients' Association
- The Picker Institute Europe

The Picker Institute and The Patients' Association had a limited number of total publications, so it was possible to search through all of them for relevant titles. On the other websites the search terms "patient" and "patient experience" were employed to generate links to reports.

Following this, the abstracts of all identified literature were screened to ensure they fit the following inclusion criteria:

Inclusion criteria:

- Study provided information on what matters most to acute inpatients
- Study explained methodological information about how results were achieved
- Study was published between 2000-2015
- Study was published in English

The remaining studies included after this screening were thoroughly reviewed and the following inclusion criteria were applied:

Exclusion criteria:

- Study was primarily focused on a setting other than acute inpatient care
- Study concerned staff experience, not patient experience
- Study was not relevant to patient experience
- Full study was not published in English

Regarding relevance to patient experience, many articles were excluded because they used “experience” to denote familiarity with a particular medical procedure or occurrence of a certain clinical condition. Articles were also excluded if they related to an experience pre-dating care. With regard to the setting of care criteria, many studies related to preferences in end of life decision-making; such articles were only included if they specifically concerned inpatients in acute hospitals. It is important to note that some of the evidence cited in **Chapter 1** to define the aspects of experience was returned in this search, but not all of it met the full inclusion criteria for systematic review.

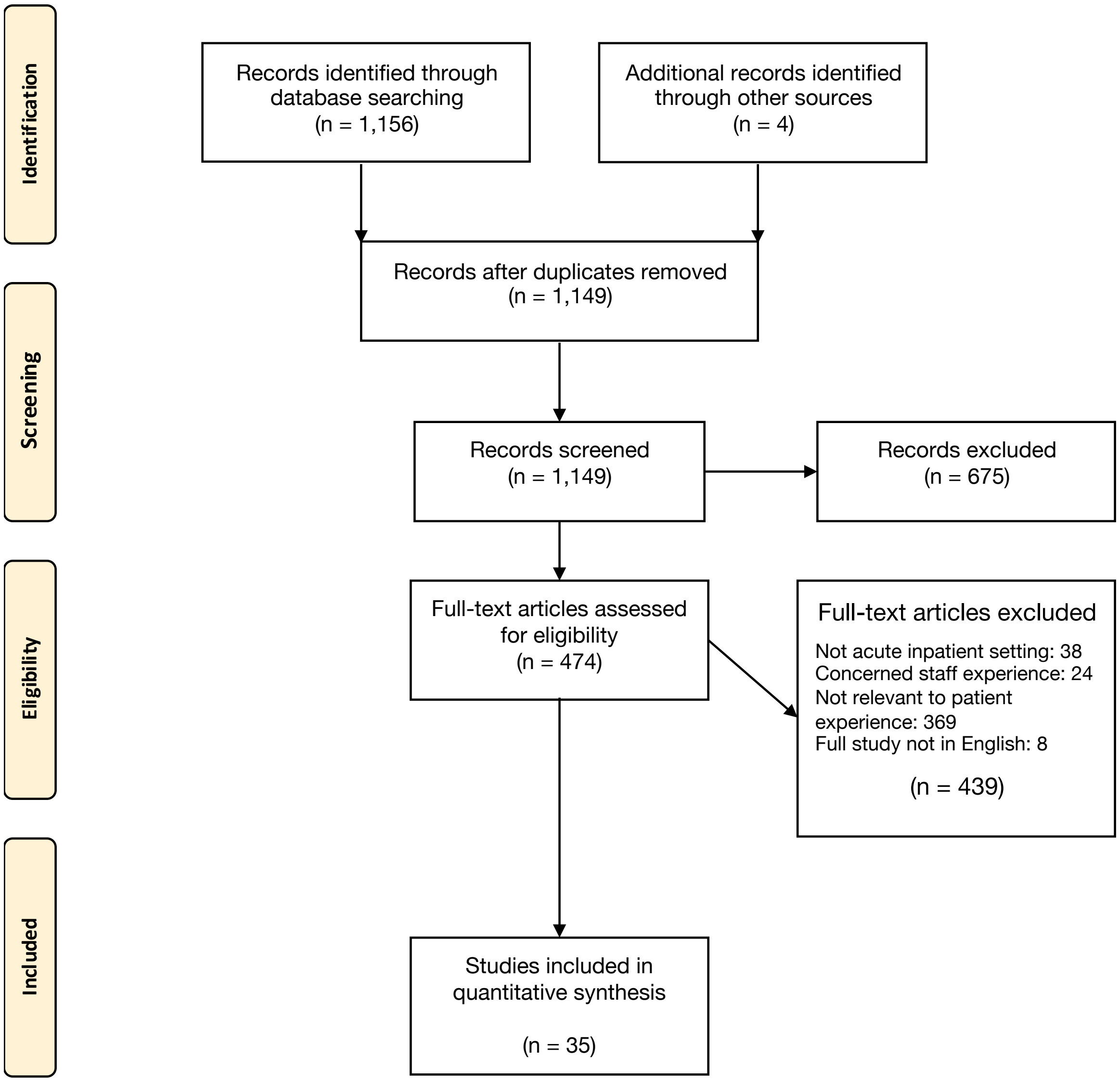


Figure 6. PRISMA search strategy flow chart

2.3.2 Literature scoring strategy

The scoring system was derived from available literature presented in **Chapter 1** about the defining characteristics of a study which precisely captures what mattered most to patients (44)(45)(84)(111)(116)(117)(118) (120)(121)(123)(115) (54). This was used in place of a scoring framework because there was no existing framework for scoring studies relating to what matters to patients. This review does not provide an appraisal of the studies in their totality, but rather investigates how much patient-driven evidence exists about what actually matters to acute inpatients. It focuses specifically on ranked information about what matters most to patients in order to apply the scoring system, however, it is important to note that this review does not necessarily capture qualitative literature available about patient priorities.

A total of five points were awarded for articles exhibiting the following qualities:

1. Studies included scope for patients to say, in an open-ended fashion, what mattered most to them
2. Studies collected data on patient priorities from patients rather than deriving them from literature
3. Studies included an explicit ranking system so patients could say what mattered *most* to them
4. Studies included rankings that were carried out by patients, rather than by statistical inference
5. Studies contextualised their results and listed the patient groups to whom their results applied

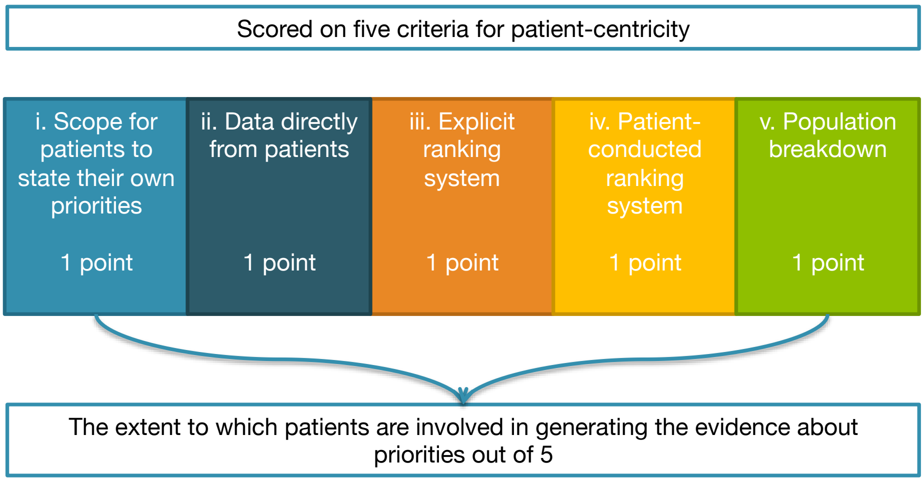


Figure 7. Scoring strategy

2.4 RESULTS

Thirty-five papers were included in the final quantitative synthesis (Table 5). All papers provided information about what inpatients prioritise in terms of care experience. A full list of all papers, authors and their characteristics including sample sizes, demographic groups included and main findings can be found in APPENDIX A.

Table 5. Final scores of the studies reviewed

Author	Citation number	Year	Patients to state own priorities	Data directly from patients	Explicit ranking system	Patient-conducted ranking system	Population breakdown	Total score
1. Krones CJ, et al.	(230)	2006	0	1	0	0	0	**1**
2. Piderman KM, et al.	(231)	2013	0	1	0	0	0	**1**
3. Huppertz JW & Smith R	(232)	2014	0	1	1	0	0	**2**
4. Doyle C et al.	(83)	2010	0	1	1	0	0	**2**
5. Jenkinson C et al.	(84)	2002	0	1	1	0	0	**2**
6. Cleary PD, et al.	(233)	2014	0	1	0	0	1	**2**
7. Fletcher KE, et al.	(234)	2007	1	1	0	0	0	**2**
8. Frampton SB, et al.	(235)	2013	1	1	0	0	0	**2**
9. Winsor S, et al.	(236)	2013	0	0	1	0	1	**2**
10. Shattell M, et al.	(237)	2005	1	1	0	0	0	**2**
11. Williams AM & Irurita VF	(238)	2004	1	1	0	0	0	**2**
12. Liu SS, et al.	(239)	2010	0	1	1	1	0	**3**
13. Elliott MN, et al.	(240)	2009	0	1	1	0	1	**3**
14. Elliott MN, et al.	(241)	2010	0	1	1	0	1	**3**
15. Hargreaves DS, et al.	(242)	2012	0	1	1	0	1	**3**
16. Krol MW, et al.	(243)	2015	0	1	1	0	1	**3**
17. Miceli P, & Clark PA.	(244)	2005	0	1	1	0	1	**3**
18. Schwappach & Strasmann	(245)	2007	0	1	1	0	1	**3**
19. Sipsma H, et al.	(246)	2013	0	1	1	0	1	**3**
20. Solheim E & Garratt AM	(71)	2013	0	1	1	0	1	**3**
21. Coulter A & Cleary PD	(45)	2001	0	1	1	0	1	**3**
22. Digby R & Bloomer MJ	(247)	2014	1	1	0	0	1	**3**
23. Clift L, et al.	(248)	2007	1	1	0	0	1	**3**
24. Ewart L, et al.	(249)	2014	1	1	0	0	1	**3**
25. Garrett PW, et al.	(3)	2008	1	1	0	0	1	**3**
26. Henderson A, et al.	(250)	2004	1	1	0	0	1	**3**

27. Wainer J, et al.	(251)	2012	1	1	0	0	1	**3**
28. Fridh I, et al.	(252)	2015	1	1	1	1	0	**4**
29. Hweidi IM	(253)	2007	0	1	1	1	1	**4**
30. You JJ, et al.	(92)	2014	0	1	1	1	1	**4**
31. Van Staa A, et al	(88)	2011	1	1	1	0	1	**4**
32. Heyland DK, et al.	(254)	2006	1	1	1	0	1	**4**
33. Davis Y, et al.	(255)	2009	1	1	1	1	1	**5**
34. Dougherty M	(256)	2010	1	1	1	1	1	**5**
35. Tsianakas V, et al.	(257)	2012	1	1	1	1	1	**5**

2.4.1 Scores applied to literature

All papers received at least one out of the five possible points. The majority of papers received between two and four points (71.4%) and only three papers (8.6%) received all five points (Figure 8).

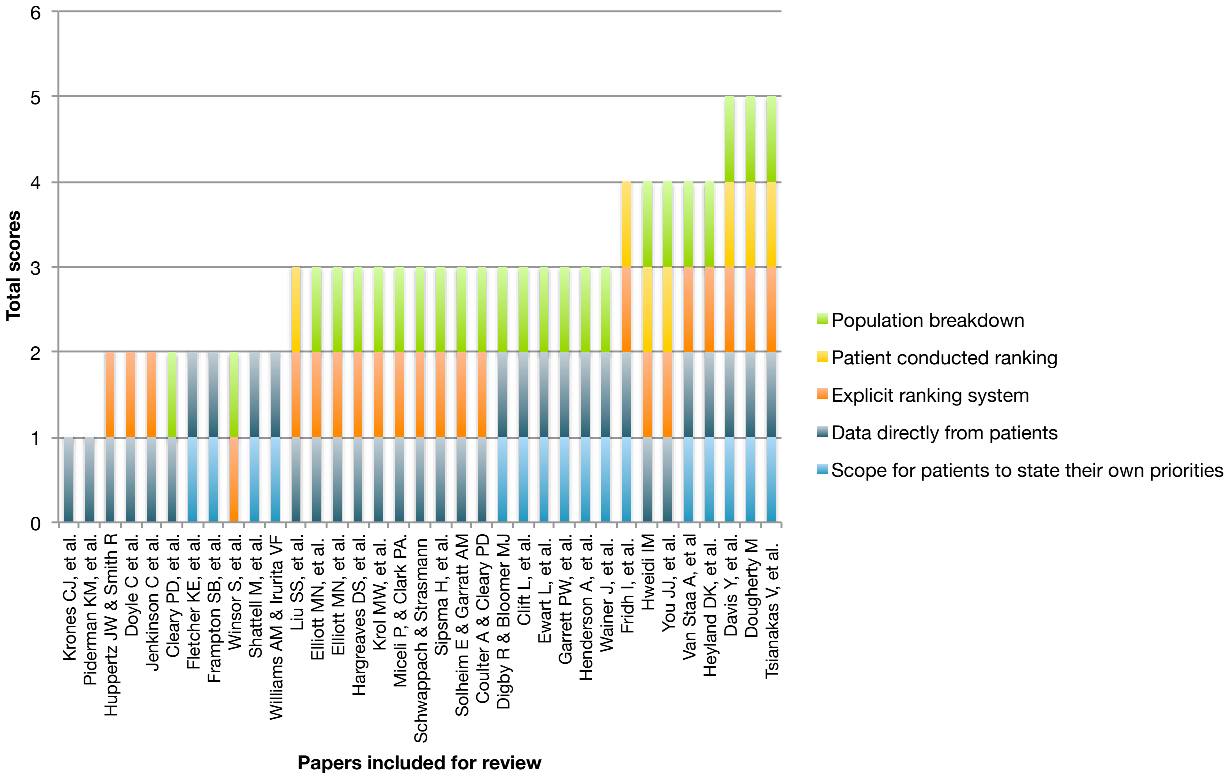


Figure 8. Total scores for each study

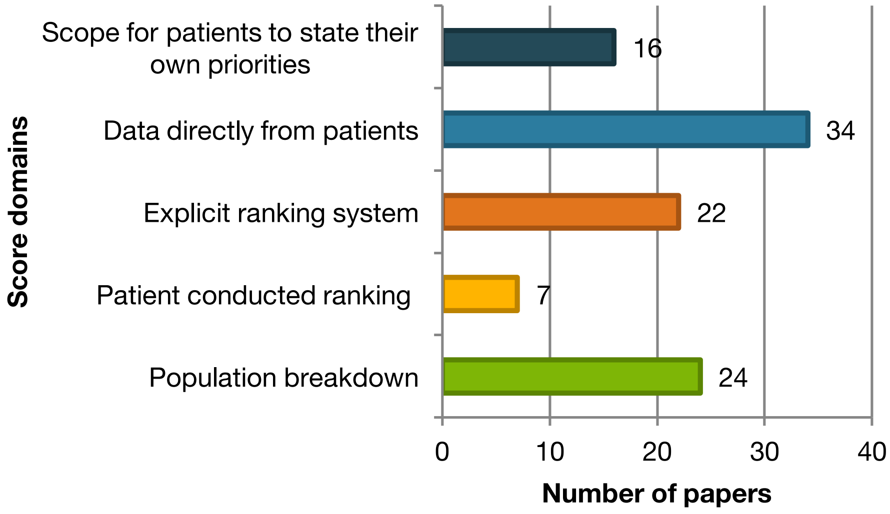


Figure 9. Number of studies receiving points for each scoring domain

Scope for patients to state their own priority

Figure 8 illustrates that only 16 studies used a methodology that included scope for patients to state their priority aspects of experience in *a priori* or open-ended way. Although many studies used data from surveys that did include open-ended questions, these did not receive a point for this criterion unless they specifically mentioned analysis of free-text responses.

Data directly from patients

Figure 9 illustrated that 34 out of the 35 (97.1%) studies collected data directly from patients.

Explicit ranking system

Figure 9 also demonstrated that 22 out of 35 studies (62.9%) employed an explicit ranking system.

Patient-conducted ranking

The most frequently missed criterion concerned the inclusion of a patient-conducted ranking system. Only 7 of the 35 studies (20%) included this. Fifteen papers employed a researcher-conducted ranking of patient priorities; eleven of which used PCA techniques to suggest the importance of an individual aspect of experience based on its association to an overall measure.

Population

Figure 8 also reveals that over two thirds (68.5%) of the studies presented findings with respect to a specific patient population. Groups identified include: age, geography, medical diagnosis, pathway type (i.e. emergency or planned), point in pathway (perioperative or post-operative), patients' hospital type and a host of socio-demographic characteristics. Studies demonstrated striking differences when they broke down results by groups related to care pathways: elective patients were more concerned with hotel factors than their emergency or unplanned counterparts who were more interested in wait times; perioperative patients prioritised communication and involvement in care (250)(258). Table 6 provides a full list of priorities by patient group.

Of the studies that employed a ranking, four did not differentiate by population group and slight discrepancies were apparent: one paper cited communication and trust as being most important to the patient population at large (83); a second cited physical comfort, emotional support and respect for preferences (84); and one did not make a conclusive statement on what matters most. Of the six papers that did use a patient-conducted ranking system or a population breakdown, results were different at the population level, but communication, empowerment and aspects of personal state of mind were important across groups (92)(239)(253)(256)(257)(258).

Table 6. Patient priorities across different patient groups

Category	Patient group	Priorities
Age	Generic age	Young adults were more likely to value ethical counsel from chaplains than older adults
	Chronically ill adolescents	A feeling of trust, voice and choice, avoiding pain and discomfort, keeping in touch with home and being entertained (less: being hospitalized with peers, being heard)
Diagnosis	Cancer patients and their carers	Patients: information and communication, the competence of their caregivers, cleanliness of the care environment, and adequacy of pain management. Family: most important needs were similar, with the addition of needs related to visitation and specific discharge information
	Breast cancer patients	Availability of nurses, pain relief, provision of information on treatment, possible side-effects of treatment and what to do after discharge and need for support at home
	Gynaecological cancers	Serious post-operative morbidity, coordination between the surgical team and general practitioners, management of pain
	Dementia patients and their carers	No ranking included
	Cardiac Patients with carers and their carers	Involving families and family visiting
Type of care	Medical patients	Exchange of information, evidence of caring from their team, involvement in teaching, knowing the team members, bedside manner
	Elective surgery patients	Hotel features, medical outcomes, provision of information, clinical care, comfort
	Surgical patients	Specialization and experience of provider, waiting times, staff continuity
	Perioperative patients	Patients: access to pain and/or nausea management, information about the condition after surgery, respect and dignity. Family member: communication with the surgeon after the procedure, opportunities to ask questions and address concerns with hospital staff, and information about the procedure
	End of life patients	Preferences for care in the event of life-threatening illness, values, prognosis, fears or concerns, and additional questions about goals of care
	Divided into levels of sickness, education, income and other demographics	Having tubes in nose or mouth, pain, lack of sleep, too much hospital noise and not being in control of yourself. Marital status, educational level, age, and income were the most significant characteristics that affected patients' perception of stressors

	Hospital type	Communication with doctors, treatment of pain, information at discharge
	Socio-demographic characteristics, hospital type and province	Communication with nurses; Age was the only socio-demographic characteristic associated with overall ratings
Socio-demographic	Patients across five high-income countries	Information and education, coordination of care, respect for patients' preferences, emotional support, physical comfort, involvement of family and friends, and continuity and transition were relevant in all five countries
	Australian non-English speakers	Language facilitation, attention to specific cultural, positive engagement, information and involvement, compassionate and respectful treatment, and involvement of their family
	Veterans acute myocardial infarction (AMI)	No specific priorities listed
Carer Groups	Parents of children who were inpatients	Disappointment with staff, unexpected waiting, information regarding new medication, staff success in easing the child's pain, incorrect treatment and number of previous admissions Socio-demographic characteristics had weak or no associations with parent experiences
	Carers of patients with chronic conditions	Understanding diagnosis, increased socialization, managing own care
	Children's parents	Sensitivity to the inconvenience that a child's health problems and hospitalization can cause, emotional and spiritual, response to concerns/complaints made during the child's stay, include parents in decisions about the child's treatment, improve the accommodations and comfort for visitors

2.5 DISCUSSION

2.5.1 Main findings

The evidence base surrounding what matters to acute inpatients was nearly entirely generated from patients themselves, rather than derived from secondary literature (97.1%); it typically included a ranking to indicate the most important aspects of experience (62%); and more than half of the studies reviewed provided a breakdown of the population to indicate to whom their findings were relevant (68.6%). The evidence base lacked patient-centricity in the sense that many studies did not allow patients to state their priorities in an open-ended way (45.7%) and often rankings were not conducted by patients themselves (20%).

Of the studies that received the highest scores, their findings on what matters most to patients were patient-driven, informed by robust rankings and presented with regard to the specific patient group to which they applied. The three top scoring studies focused on distinct, but highly important, groups of patients. This included perioperative patients, cancer patients and carers and breast cancer patients (256)(257)(258). Perioperative patients prioritised access to pain medication, information about their condition after surgery and being treated with dignity (258). These results are not surprising as they mirror existing generic principles of patient experience. However, what these results contribute is very important to making feedback more useful: they elaborate on generic principles of patient experience and begin to articulate how these principles are manifested in different types of care.

They also, in some cases, indicate how such principles might differ according to certain patient groups. They demonstrate that access is important, but access to perioperative patients, specifically refers to pain medication; information is important, but the most important information is about conditions after surgery. Cancer patient carers also valued information, but prioritised the discharge process rather than the condition and they were distinctly uninterested in information related to nurse staffing and the hospital setting (256). Breast cancer patients, on the other hand, prioritised information on side effects, what to do at home and the availability of nurses in the hospital. It is notable that some of the top-scoring evidence indicated a trend towards patients prioritising information and support outside of hospital. This is a key aspect of experience and should be considered when reviewing the hospital experience.

2.5.2 Findings in relation to existing literature

The impact of deficient patient input

Existing evidence around what matters to patients is notably lacking in its levels of patient involvement. Less than half of the studies included in this review (45.7%) directly consulted patients about their preferences in open-ended conversation. In terms of providing a free-text, *a priori*, response to the question, *“What matters most to you as a patient?”* or something similar, the good examples are sparse. This is because most studies use secondary data from closed-ended survey questions or their own preconceived survey questions. While this is methodologically reasonable, such questions do not allow insight into what else might matter to patients. Extensive preliminary development work has been conducted on most national patient experience surveys to determine whether or not it captures everything that is relevant to patients. However, there has been very little evidence of qualitative engagement with patients in recent years, even though service delivery is constantly changing (144).

This is evidenced by the fact that when patients in identified studies were asked directly what mattered to them, their responses would not always have been picked up in existing NPSP surveys or categorised neatly into the NHS Patient Experience Framework (78). For instance, Shattell et al. discuss what matters to patients more theoretically, and patients revealed that an appropriate sense of freedom versus confinement was highly important to them (237). While this might be related to emotional support in the existing principles of experience, it is actually relatively novel in the discussion of patient experience and deserving of further attention. Another priority revealed in open-ended discussion in Garrett et al. was patients' need for language facilitation (259). This can be subsumed by the existing principle around communication; however, language is specific to a certain group of patients and often overlooked in terms of communication. It refers to more than communication as well, because people with long-term care pathways need to be signposted to language support at each point on the pathway even if that is outside the health service. In terms of more demographic-specific priorities, patients in Heyland et al. expressed the importance of not being kept alive when they had no hope of recovery (254). Again, this represents a patient preference and can be combined with that existing principle. However, it is novel in the sense that it requires more than simple respect for preferences to achieve; it requires bridging disciplines between law, medicine and emotional support. Finally, Dougherty's study reveals that when asked directly, patients also prioritise evidence of clinical competence, directly linking priorities for experience to priorities for effectiveness (256).

Disregard for individual patient priorities can lead to tools that disregard important aspects of experience, therefore compromising the utility of resulting data, as individual preferences are likely to be characteristic of a broader group.

Importance of patient-centric methodologies

What matters most to specific groups of patients provides a much more useful guide for improvement as opposed to reiterating what is already known to be broadly important.

In the studies identified, many rankings were done through principle component analyses or otherwise researcher-conducted systems of ranking. As discussed before, studies that measure statistical association to an overall metric are problematic and probably not accurate considering overall scores tend to be inflated (44)(45)(123). Studies where patients actually did perform the ranking presented highly useful information for service improvement for particular groups. Hweidi's study of critical care patients revealed many basic hospital features that detracted from a positive experience of care such as hearing too many buzzers, but also personal support aspects like feeling in control of oneself (253). In the case of end of life carers, they ranked respect for preferences higher than the comfort aspects described above. In a more generic study by Tsianakas et al., patients ranked availability of nurses highly as well as provision of information about treatment and side effects (257).

Understanding what matters most to patients requires extension of the more patient-centric methodologies identified through this analysis to allow more patients to delineate what matters to them given their specific medical and socio-demographic needs.

The utility of a granular patient feedback

While many of the studies (68.6%) differentiated their results by patient sub-groups, groups were usually defined by a single demographic or medical variable rather than complex clustering of multiple variables that provide more advanced healthcare consumer insights. It is likely that a more granular, data-driven, population segmentation could help providers tailor quality improvement initiatives to specific groups of patients. Staff members have specified that aggregate survey data can obscure patient experience insights and that data would be most useful if broken down by the patients or patient groups to which they apply (6). However, it is important to note that evidence from population segmentation suggests that the most accurate way to disaggregate data is not always by single-variable, pre-determined demographic or medical groupings (260). In the case of patient experience, simply because there is evidence that a generic age group has a certain preference around accessing care, it is not sufficient information to guide service improvements, as the preference might vary depending on additional variables such as medical needs or geographic location (260).

Of the studies that did break down results by distinct patient population, they revealed that there are many ways to group patients. While most studies used basic demographics (race, age, gender, medical condition), some were more nuanced. Some studies disaggregated results in terms of service delivery. Elliot et al. interrogated HCAHPS data in America to determine if different sets of patient health characteristics (i.e. different patient case mix) led to different experience at a hospital level (241). Krol et al. broke down results by hospital and department type with feedback from over 15 thousand patients and found significant differences at department levels. They additionally found that patient experience feedback was thought to be most useful when applied at a sub-organisational, granular level (243). Medical needs were the most commonly used to report results. This review found results that applied to patients dealing with dementia, cancer, chronic conditions and surgical procedures. Some studies went beyond simply stating to whom the results applied, but actually breaking the results down by sickness levels, such as Hweidi's study of patients after discharge from Critical Care Units (CCU) in Jordan, which explains that single and older patients of lower affluence require more support than other patients after the CCU (253). Van Staa et al. focused on chronically ill adolescents, acknowledging certain disease groups have different priorities for care as well as different demographics within this disease group (88). It is important to note that these very broad medical and social classifications can be further subdivided without risking over-individualisation.

The crux of this investigation into the evidence around what matters to patients is how well findings are explained. A critical component of that is how well they are explained within the context of the sample population. Seeing as experience is arguably the most subjective domain of quality, it is essential to find patterns in this subjectivity by exploring how priorities vary depending on social and medical needs.

2.5.3 Limitations

The primary limitation of this study is the nature of the evidence base and the extent of literature commenting on what matters to patients. While this search strategy was developed in partnership with expert librarians, the lack of relevant Medical Subject Headings (MeSH) terms indicates that other relevant studies might not have been captured (74).

The focus on acute inpatient care was necessary to maintain a manageable scope and obtain coherent findings; however, it excludes findings outside of the inpatient setting, which, in some cases, could have been extrapolated for the purposes of this research. For instance, specific evidence about outpatient priorities has been published; however, such studies are not necessarily more patient-centric (261). Research on experience of specific care pathways like cancer care may not have been returned in this search even though they would intersect the inpatient setting at some point. Furthermore, while this strategy does incorporate some UK grey literature, it is likely that relevant information is contained within individual NHS organisations' own records as well as international organisations' publications. Gathering more insights through targeted conversations with NHS organisations would be a useful approach to advancing this research.

Another limitation of the search strategy was the reliance on literature that allowed patients to rank the importance of certain aspects of patient experience. While this was done to understand what mattered *most* to patients, it critically limited input from qualitative studies, which do not typically include rankings. Literature concerning how patient experience is measured would suggest that including more studies concerning non-ranked, qualitative sources of patient feedback would be a useful addition to this research (81).

A final theoretical limitation is that this study covers what is important to inpatient groups, but does not allow insight into patient priorities across the care pathway. This helps understand what different inpatient groups prioritise; however, it would be advantageous to move beyond thinking of care as punctuated by specific settings, and understand it rather as a continuous pathway to ensure groups' preferences are accounted for consistently.

2.5.4 Implications of findings: Untangling discrepancies in the evidence

The literature explored in this review is rich in information about what matters to patients; however through this analysis it is clear that the evidence is compromised by the limited input that patients have into it, the collection and analytical techniques used and the lack of population segmentation applied. This is not necessarily to say that the papers themselves are compromised, but that their utility within the evidence base around what matters to patients is limited. They do, however, present a useful starting point that begins to explore what is most important to patients.

On a larger scale it is necessary to work with other sources of patient information and apply population segmentation techniques to understand which groups exist within the patient population and how feedback differs across these groups. This idea is relatively novel in healthcare, but well established in commercial industries, which regularly use consumer data to optimise services for different types of clientele (149)(150). A segmented framework of what aspects of experience matter most to data-driven patient groups will provide the business intelligence needed to deliver relevant service improvements. In the endeavour to improve the usefulness of patient experience feedback, it is paramount that patients are not seen as a homogenous group with consistent needs and preferences.

2.6 CONCLUSION

Improving the usefulness of patient experience feedback locally requires ensuring that the information relied upon to develop patient feedback tools comprehensively reflects patients' priorities.

This review has interrogated studies that provide information on what matters to patients. Firstly, it scored studies on whether or not they included scope for patients to say, in an open-ended fashion, what matters to them. Secondly, it scored studies on whether or not patients provided the insights, whether they included a ranking system so patients could indicate what mattered *most* and whether that ranking was done by patients or derived by statistical inference. A final point was awarded to studies that contextualised results with reference to the exact patient groups to whom their results apply.

While the evidence contained in these studies helps explain what matters to patients generally, the findings of this review reveal some cause for concern. Substantial research is needed to reconcile the discrepancies in the evidence around ranked priorities of patient experience and more attention needs to be given to open-ended, patient-driven sources of what matters most. This review also highlights the importance of providing a breakdown of patient priorities. It suggests that a failure to provide this could be the source of some of the discrepancies and render studies ill-equipped to inform the development of PREMs surveys.

In the long-term, these concerns can be resolved with greater patient involvement in determining what matters most to what patients. More immediately, however, the utility of patient experience data can be improved by providing a more granular breakdown of patient priorities. Population segmentation techniques can be applied to existing data to ascertain where patient experience feedback differs across patient groups. Until a more patient-centric evidence base is established, a segmented framework of what different patients prioritise would offer organisations a more useful, meaningful presentation of data from which to drive improvement.

CHAPTER 3

MAKING DATA RELEVANT TO PROVIDERS: BREAKING DOWN EXPERIENCE FEEDBACK BY DATA-DRIVEN PATIENT GROUPS

3.1 INTRODUCTION

Evidence presented in the **Chapter 1** narrative review emphasized that, in order to deliver useful insights to local providers, national patient experience data should be presented with sufficient granularity (5)(6)(14). Furthermore, the previous chapter argued that the literature base that currently guides patient survey development should include clearer breakdowns of patient groups and their preferences (117)(226). In addition to improving this evidence base, however, there are also analytic techniques, like population segmentation, that can be applied immediately to glean more data from national patient experience data. As concluded in Tsianakas et al's paper, such disaggregated survey data about patient preferences can highlight specific potential problems that can be investigated further using qualitative techniques and quality improvement methodologies (257).

Segmentation techniques are relatively novel in healthcare, but they have been enormously successful in other industries (149)(150). At the most basic level, segmentation techniques group members of a population based on observed similarities (122). When applied to large datasets, these techniques have the potential to expose previously unknown diversity within a population. As described in **Chapter 1**, consumer retailers use these techniques regularly to map differences in their clientele and tailor sales offerings accordingly (149)(150). Applying these techniques to patient experience datasets, over time, could facilitate a more refined understanding of patients' preferences, and begin to curb the problems associated with silent misdiagnosis discussed in **Chapter 1** (148).

Segmentation can be applied to national patient experience datasets to group patients based on their clinical characteristics or based on patterns within their feedback. Although still novel in healthcare and patient experience, one study has successfully identified data-driven groups of patients based on their experience, and overall perceptions of safety and outcomes as reported in the 2011 Norwegian Knowledge Centre for the Health Services patient experience survey (56). This work demonstrated that despite overwhelmingly positive patient experience ratings, distinct groups can be identified that have significantly worse experience. It also indicates that more work is needed to develop these clusters and understand the profiles of patients within them (56). Specifically, an unsupervised clustering technique called TwoStep Cluster analysis, would be appropriate, as it is typically applied to large, numeric datasets when there is no target output field (122). This type of clustering was used in the Norwegian study referenced above and is less impacted by outliers than most correlative or data reduction techniques, and unaffected by multi-collinearity (122). Furthermore, it is important to note that the TwoStep procedure does not generate a fixed number of clusters, but rather the amount necessary to classify the population based on the data input. Moreover, results from cluster analyses would allow patient experience data to be presented in a disaggregated fashion, delineating the characteristics of patient groups and their experiences.

To test how well the TwoStep Clustering technique can generate groups from variables included in patient experience datasets, this work trials the technique with the largest NHS repository of patient experience feedback, the AIPS dataset (65). However, to create a breakdown of patients that is useful for quality improvement, the demographic and clinical data fields contained within publically available AIPS datasets are insufficient. Data from one clinical speciality within the NCPES dataset would be more appropriate for creating this breakdown. The only NCPES clinical speciality dataset that was available for this research, however, was that of urological cancers (262)(263). Despite this restriction, the dataset was fit for purpose. The NCPES urology dataset contained the patient-level details necessary to create a breakdown of patient groups and their experiences that would be useful for local quality improvement.

3.2 AIMS & OBJECTIVES

The aim of this study was to explore whether population segmentation techniques could provide better consumer insights from patient experience feedback, which could more specifically inform quality improvements in the health service.

The two specific objectives were:

i. To conduct an exploratory cluster analysis of patient experience data to determine whether such techniques can identify previously unknown patient groups
ii. To conduct a series of cluster analyses on a specified clinical group (urological cancer patients) in order to generate a segmented framework that delineates data-driven patient groups, their characteristics and where they exhibit the greatest concerns relating to experience.

3.3 METHODS

First, an exploratory cluster analysis was conducted to better understand how population segmentation techniques perform when applied to national patient experience datasets. This was necessary in order to test the proposed approach.

3.3.1 Exploratory cluster analysis

AIPS dataset

This analysis used data from the 2013 return of AIPS, as it was the most recent at the time of analysis. AIPS mandated that every acute organisation participating sample 850 patients who had spent one night or more in hospital. Samples were drawn from patients discharged in June, July or August 2013. The actual survey fieldwork ran for 18 weeks commencing 9th September 2013. AIPS data from 2013 included patient-level responses to 70 patient experience questions (145). Demographic details had been supressed in the public dataset, meaning there was no demographic information other than age group (in fifteen year blocks) and gender.

Table 7. Summary of 2013 AIPS data return

Sources: Health and Social Care Information Centre. Available from: http://hefs.hscic.gov.uk/Downloads/DataDefinitions2003-04.PDF ; Care Quality Commission. National Adult Inpatient Questionnaire [Internet}Available from: http://www.nhssurveys.org/Filestore/Inpatient_2013/IP13_Scored_Questionnaire_v1.pdf

Total Number of organisations: 156, Total respondents: 62,443
Range respondents per organisation: 164 – 600
Average respondents per organisation: 400.28, Median respondents per organisation: 400

Demographic	Variables	Percentage of respondents (n=62,443)
Gender	Male	46.30%
	Female	53.70%
Age	16-35	7.00%
	36-5-	12.00%
	52-65	24.30%
	66+	56.70%
Days in hospital		Range 1 to 448, Mean 5.67
Route of admission	Emergency or urgent	57.50%
	Waiting list or planned in advance	35.40%
	Something else	2.80%
	Missing responses	4.30%
Visit included A&E	Yes	53.20%
	No	8.30%
	Inapplicable	35.40%
	Missing responses	3.00%
Visit included critical care unit	Yes	20.60%
	No	72.40%
	Don’t know/Can’t remember	5.00%
	Missing Responses	2.00%
Visit included an operation or procedure	Yes	60.50%
	No	36.70%
	Missing Responses	2.80%
Number of respondents by commissioning region	London	13.20%
	Midlands and East of England	30.30%
	North of England	30.10%
	South of England	25.80%
Number of respondents by organisation size	Large	23.90%
	Medium	22.20%
	Small	24.00%
	Multi-service	2.10%
	Specialist	10.50%
	Teaching	16.60%

Cluster analysis & data reduction

In SPSS the TwoStep Cluster analysis was conducted in two distinct steps. First, a large number of small clusters were identified and their distance from one and other recorded. These small clusters, referred to as, 'pre-clusters' were determined based on the mean and variance of each explanatory clustering variable. Second, the pre-clusters were grouped together based on their similarity. This yielded the final clusters, which were considered to be "internally coherent and distant from the others" (122).

The following AIPS patient-level characteristics were used as explanatory clustering variables:

1. Emergency vs. planned admit
2. Visit included A&E
3. Visit included critical care unit
4. Length of stay
5. Visit included an operation or procedure

The measurement fields were all uniform, so there was no risk of larger measurement fields accounting for increased variability (122).

Principle component analysis (PCA)

Although this analysis aimed to cluster patients based on a complex array of care characteristics, it was also important to observe variability in experience scores across the resulting clusters. In order to determine which AIPS questions to compare across groups, a PCA was conducted in SPSS on all scored AIPS questions to determine which accounted for the most variability. The following AIPS questions accounted for 56.7% of the variance:

1. Do you feel you got enough emotional support from hospital staff during your stay?
2. When you had important questions to ask a nurse, did you get answers that you could understand?
3. Overall, did you feel you were treated with respect and dignity while you were in the hospital?
4. Do you think the hospital staff did everything they could to help control your pain?

5. Did you have confidence and trust in the doctors treating you?
6. Did you find someone on the hospital staff to talk to about your worries and fears?
7. Did a member of staff tell you about medication side effects to watch for when you went home?

Scores from these seven questions were used to compare clusters and a one-way ANOVA using Bonferroni adjustment for multiple comparisons was conducted to observe whether cross-cluster differences were significant at a 95% confidence level.

3.3.2 NCPES segmentation

Moving beyond testing the clustering technique, TwoStep Cluster analyses were applied to NCPES to identify patient groups and their differences in experience.

NCPES urological cancer patients dataset

NCPES has been conducted in the NHS annually since 2012 and collects information from a sample of approximately 118,000 patients per year (262). The survey is developed and directed by the National Cancer Patient Experience Advisory Group, and commissioned and managed by NHS England.

Pseudonymised patient-level, patient-reported data from the 2014 NCPES was used to identify groups based on the experience feedback of urological cancer care. Again, this was the most recent dataset at the time of analysis. This clinical speciality dataset included patients who had been diagnosed with the following cancer types: penile, prostate, testis, other male genital, kidney (exc. renal pelvis), renal pelvis, ureter, bladder, other urinary and other urological tumours. The total number of respondents with one of these conditions was 17,520.

Table 8. Summary of 2014 NCPES returns for urological cancer patients

Demographic	Variables	Percentage of respondents (n=17,520)
Gender		
	Male	87.1
	Female	12.9
Age		
	0	0.1
	20	0.4
	30	1.1
	40	2.9
	50	12.8
	60	36.3
	70	34.0
	80	11.2
	90	0.7
Income Quintile *	1	23.9
	2	25
	3	20.6
	4	16.5
	5	12.7
Cancer Type		
	Penile	0.8
	Prostate	43.3
	Testis	1.6
	Other male genital	0.1
	Kidney (exc. renal pelvis)	7.6
	Renal pelvis	0.7
	Ureter	1.3
	Bladder	43.9
	Other urinary	0.4

* 5 represents the highest deprivation level and 1 the lowest.

The survey included 57 questions about patient experience, each of which fell within one of the following 15 sections:

1. Seeing the GP
2. Diagnostic tests
3. Finding out what was wrong with you
4. Deciding the best treatment for you
5. Clinical nurse specialists
6. Support for people with cancer
7. Operations
8. Hospital doctors
9. Ward nurses
10. Home care and support
11. Hospital care and treatment
12. Hospital care as a day patient
13. Outpatient appointment with doctors
14. Care from GP
15. Overall

The dataset included patient-level scores on questions about experience ranging from 1 – 10. The scoring method that had been applied to responses was based on a “partial credit” technique, proven to be a reliable survey scoring method (126)(143). For example, the bold numbers to the right of the response options below represent how scores were applied:

Q9. Were the results of the test(s) explained in a way you could understand?
Yes, completely = **(10)**
Yes, to some extent = **(5)**
No, but I would have liked an explanation = **(0)**
I did not need an explanation = **(no score)**
Don’t know / can’t remember = **(no score)**

Each of the 57 questions contributed to a section score. Section scores, also included in the dataset, represented the average question score in each section. Questions that received a “no score” mark were not considered in this average. The dataset also included patient-level demographic sampling data (i.e. data that was not reported by patients, but obtained by survey contractors via organisational patient records). The fields included were gender, age, deprivation, and cancer type (Table 8).

3.3.3 Description of NCPES segmentation approach

In the NCPES analyses, a traditional PCA as described above was not conducted, however, section scores were used to reduce experience data. Section scores can be considered components of care and help explain variability in experience. This was done to ensure that all aspects of the care pathway were included, but also that data dimensionality was reduced. Clusters are theoretically most meaningful if derived from the continuous variables like patient experience scores; therefore, categorical patient characteristics in NCPES were only used to identify demographic patterns across the clusters (122).

First, a cluster analysis was applied to the data for all urological cancer patients who responded to the NCPES. The second analysis further segmented the cluster with the poorest experience to provide more granularity around the types of patients reporting poor experiences. These two analyses revealed that many respondents could not be included in the analysis because they did not have scores for each of the sections on the survey. This was mainly because patients whose pathway included an operation had been required to answer different survey questions than those whose pathway did not include an operation. In order to address this problem and account for the effect a pathway could have on experience scores, a third cluster analysis was conducted on each of two groups: those who had an operation or procedure and those who did not. The NCPES segmentation flow chart is shown in Figure 10.

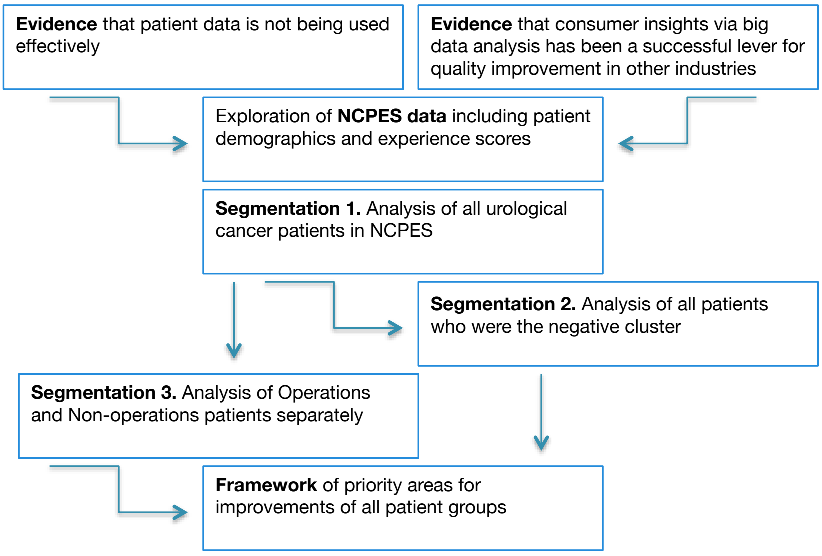


Figure 10. NCPES segmentation flow chart

Cluster analysis of all urological cancer patients within NCPES

The first NCPES TwoStep Cluster analysis was conducted in SPSS using all urological cancer respondents' (n=17,520) section scores as explanatory variables.

All the section scores were included in the cluster analysis aside from the "Overall" section. The "Overall" section was removed because of evidence suggesting it typically receives inflated scores and does not identify specific concerns for improvement (**Chapter 1**). A variable was created to indicate each respondent's cluster membership:

1 = Best Experience
2 = Middling Experience
3 = Worst Experience

Cluster analysis of all patients within the poorest experience cluster

Considering the aim of the segmentation approach was to understand where improvements are needed, the Worst Experience cluster was segmented again. Filtering for just respondents in this cluster (n=3,347), the same TwoStep method was applied. The groups derived from this analysis were called sub-clusters.

Cluster analysis based on urological cancer care pathway

The respondent population was divided into Operations (n=9,297) and Non-Operations (n=8,223) to represent differences in care pathways and account for the different questions that each of these groups answer on the NCPES questionnaire. Two more TwoStep Cluster analyses were conducted.

Before section scores were inserted into each of these TwoStep models, a frequency analysis was conducted to determine the number of respondents who received a score for each section. If any section was missing over 1,350 responses (approximately 15% of the population of interest), the section score was dropped from the model. This ensured the clustering was based on as many respondents as possible.

The two cluster analyses excluded the following sections because they lacked scores from over 15% of the relevant population:

Operations excluded sections:

- Clinical nurse specialists
- Home care and support
- Hospital care as a day patient
- Outpatient appointment with doctors

Non-Operations excluded section:

- Clinical nurse specialists
- Operations
- Hospital doctors
- Ward nurses
- Home care and support
- Hospital care and treatment
- Outpatient appointment with doctors

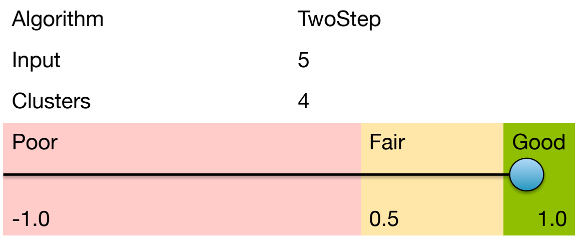
Framework construction

After each cluster analysis was conducted, a variable was created for cluster membership. Profiles were then created to identify the characteristics of patients within each cluster and their concerns regarding patient experience. The demographic details included in these profiles were gender, age, deprivation and cancer type. A framework for improvement was created based these profiles.

3.4 RESULTS

3.4.1 Exploratory cluster analysis

The TwoStep Cluster analysis yielded four distinct clusters of AIPS patients (Figure 11). The groups all had more emergency admissions than non-emergency admissions, but otherwise varied in terms of characteristics (Figure 12).



Algorithm	TwoStep
Input	5
Clusters	4

Figure 11. Accuracy of the TwoStep to classify patients

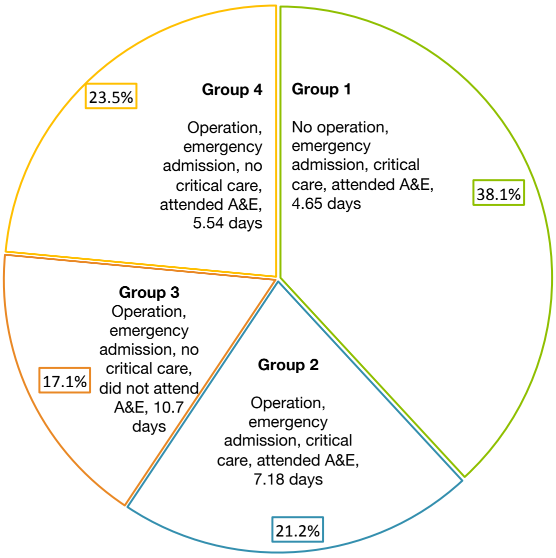


Figure 12. AIPS segmentation cluster sizes and patient characteristics

Group 2, composed of patients who received emergency care, critical care and operations, had the most positive experience scores across all questions (Table 9). Group 1 included patients with the shortest average length of stay and fewer operations, but had the worst experience score across questions (Table 9).

When examined with respect to different aspects of experience, the four clusters had significantly different results for each of the seven questions identified in the PCA ($p<0.05$). Mean scores for confidence and trust in doctors were significantly different between all groups ($p<0.05$). Mean scores for the questions about emotional support, finding someone to answer questions and staff being available to discuss worries and fears were significantly different between all groups except between groups 2 and 3. Mean scores regarding overall dignity and whether or not staff discussed medication side effects were also significantly different between all groups except between groups 3 and 4. Mean scores for the question about whether staff did everything they could to control patients' pain were only significantly different between group 1 and all other groups, while the difference between groups 2, 3 and 4 was not significant ($p<0.05$) (APPENDIX B).

While these clusters were statistically meaningful, in order to be practically useful, patient feedback patterns require exploration with reference to variables that can clarify which patient groups report positive and negative experiences of care and where they exhibit specific concerns.

Table 9. Key experience scores across AIPS exploratory clusters

Group	Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Did you have confidence and trust in the doctors treating you?	Do you think the hospital staff did everything they could to help control your pain?	When you had important questions to ask a nurse, did you get answers that you could understand?	Did you find someone on the hospital staff to talk to about your worries and fears?	Did a member of staff tell you about medication side effects to watch for when you went home?	Did you have confidence and trust in the doctors treating you?
1	1.3	1.31	1.45	1.48	2.02	2.26	1.34
2	1.21	1.25	1.35	1.39	1.79	2.07	1.23
3	1.25	1.29	1.38	1.39	1.82	2.04	1.26
4	1.27	1.31	1.38	1.4	1.87	2.09	1.28

Note: AIPS scores from 2013 ranged from 1 to 3, with 1 indicating the best experience

3.4.2 NCPES segmentation results

Descriptive NCPES findings

Urological cancer patients who responded to the 2014 NCPES were predominantly male (87.1%). Deprivation level was more evenly distributed, however the population was relatively affluent, with the top two income quintiles accounting for virtually half of all respondents (48.9%). In terms of age, 83.1% of respondents were over 50. Bladder and prostate cancer dominated the profile, accounting for 87.2% of respondents collectively. Kidney, testis and ureter were the next three most prevalent cancers, accounting for 7.6%, 1.6% and 1.3% respectively. All other cancers accounted for less than 1% of respondents each.

Descriptive survey results demonstrated very high patient experience scores across all sections (Table 10). Only two sections fell below 7/10. Seeing a GP, Finding out what was wrong, Diagnostic tests, Clinical support nurses, Hospital doctors, Outpatient appointments with doctors and GP care all scored 8.5/10 or higher. It is important to note that the NCPES was scored differently than the 2013 AIPS return: Possible scores ranged from 1 to 10 with ten being the most positive experience.

Table 10. NCPES section scores: All urological cancer patients

Sections	Average score
1. Seeing a GP	8.7
2. Diagnostic tests	9.0
3. Finding out what was wrong	8.5
4. Deciding treatment	7.8
5. Clinical support nurses	9.0
6. Support for people with cancer	7.3
7. Operations	8.4
8. Hospital doctors	8.7
9. Ward nurses	6.4
10. Hospital care and treatment	8.8
11. Home care	6.8
12. Hospital care as a day patient	8.4
13. Outpatient appointments with doctors	9.6
14. GP care	8.8

Cluster analysis of all urological cancer patients within NCPES

The first cluster analysis of all urological patients yielded three clusters:

Cluster 1 = Best Experience
Cluster 2 = Middling Experience
Cluster 3 = Worst Experience

These clusters were derived from data from 17,520 patients, however 225 were automatically removed from the analysis because they did not have sufficient data to be included in the cluster analysis. The only section that consistently received the high scores across the clusters was Outpatient appointments (Table 11). The Ward nurses section was the lowest, while Home care and Support for people with cancer were also lower than average. Mean scores for each section were significantly different between all three sub-clusters ($p<0.05$).

Table 11. NCPES section scores by cluster

Section	Best Experience (n=4,488)	Middling Experience (n=9,460)	Worst Experience (n=3,347)
1. Seeing a GP	9.3	9.0	7.5
2. Diagnostic tests	9.6	9.2	7.5
3. Finding out what was wrong	9.3	8.8	6.8
4. Deciding treatment	8.9	8.1	5.5
5. Clinical support nurses	9.6	9.2	7.5
6. Support for people with cancer	8.5	7.5	4.9
7. Operations	9.3	8.7	6.6
8. Hospital doctors	9.4	9.1	6.9
9. Ward nurses	6.9	6.5	5.3
10. Hospital care and treatment	9.5	9.0	7.2
11. Home care	8.5	7.2	3.9
12. Hospital care as a day patient	9.4	8.8	6.0
13. Outpatient appointments with doctors	9.8	9.7	8.8
14. GP care	9.6	9.1	7.0

Clusters were significantly different in terms of the proportion of females, proportion of young patients and levels of deprivation they contained (*p*<0.05) (Figure 13). Women, young patients and more deprived patients were more concentrated in the Worst Experience cluster (Figure 13). Clusters were also significantly different in terms of cancer type (*p*<0.05), but cancers were relatively evenly distributed and prostate and bladder cancers dominated the sample (Figure 13) (APPENDIX B).

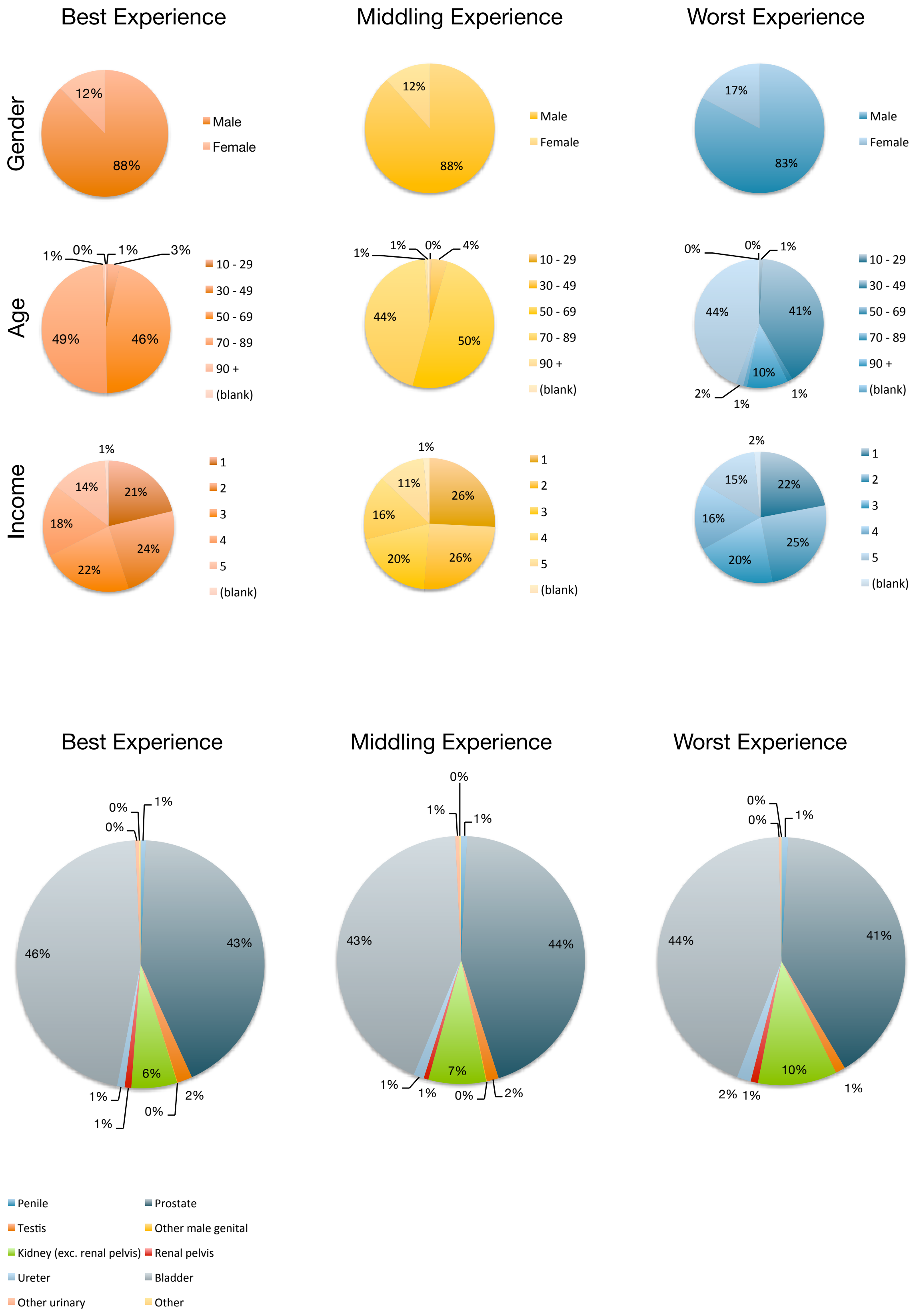


Figure 13. Demographic profile of each cluster

Table 12. Distribution of demographic characteristics across clusters

Demographic	Best Experience (n=4,488)	Middling Experience (n=9,460)	Worst Experience (n=3,347)
Gender			
Male	3,932	8,359	2,769
Female	556	1101	578
Age			
10 - 29	17	46	63
30 - 49	139	380	632
50 - 69	2,080	4,706	1,738
70 - 89	2,212	4,207	1,381
90 +	25	64	23
(blank)	15	57	22
Cancer type			
Penile	31	75	29
Prostate	1,908	4,191	1,359
Testis	88	148	43
Other male genital	3	9	
Kidney (exc. renal pelvis)	268	710	345
Renal pelvis	39	59	32
Ureter	44	128	61
Bladder	2,076	4,069	1,466
Other urinary	21	49	8
Other	10	22	4
Deprivation level			
1	956	2,438	738
2	1,065	2,422	837
3	1,012	1,868	666
4	797	1,510	552
5	617	1078	503
(blank)	41	144	51

Cluster analysis of all patients within the Worst Experience cluster

The second cluster analysis, which further interrogated the Worst Experience cluster, resulted in three sub-clusters and provided more granular information about the negative experiences of different types of patients. However, most patients within the negative cluster did not have data for each clustering field, so only 617 were included. Patients fell into the following sub-clusters based on where they encountered the worst experience:

Sub-cluster 1 = Ward nurses and home care concerns
Sub-cluster 2 = Support and hospital concerns
Sub-cluster 3 = Substantial concerns (referring to patients who had concerns across nearly all domains of experience)

Patients' ratings of different aspects of experience varied across the sub-clusters. The Ward nurses and home care concerns sub-cluster had the best experience comparatively (Table 13). Despite being in the overall Worst Experience cluster, this sub-cluster scored very highly in most categories, especially pre-hospital areas like Seeing a GP, Diagnostic tests and Deciding treatment. The Support and hospital concerns sub-cluster had a moderate experience compared to the other sub-clusters (Table 13). Their most pronounced concerns were in sections like Deciding treatment, Home care and many hospital-related sections like Day patient care, Hospital doctors, Ward nurses and Operations. Finally, the Substantial concerns sub-cluster had a poor experience across almost all sections, only scoring above 6/10 on Outpatient appointments and Seeing a GP (Table 13).

There were significant differences in the mean scores for each section, except the GP care section, between all three sub-clusters ($p<0.05$) (APPENDIX B).

Table 13. Section score averages for poorest experience sub-clusters

Section	Ward nurses and home care concerns (n=196)	Support and hospital concerns (n=242)	Substantial concerns (n=179)
1. Seeing a GP	8.9	7.3	6.2
2. Diagnostic tests	9.1	8.2	5.5
3. Finding out what was wrong	8.6	7.4	4.7
4. Deciding treatment	8.0	6.0	3.6
5. Clinical support nurses	8.9	7.3	5.1
6. Support for people with cancer	8.3	4.3	2.9
7. Operations	8.7	7.1	5.0
8. Hospital doctors	8.5	7.5	4.6
9. Ward nurses	6.2	5.2	4.3
10. Hospital care and treatment	8.6	7.3	5.6
11. Home care	6.2	3.6	2.6
12. Hospital care as a day patient	8.4	5.7	4.0
13. Outpatient appointments with doctors	8.7	10.0	6.2
14. GP care	7.6	7.8	4.8

In terms of demographic profiles, sub-clusters were also significantly different in terms of gender, deprivation and cancer type ($p<0.05$). The Support and hospital concerns sub-cluster had the highest proportion of women (26%) and concentration of patients in the highest two deprivation levels (31%) (Figure 14). The Substantial concerns sub-cluster also had a high proportion women (25%) and the highest concentration of patients in the highest deprivation level (21%) (Figure 14). In terms of the most prominent cancers, the Support and hospital concerns sub-cluster, as well as the Substantial concerns sub-cluster, had high concentrations of bladder cancer. Prostate cancer was more concentrated in the Ward nurses and home care sub-cluster (Figure 14). Unlike the initial clusters, sub-clusters were not significantly different in terms of age (APPENDIX B).

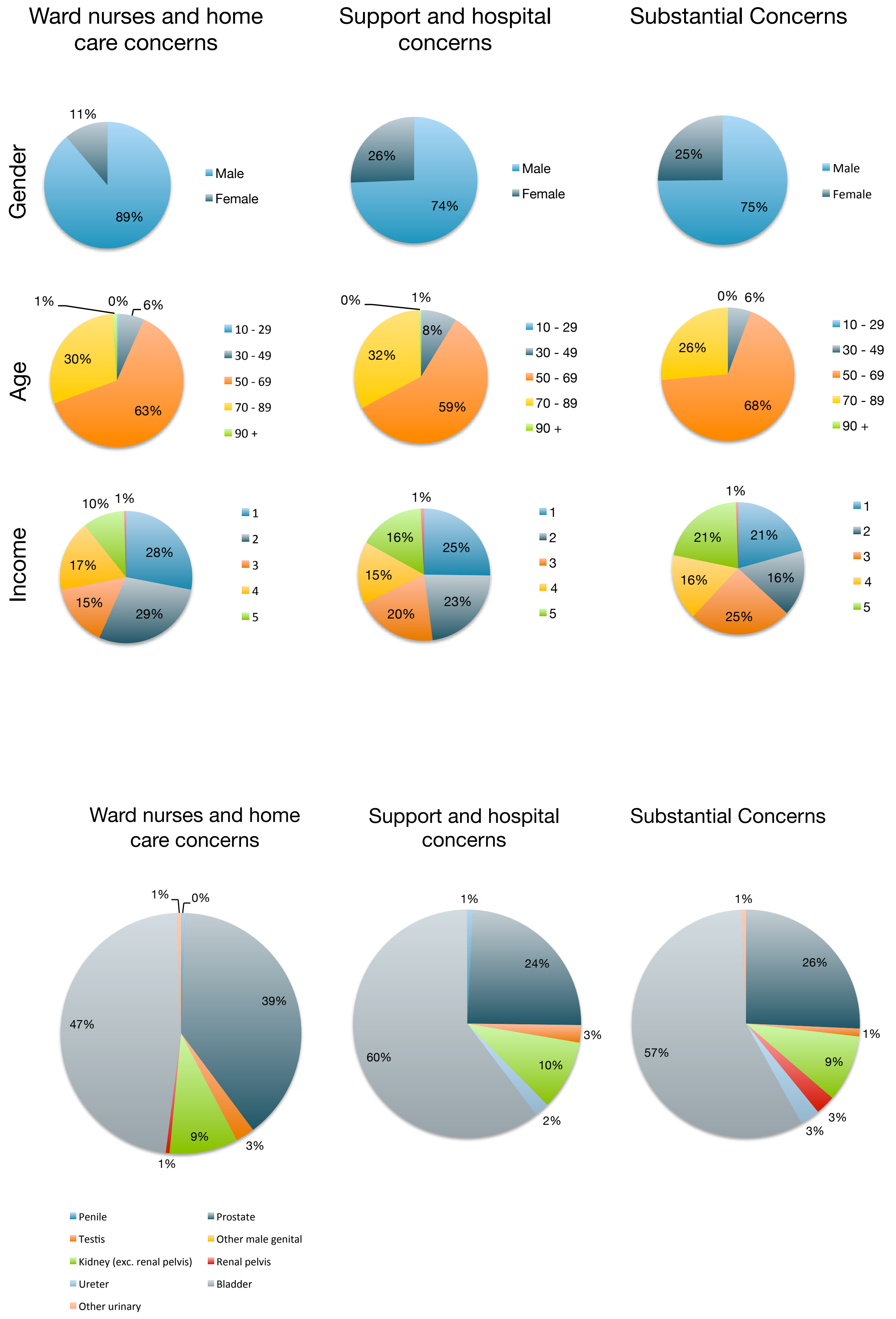


Figure 14. Worst Experience sub-clusters profiles

Table 14. Distribution of demographic characteristics across Worst Experience sub-clusters

Demographic	Ward nurses and home care (n=196)	Support and hospital concerns (n=242)	Substantial concerns (1=179)
Gender			
Male	174	180	134
Female	22	62	45
Age			
10 - 29	1	1	0
30 - 49	12	20	10
50 - 69	123	141	121
70 - 89	58	78	47
90 +	2	1	
Cancer Type			
Penile	1	2	
Prostate	77	59	46
Testis	5	6	2
Other male genital	18	24	17
Kidney (exc. renal pelvis)	1		5
Renal pelvis		5	5
Ureter	93	146	103
Bladder	1		1
Other urinary	0	0	0
Deprivation level			
1	55	61	37
2	56	55	29
3	30	48	45
4	34	37	29
5	20	39	38
(blank)	1	2	1

Cluster analysis based on urological cancer care pathway

In order to account for differences within cancer pathways, the third analysis filtered respondents by whether or not they had an operation. This analysis only used relevant section scores to perform cluster analyses on each group. Again, the cluster analyses yielded three distinct clusters within both the Operations and Non-Operations groups:

Cluster 1 = Best Experience
Cluster 2 = Middling Experience
Cluster 3 = Worst Experience

These clusters reveal a different, in some cases less positive, picture than the initial clustering, which did not differentiate by pathway (Table 15). Significant differences in mean section scores for all relevant sections were found between clusters within the Operations and Non-Operations groups ($p<0.05$) (APPENDIX B).

Table 15. Patient experience results by Operations/Non-Operations cluster

Section	Operations			Non-Operations		
	Best (n =5,812)	Middling (n= 954)	Worst (n=1,958)	Best (n=3,731)	Middling (n=587)	Worst (n=1,206)
1. Seeing a GP	9.9	2.5	8.7	10	2.5	8.1
2. Diagnostic tests	9.7	8.9	7.1	9.7	9.3	6.6
3. Finding out what was wrong	9.4	8.1	6.3	9.4	8.9	5.9
4. Deciding treatment	8.9	7.7	4.6	9	8.1	4.9
5. Clinical support nurses						
6. Support for people with cancer	8.3	6.8	3.9	9.3	8.5	7.8
7. Operations	9.3	8.6	6.1			
8. Hospital doctors	9.4	8.7	6.9			
9. Ward nurses	6.8	6.3	5.1			
10. Hospital care and treatment	9.4	8.7	7.2			
11. Home care						
12. Hospital care as a day patient				9.1	8.6	6.7
13. Outpatient appointments with doctors						
14. GP care	9.3	8.2	7.5	9.3	8.5	7.8

Although a full demographic break down was not necessary to repeat, amongst patients who had an operation, clusters were significantly different in terms of gender, age, deprivation and cancer type ($p<0.05$). Amongst patients who did not have an operation, clusters were also significantly different for all of these variables aside from deprivation ($p<0.05$) (APPENDIX B). Across both Operations and Non-Operations groups, women, younger and less affluent patients were more concentrated in the Middling or Worst Experience clusters than the Best Experience clusters. Both Middling clusters demonstrated severe concerns around being able to see a GP, a trend worth further investigation.

In terms of cancer type variation, trends were similar across Operations and Non-Operations groups. Bladder and kidney cancer were concentrated in the Worst Experience clusters, while prostate cancer was more concentrated in the Best Experience cluster. It is important to note that bladder cancer dominated all clusters within the Operations group, and prostate cancer dominated all clusters within the Non-Operations group (APPENDIX B).

3.4.3 Segmented framework of patient groups and experiences

Based on the results of the NCPES cluster analysis of patients who had a negative experience and the breakdown of patients by whether or not they had an operation, a framework was developed to highlight areas for improvement (Table 16). It delineates the clusters, the characteristics of patients within them, where they have indicated positive experiences and where their negative feedback indicates room for improvement. The data presented in this framework provides relevant information from which to instigate quality improvement processes. In order to be effective and sufficiently robust, such processes also require further in depth investigation using narrative research techniques that help obtain insight into the problems identified through data segmentation (264).

Table 16. Segmented framework of patient experience feedback

Sub-cluster	Patient demographics	Areas of success	Actions for improvement
Ward nurses and home care concerns	• Highest proportion of males • Majority between 50-70 • High affluence • High concentration of prostate and testis cancers	• Almost all aspects of care are satisfactory for this group	• Ward nurses & home care require some attention for this group • Build evidence base around what these types of patients want in terms of relational aspects of care with ward nurses and home healthcare assistants
Support and hospital concerns	• Includes a high proportion of women in relation to the number of women using the service • Relatively high affluence • Includes the highest proportion of very old and relatively young patients • High concentration of ureter and relatively high concentration of penile cancers	• Diagnostic tests • Seeing a GP • Outpatient appointments	• Support before treatment like deciding treatment • Support after care like home care • Ward nurses, and general hospital care also require improvement in this group • This section contains some vulnerable groups and it is important that support is improved for them
Substantial Concerns	• Includes a high proportion of women in relation to the number of women using the service • Typically 50s and 60s • Highest deprivation • Highest concentration of renal and bladder cancer	• This group has identified no outstanding areas	• Nearly every hospital aspect of care is rated poorly • Specific concern should be given to sections relating to support, finding out what was wrong and deciding treatment • Important to explore the role of deprivation in access to outreach services as well as the different pathways a patient might experience depending on their tumour type

Pathway type	Patient demographics	Areas of success	Actions for improvement
Operations	• Higher proportion of men • Majority between 50-70 • Relatively high affluence • High concentration of prostate cancers	• GP care • Diagnostic tests • Hospital care	• Being able to see a GP • Support for people with cancer • Deciding treatment • Ward nurses • Operations in general
Non-Operations	• Very high proportion of women • Majority between 50-70 • Relatively high affluence • High concentration of bladder and kidney cancers	• Support for people with cancer • GP care • Day patient care	• Being able to see a GP • Deciding treatment • Finding out what was wrong

3.5 DISCUSSION

3.5.1 Statement of results

Exploratory cluster analysis of AIPS

The exploratory cluster analysis of AIPS used multiple demographic factors to define four distinct groups. These results are mainly exploratory, but have two primary implications for further studies: first, they demonstrate that there are homogenous groups of patients within a diverse patient population and that those groups are driven by multiple factors, rather than simple demographic characteristics. Second, they indicate that positive experience in one area of care corresponds to positive experience in others; however, there are variations across groups, which necessitate further, more targeted exploration. While AIPS segmentation provides a high-level proof of principle, in order to create a segmented framework of patients from which to drive quality improvement, it was necessary to use data with more specific patient characteristics.

NCPES cluster analyses

The initial cluster analysis of all urological cancer patients who responded to NCPES revealed three distinct clusters representing ascending levels of experience: Best Experience, Middling Experience, and Worst Experience. These large clusters helped identify what sections within the NCPES survey required improvement nationally and what demographic groups reported the best and worst experiences of care. The Worst Experience cluster contained significantly more women (17.0%), patients under the age 40 (20.6%) and patients from the highest deprivation levels (15.0%) ($p<0.05$). It is important to note that each cluster was dominated by patients in their 50s-70s, a feature of the prevalence of urological cancers in these age groups.

The second NCPES cluster analysis, applied to just those patients in the Worst Experience cluster, produced more granular information about where improvement is needed. These sub-clusters revealed that urology patients reporting poor experience exhibited three different types of concerns: Ward nurses & home care concerns, Support & hospital services concerns and Substantial concerns with all areas of care. Although sub-clusters were not significantly different in terms of age, the Support & hospital services concerns sub-cluster and Substantial concerns sub-clusters had significantly more women and more deprived patients ($p<0.05$). 21% of the Substantial concerns sub-cluster was from the highest deprivation level and 25% of the patients within it were women. This is nearly double the population-level concentration of 12.7% and 12.9% respectively.

The results of the final NCPES cluster analysis, which split all urological cancer patients based on whether or not they had an operation, confirmed a similar pattern; that there are generally three levels of patient experience. However, the concerns of the more negative clusters were different between the Operations and Non-operations groups. The Operations group had more requirements around hospital-based factors whereas the Non-Operations group indicated more problems with support services and day patient care.

3.5.2 Findings in relation to existing literature

The utility of this population segmentation approach has been demonstrated extensively outside of healthcare (149)(150). These findings also add to emerging evidence that such techniques also have a useful application for healthcare quality improvement, particularly around patient experience data (56). Results suggest that these techniques have the potential to provide desired granularity to existing national patient experience datasets, however they suggest fewer segments than previous cluster analyses based on patient experience data (6)(56).

Previously published evidence from *a priori* demographic groups (age, gender, affluence) suggests that not all patients have an equal experience interacting with the health service (88)(242)(246). The results from the NCPES cluster analyses corroborate such evidence and indicate that differences are also exhibited across the urological cancer patient population (152)(155)(265). Findings from the Middling and Worst Experience clusters suggest key demographics to focus on in terms of improvement: women, younger patients and more deprived patients. Although women do tend to be more critical of care in patient surveys, this is not necessarily a bias, but possibly a result of worse care (266). These findings deserve further exploration in relation to prevalence to understand whether women and young people receive poorer representation within urological cancer care.

The findings about affluence also resonate with existing studies, which state that marginalised social groups tend to have worse experiences of care (153).

The NCPES cluster analysis results add testament to the theories presented in marketing literature, which suggest that data-driven groups defined by patterns in feedback can provide a granular understanding of consumer preferences (239). Furthermore, as seen in the NCPES cluster analysis that filtered for patients within the Worst Experience cluster, patients revealed specific concerns around support for people with cancer. This is consistent with other findings that cancer support outside of hospital is a patient priority and often a neglected area of care (254)(257). These results add to the existing literature to suggest that while it is known that vulnerable groups and support services are priority areas, it is the intersection of these two areas that requires particularly more attention; this would be a beneficial place to focus more in depth improvement processes. Furthermore, the final cluster analysis focusing on whether or not patients had an operation revealed that support was a more important concern for patients who had an operation than those who did not. In theory, this helps refine the quality improvement priority further to focus on support for vulnerable patients undergoing an operation.

The findings ultimately bolster literature demonstrating the utility of population segmentation as well as literature exposing the diversity of the patient populations. They suggest a more useful approach to analysing and presenting national patient experience feedback.

3.5.3 Limitations

The exploratory analysis of AIPS data employed categorical variables to determine how well the clustering technique could be applied to large patient experience datasets. This is a valid technique, however, data reduction literature would suggest the exploratory analysis could have been optimised using continuous variables, as were used in the NCPES analyses (122). Also related to the exploration, a PCA was conducted to determine which AIPS questions to use as comparators across the clusters. As discussed in **Chapter 2,** this type of PCA does not necessarily indicate what is most important to individual patients.

The findings of the NCPES segmentation analyses could have been enhanced with more extensive demographic characteristics like information on ethnicity, geography, personal health and habits, stage of cancer at time of detection, extent of healthcare service utilisation and of family and social support. A more detailed cluster profile would make it easier for providers to identify which clusters are most prevalent within their clinical services. Furthermore, a larger number of responses to certain sections would have also enabled more sections to be included in the final cluster analysis regarding differences across pathways.

Additionally, sections within NCPES vary in size between 1 – 10 survey items, calling into question whether the sections with fewer items are as robust as sections with more items. Finally, the segmentation is premised on the idea that the section scores represent the most important aspects of patient experience for urological cancer care. In fact, these are generic measures of cancer experience, and section scores do not necessarily represent aspects of experience that are unique to urological cancer care.

Finally, it is necessary to recognise structured data does not always provide enough richness in detail to guide improvement; therefore the segmentation would have been enhanced with qualitative feedback from patients in order to direct improvement efforts. Future research should focus on a more in depth exploration of the potential problem areas identified through the survey data segmentation.

3.5.4 Implications of findings

The results indicate that population segmentation techniques provide a promising solution for enhancing data utility for local providers in priority setting for improvement. Frameworks like the one included in Table 16 allow providers and commissioners to visualise where problems are and for whom they are worst. Rather than deploying a vast programme of interventions without exact knowledge of what needs improving, they can break down the population according to its component groups and target more in depth quality improvement processes towards specific concerns identified through the data..

A segmented view lets the data speak louder than it could in aggregate. Initial descriptive NCPES results aggregated at the organisation level promote an explicitly positive image of patient experience for urological cancer patients. This has proven unhelpful to local providers, as it does not inspire improvement nor does it indicate where improvement is needed (6). Local organisations are aware of the complexity of their own patients' preferences, but the data they receive from national surveys makes it impossible to identify the most pressing areas for improvement (151).

The segmented view also eschews the tendency to remain complacent with moderately high scores. While the focus has been on the ability of the framework to indicate where improvement it needed, clusters exhibiting positive experience also present more useful data. Because patient experience data tends to plateau at a relatively high level, identifying areas of exceptional experience provides a useful mechanism to move from good to excellent.

Such strategies have been a hallmark of market research for decades and these clusters demonstrate how useful they can be in terms of creating more useful patient experience data. These results provide a proof of principle, indicating that this technique would help generate patient experience insights that can be embedded within local organisations. In the future, this segmentation can be trialled to test whether it offers a more palatable presentation of data for priority setting in local quality improvement processes. While segmented results might help, there are a multitude of system-level actions that may need to accompany this type of data presentation and analysis in order for data to be most useful. This requires further exploration with NHS staff.

3.6 CONCLUSIONS

Patient experience feedback is an important vehicle in the movement towards patient-centricity, yet the data available has been ineffective in driving local change. This is not due to lack of availability, but due in part to lack of granular understanding of the patient population. These segmentations build on techniques used by other industries to better understand their consumers through data-driven groupings and develop services differently based on their needs. These analyses demonstrate that within urological cancer care there are three overall groups - those who have a very positive experience, those who have a middling experience and those who have a poor experience - but that within these groups, there are more interesting sub-groups who have particular concerns based on their demographics, the type of care they receive and the specifics of their pathway.

These profiles provide a new faculty for improvement and present data in a more constructive, useful way. They move towards a style of improvement that is insight-led and level the playing field within organisations for determining which areas require most support to drive improvements. The success of techniques used in this research, and the frameworks they are capable of yielding, indicate that segmentation analysis could provide useful disaggregation of data from national patient survey programmes that could be more useful to priority setting in quality improvement than aggregate data. Scaling up these segmentation techniques is the next step in translating data into improvement. However, this process also hinges on actors within national survey programmes putting in place all of the other necessary mechanisms to support the staff responsible for driving improvement. Understanding how best to achieve that requires frontline perspectives on how to make patient experience data most useful.

CHAPTER 4

IMPROVING THE USEFULNESS OF NATIONAL PATIENT SURVEY PROGRAMMES AND THE DATA THEY YIELD: VIEWS FROM THE FRONTLINE

4.1 INTRODUCTION

In 2007 Reeves and Seccombe found that staff identify lack of data specificity as a primary barrier to using patient experience data (6). In 2017, however, national patient experience data continues to be reported in organisation-level aggregates that do not account for heterogeneity of the population, nor patients' varying needs (10)(146). The previous chapter establishes that even within specific services, there are diverse patient groups with their own priorities for patient experience improvement. The disaggregation of data into a table of different groups of patients and the positive and negative experiences they reported, such as the one presented in the previous chapter, would likely mediate some of the barriers to using patient experience data and enable more tailored improvement (6). In addition to providing this level of granularity, there are considerably more adaptations that the national system around patient experience feedback can pursue to enhance data utility for local use (112)(117).

In the 2007 study, staff also focused on lack of resources, under-prioritisation of patient experience and deficits in their own statistical ability as key barriers to using data (6). These findings helped position the importance of patient experience as a health service priority. Patient experience is now central to national and international health policy strategies and embedded within training schemes for clinical and managerial staff (147)(183)(228)(267). Ten years on and despite these theoretical advancements, however, the lag in data use persists (5).

As discussed in **Chapter 1** there is an extensive system of regulators, contractors and survey coordination centres that surrounds the NPSP. It is important to identify where there is appetite for organisations to innovate their patient feedback use, but it is potentially more critical to understand how all stakeholders within this system can facilitate these improvements. Understanding the intricacies of data utility, and prioritising where to make improvements, requires the perspective of NHS staff who work with patient experience data (specifically NPSP data) and are responsible for deriving insights from it (163). Refreshed staff insights will elucidate how the current system, new policies and demographic shifts have changed and added barriers to using feedback. Staff experiences handling data and their attempts to integrate it into quality improvement can shed light on the technical and underlying concerns that effect data use.

While previous work has focused on barriers to data use, it is also necessary to capture areas of local success and proven facilitators to data use. It is therefore necessary to identify organisations that have been able to improve patient experience scores on surveys and showcase their approaches. Gathering these examples through qualitative methods will provide insight into what staff need from the system, promote learning and inspire action. Feedback from frontline staff will yield suggestions for the national system to optimise technical survey procedures, methods and reporting mechanisms to make data most useful.

4.2 AIMS & OBJECTIVES

The aim of this study was to collect views from NHS staff about their local priorities for enhancing the utility of patient experience data, in order to guide research and inform future iterations of national surveys. The two objectives were as follows:

i. To understand the barriers that still impede the use of patient experience data and gather staff ideas for improving them
ii. To identify and showcase successful attempts to use patient experience data for improvement and generate a platform for shared learning.

4.3 METHODS

4.3.1 Case study sample selection

A qualitative case study design was selected in order to gather input from a range of organisations. Organisations were selected based on their AIPS results, as it is currently the largest and most robust source of patient experience feedback. Specific questions from AIPS were selected via the PCA conducted in the previous chapter. **Chapter 3** used the 7 questions responsible for 57% of variance in survey responses, while this study used the 12 that accounted for nearly all variance (99%). These 12 questions were also agreed with Picker Institute Europe as good indicators of whether or not organisations exhibited meaningful shifts in experience (Table 17).

Table 17. Questions used to select organisations based on PCA

AIPS questions
1. Do you feel you got enough emotional support from hospital staff during your stay?
2. When you had important questions to ask a doctor, did you get the answers that you could understand?
3. Overall, did you feel you were treated with respect and dignity while you were in the hospital
4. Do you think the hospital staff did everything they could to control your pain?
5. Did you have confidence and trust in the doctors treating you?
6. Did you find someone on the hospital staff to talk to about your worries and fears?
7. Did a member of staff tell you about medication side effects to watch for when you went home?
8. Were you involved as much as you wanted to be in decisions about your care and treatment?
9. In your opinion, how clean was the hospital room or ward you were in?
10. Did doctors talk in front of you as if you weren't there?
11. In your opinion were there enough nurses on duty to care for you in hospital?
12. Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you?

Organisations that demonstrated a significant increase or decrease in relation to any of these questions were recorded. Changes were considered significant if they were outside the expected range of results for that organisation[1]. Twenty-one organisations demonstrated at least one significant increase in relation to the 12 key questions. Six organisations demonstrated at least one significant decrease in relation the same questions (Table 18). All other organisations remained consistent in relation to the questions. Three-letter organisation codes used by NHS England to identify organisations were used instead of full organisation names and will appear in subsequent analyses as well (268).

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[1] Expected ranges are calculated by Patient Survey Coordination Centre at Picker Institute Europe (146).

Table 18. Organisations’ changes in scores on 12 key AIPS questions

Question text	Organisations with score increases	Organisations with score decreases
1. Do you feel you got enough emotional support from hospital staff during your stay?	REM, RAL, RTX	
2. When you had important questions to ask a doctor, did you get the answers that you could understand?	RRF	None
3. Overall, did you feel you were treated with respect and dignity while you were in the hospital	RJD	
4. Do you think the hospital staff did everything they could to control your pain?	RAL	RVJ
5. Did you have confidence and trust in the doctors treating you?	None	None
6. Did you find someone on the hospital staff to talk to about your worries and fears?		RVJ, RN3, RPA
7. Did a member of staff tell you about medication side effects to watch for when you went home?	RP5, RJD, RM3, RJ7, RWG	
8. Were you involved as much as you wanted to be in decisions about your care and treatment?	REM, RTK, RAL, RM3	RJ2
9. In your opinion, how clean was the hospital room or ward you were in?	REM, RTK, RBD, RDU, RCD, RD7, RWF, RJD, RVJ	None
10. Did doctors talk in front of you as if you weren't there?	RBD, RJ1, RAL	None
11. In your opinion were there enough nurses on duty to care for you in hospital?	RBD, RDU, RCD, RJD, RXF, RDZ, RFW, RWP	RWA, RCJ
12. Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you?	RBD, RAL	RRV

A list was compiled of all the organisations that were recorded to see which organisations had the *most* increases and decreases. Three organisations were selected based on demonstrated increases in scores between 2012-2014, as this was the most recent data available at the time of case selection. Three others were selected based on demonstrated decreases in scores during the same time. Of the three organisations with the most increases, one had 5 increases and the others had 4 increases respectively (Figure 15). Of the three organisations with the most decreases, one had 3 decreases while the others had 2 respectively (Figure 15).

Figure 15. Organisations with one or more significant increase or decrease on the 12 key AIPS questions

A final three organisations whose scores remained consistent for the same years were also selected. With regard to these organisations, selection consideration was given for size and geography in order to maintain a degree of diversity, as there were many organisations that demonstrated no changes on the 12 questions.

The final 9 organisations sampled and their characteristics are presented in Table 19. It is important to note that the sampling strategy did not account for the baseline from which organisations' scores changed. This ensured that any organisation demonstrating improvement could be included regardless of how high or low experience scores were to begin with. The final selection of organisations was diverse, representing three organisations from a range of small, medium, large and teaching hospitals from across the country (Table 19).

Table 19. Organisations selected in sampling

Organisation	Status	Strategic Health Authority (Region)	Size / Type
RAL	Increased	London	Teaching
RBD	Increased	South West	Small
REM	Increased	North West	Medium
RVJ	Decreased	South West	Large
RWA	Decreased	Yorkshire and the Humber	Teaching
RRV	Decreased	London	Teaching
RYJ	Consistent	London	Teaching
RTD	Consistent	North East	Teaching
RC1	Consistent	East of England	Small

4.3.2 Semi-structured interviews

The patient experience teams of selected organisations were contacted in late 2015 and asked to nominate 1-3 members of staff who would be most familiar with using patient experience data to participate in interviews. Interviews took place between September 2015 and January 2016. Face to face, semi-structured interviews were conducted with staff members responsible for managing patient experience within the organisation. The interview design was chosen so that NHS staff could provide ideas for the system's improvement that align to their needs and NHS operational realities.

The topic guide was developed with experts from Picker Institute Europe who are familiar with the data in the NPSP and the limitations it has for actual use. It covered questions such as staff responsibilities for using the patient experience data, preferences for using it, barriers to using, current likes and dislikes regarding survey programmes and changes they would like to see made to it (APPENDIX C). Organisations in the increased scores group were asked to share their strategies for using patient experience data as a vehicle for shared learning. Staff from the increased score group also submitted organisational information about how they had used patient experience data in action planning and improvement.

4.3.3 Thematic analysis

Interviews were recorded and transcribed if the participants gave explicit permission in their consent form. Two interviewees consented to interview, but declined to be recorded. In these two cases, notes were taken by a team member and used in place of a full transcript.

Transcripts were then uploaded into the qualitative analysis software NVivo. A thematic analysis was conducted to demarcate different themes or topics within the transcripts. This study used thematic analysis to identify information relevant to the experience of using patient experience survey data to generate improvements (269)(270).

The codes were developed *a priori* for the most part, as they were taken from the background literature about possible barriers and facilitators to data use. Some codes were identified *a posteriori* as they occurred unexpectedly but were important to answering the research question. Specifically, the coding looked for mention of themes relevant to answering the research question and then sub-themes mentioned in relation to the primary themes. Sentiment was coded to capture how respondents felt about any particular theme, particularly whether staff referenced sub-themes negatively (as barrier to data use), positively (as a facilitator to data use) or as a desire for change in patient survey data (staff wish list).

4.3.4 R&D approval

R&D approval was obtained from all participating organisations and this study was sponsored by the Imperial College London Joint Research Compliance Office (JRCO) (Reference Number: 15SM2834).

Following participant recruitment, Picker Institute Europe facilitated initial contacts with each of the organisations as they held existing relationships with nearly all patient experience leads interviewed. Then the Centre for Health Policy (CHP) at Imperial College London conducted all other correspondence.

4.4 RESULTS

4.4.1 Case study participation

Out of the 9 organisations sampled, 8 agreed to participate; the only one to not take part was one of the consistent organisations.[2] The organisations nominated between 1 and 3 staff members to participate in interviews, and their most common job titles were Patient Experience Lead, Patient Experience Administrator or Director/Deputy Director of Nursing. In total 18 staff members were interviewed, seven from the increased score group, seven from the decreased scores group and four from the consistent score group.

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[2] One organisation demonstrated 4 improvements, but was not selected for interview due to the political controversy around the organisation and the likely impact that had on scores.

4.4.2 Interview findings

Four primary themes were identified with a range of sub-themes relating to each of them. The sub-themes were expressed with different sentiments, which fell into three distinct categories: negative (barriers to using data), positive (facilitators to using data) and desire for change (staff wish list). The themes, sub-themes and sentiment are mapped below.

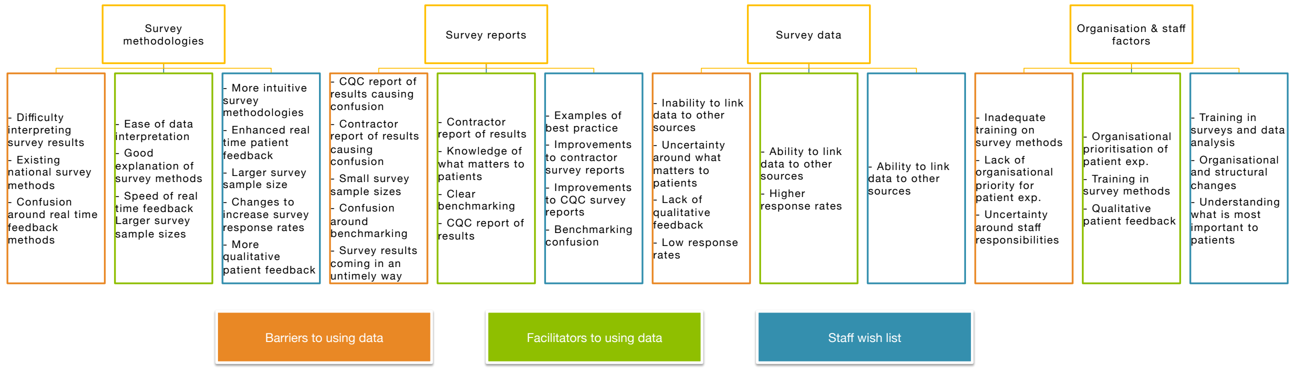


Figure 16. Map of themes, sub-themes and sentiment

While staff were specifically probed about their ability to use NPSP data, transcripts of the conversations naturally exposed the types of data staff found most useful. Transcripts also revealed the variation in sentiments towards themes and sub-themes. For example, staff would reference a particular theme (i.e. survey data) and sub-theme (i.e. the inability to link data) as a barrier, and then that same sub-theme (i.e. the ability to link data) as a facilitator. The sentiment behind each theme was coded to categorise sub-themes.

The four primary themes identified in interview transcripts related to survey methodologies, survey reports, survey data and organisation and staff factors that impact the ability to use patient experience data.

Survey methodologies

While discussing how they used patient experience survey data, one of the most common topics staff mentioned was the survey methodology used in NPSP surveys. It was clear from staff that difficulty interpreting results, and lack of clarity around the reasons for certain methods, created barriers to using the data. Staff were concerned that the methods not only led to confusing results, but were also inappropriate given the size of their organisations, as illustrated by two quotations below. Staff mentioned that in order to facilitate data use, methods should be more intuitive to staff who do not have survey training and should also include scope for larger sample size. Some staff also expressed a desire for more real time and qualitative methods to accompany NPSP results.

> *“The other problem with the national survey is the way that they actually design it; the CQC part of it makes it really difficult.”*

> *“So in a Trust that sees 1.6 million patients a year, although the majority are out-patients, 850 is a tiny sample. I know it’s increased this year but it’s still quite small”*

> *“[the free text is] so much better because what it does is it elicits the things which matter to people not what we think matter to them.”*

Survey reports

The second primary theme related to survey reports and how data is presented back to staff. In terms of data from the NPSP surveys, reports from the CQC and survey contractors are the principle source of patient survey data provided to NHS organisations. Staff felt that often these reports caused confusion. Despite many staff referencing these reports as barriers, other staff members gave examples of where contractor reports facilitated the use of feedback. This related mostly to contractors' ability to provide a report with more personalised information for each organisation than available in CQC reports. They also cited contractors' reports being accompanied by workshops to explain the results. In terms of how staff discussed this theme in relation to their wish list of changes, the main desire expressed was for enhanced opportunity to share success stories, rather than simply receiving benchmarking tables.

> *"So we got amber on every single question. Every single question we got the same as everybody else which just happens to be the same score that Morecombe Bay got who are in special measures…"*

> *"So both having those stories and the information but also make the workshops not just around the outcome and the talks but actually the best practice workshops, maybe on a regular basis, so someone from Newcastle getting up and presenting to all the other Trusts who want to be there about discharge, next it will be Birmingham about food or whatever it might be but Picker being almost a co-ordinating body for that because that's the vehicle with which it's been done. Something like that would be good. "*

Survey Data

The third primary theme identified related to the actual survey data that staff received from NPSP surveys. The majority of conversation around this related to the ability to link data to other quality indicators. Staff found NPSP data difficult to work with because it could not be compared at a granular level to other data sources and left them with an inexact picture of how patient experience data fits in with other organisational data. Another prominent sub-theme revolved around the inability to glean what NPSP data points matter most to patients. Staff expressed an interest in more explanation around the data, support to analyse it and better indication of what was most important from a patient perspective.

> "*This could be related to any survey, but the idea of linking results at the patient level would help the patient know they were listened to see feedback on incident reporting to support the need for response to feedback"*

> *"What I would want is that to be linked in with complaints, so I'd love to have some kind of dashboardy thing that pulls all that stuff together."*

> *"In terms of understanding the data, I think when they come and do workshops with us or present the data we need- that's very helpful but I need- we need them, in there, telling the story of how they collected the data and how it's reliable."*

> *"For example the question about the call button may mean different things to different patients, and they need to know what to improve."*

Organisation and staff factors

The final theme identified related to the factors outside of survey programmes that impacted how staff could use NPSP data. The sub-themes related to aspects of organisational structure, the extent of training staff had in using survey data and the priority given to patient experience within organisations. Some staff members mentioned that there was sometimes lack of clarity around whose responsibility it was to use patient experience data, and more frequently, the people in charge of using data did not feel sufficiently trained to do so. Very few staff members were concerned about the priority given to patient experience in their organisation; however, some did cite it as a key factor in being able to pursue improvements. This led to many staff members desiring more information about what other organisations had done to achieve success in patient experience.

> *"And I think sharing that nationally, because I want to know what other people are doing, because even if it's things that we're doing well but we could do better, I don't want to re-invent the wheel"*

> *"what I'd be interested in, is sharing best practice and stories from others."*

In terms of the sentiment related categories that the sub-themes fell into, Figure 17**,** Figure 18 and Figure 19 respectively demonstrate the number of times each theme was mentioned as either a barrier or a facilitator to using patient experience data, or when it was mentioned in relation to staff's wish list for improvements.

In addition to the themes, numerical analysis was used to present a sense of patterns in the data; however, it is important to note that these cannot be extrapolated as evidence of frequency in the qualitative data.

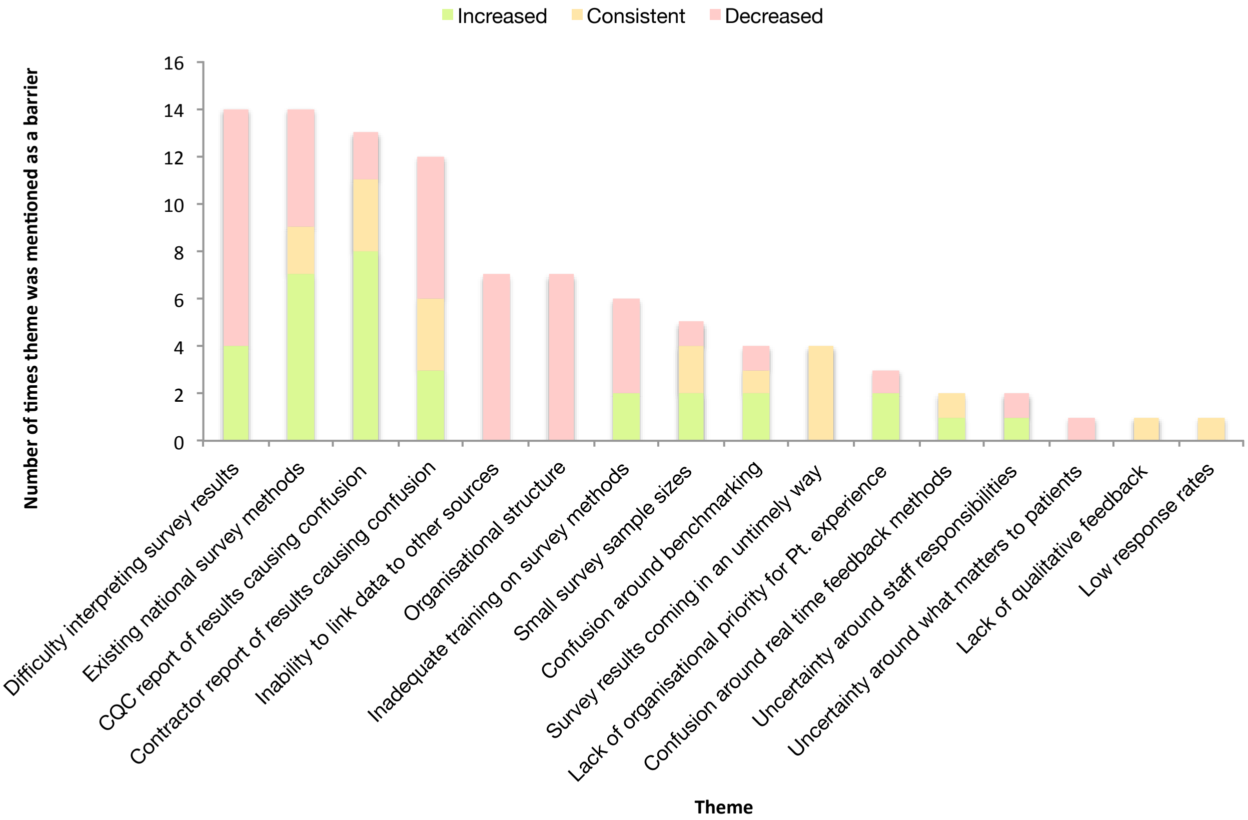


Figure 17. Themes mentioned in relation to barriers

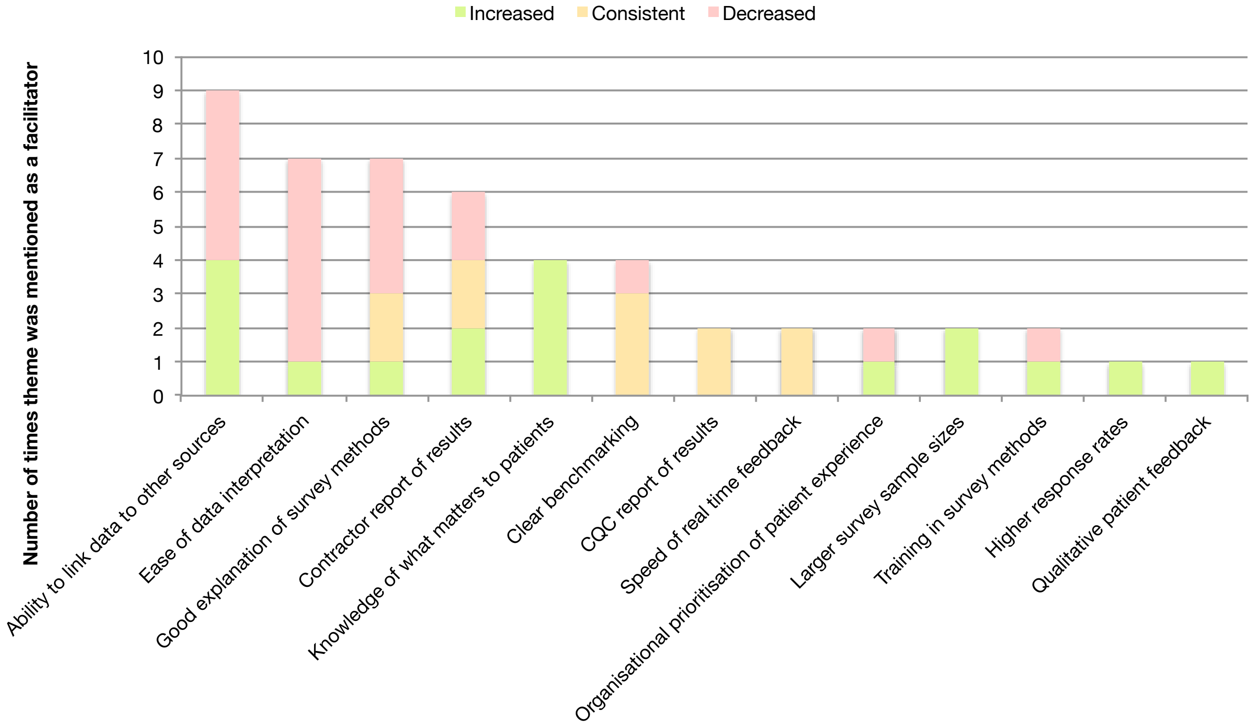


Figure 18. Themes mentioned in relation to facilitators

Figure 19 depicts what staff specifically said they would put on their wish list of changes in order to improve how patient experience data is collected, analysed and presented. Staff prioritised survey methodologies that provide more locally relevant insights (Figure 19).

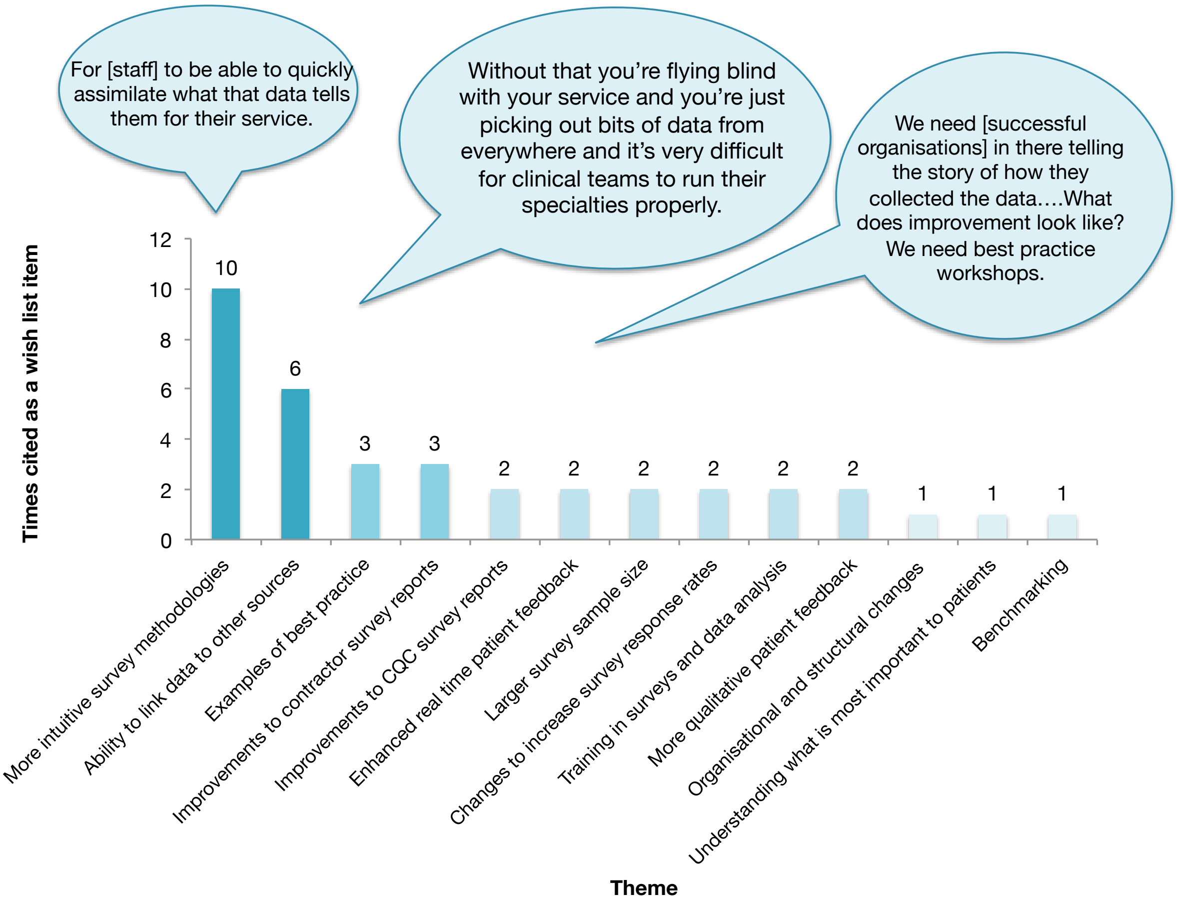


Figure 19. Staff wish list

4.4.3 Ideas for improvement strategy using NPSP data

Finally, Table 20 lists the examples of how organisations in the increased scores category overcame identified barriers, and developed strategies to use patient experience data in an effort to improve their service and their survey scores. The left hand column reveals the general technique used and the right hand provides a full description of that process.

Table 20. Examples of improvements

The worry is that sometimes the tried and tested stuff gets you the results. What we're after isn't necessarily the results; we're after that kind of world-class patient experience, which means that you've got to do staff that's different. ~ Deputy Director of Patient Experience at RAL

Improvement Technique	Improvement strategy
Data triangulation	We will look at [the data] and if there's any concerns to start with... then my job will be to really cross-reference it with any of the other data that we have in the organisation. So if ...some statistically significant change has happened, then I'll be looking and saying, "Right, do we have any complaints or compliments around this area? Do we have any friends and family test data about it? Is this actually an anomaly or…is it something that we're seeing across the board?" I drill all [the data] down to make sense of it for the teams.
Emotional intelligence training	If you can improve emotional intelligence across an organisation you'll get all those other things rights. [For example] doctors talking as if I'm not there, that's emotional intelligence. That's emotional intelligence because that's about looking after each other and making sure we're all talking from the plan and that we communicate with each other, so it's all about communication skills. Now I am constantly delivering this training across the trust.
Identifying communication breakdowns	I map complaints to the emotions of the complaint... the staff experience and how they were feeling emotionally.... I map the points in the patient journey of the complaint and it's usually about communication. 50% of complaints in the [organisation] are about communication. That's all that soft skills stuff and unfortunately in general acute trusts they have less of the soft skills stuff because it tends to be quite task orientated.
Bespoke methodologies across services	I do bring a bit of a difference to the way they've done patient experience work here in the past... so now I get a lot of people approaching me. Basically anybody that wants to do patient experience surveys within their department will come to me first and we'll talk about what their needs are and what the best way of capturing that data is because it's not always about a survey. I've got probably about 45 to 50 departments working with me.
Feedback follow up	A&E really use the friends and family test. [They] got consent from patients to contact them if there was negative feedback and discussed their experiences with them and made service improvements as a result...That had an impact on the CQC national survey and you saw that we were the best in the country [on certain questions] in our A&E departments, so we were delighted with that.

Provision of better information	We made "Welcome Packs" which had lots of information including details about how to complain, ward routines, when the ward rounds were and how the staff will help them manage their pain, ear plugs, eye masks, socks to prevent falls, paper and pens. [Pens were] given because often patients would think of a question to ask doctors but then not remember it by the time the ward round happened ... We saw immediate climb in results around [related] questions.
Values based improvement	So we've got our values and what we try and do now is base the improvements around the values in the strong belief that if they are the right values you will see a shift in our experience scores. So rather than chasing the score, we chase everything to do with the patients and the values and underpin the values. So if we're visibly reassuring, which is one of our values, then all of those questions around confidence and trust should go up. So rather than trying to chase, "Did you trust your doctor? "Did you have an action plan?" we're saying, "Are we visibly reassuring and why are we visibly reassuring?" as kind of an example of one of the values and that's the approach that we've now shifted much more towards because we think, as I say, we contract the values and we can start delivering against those values, we should see some shift.
Competition for innovations	One of the things we're developing at the moment is a competition for staff and teams so the idea is that wards and teams, doesn't have to be clinical, come up with a patient experience improvement idea at very high-level. We've then got some… respected businessmen locally that have said that they'd like to be involved with helping so they'll go along and talk to the ward and help develop that into much more of a plan. We'll then have a presentation…where the top two or three come and do a presentation…and then the one that comes out top, we'll give up to £10,000 to pay for that improvement idea and automatically it's going into next year's quality account.
Packs for better ward comfort	So we've come up with, and we're just about to pilot it, something from America. It's a quiet pack and its a little pack that we give to patients- it's a bit like you get on an aeroplane. It's got an eye mask in it; it's got a lip balm in it; it's got Sudoku in it; it's got a crossword in it; it's got a pencil in it and some paper. On the basis [that] at home if you can't sleep and you pick up a book and read it, you soon fall asleep. Actually, if you try and do something you soon fall asleep. If you are worried about something, we always say to people, if you are worried write it down but actually we don't give people in hospital pens and paper to write it down; so at home we'd say that if you can't sleep write it down and park it until morning.

Including experience in inductions	To try and get staff engaged in actually how do you drive forward experience it's really quite difficult. Here, you know, people have come here as a member of staff expecting to work at a world-class place, so you've got much more ability to say to staff, … "We expect you to deliver a word-class…" and what we do here, when staff join, is quite a lot of work around what the values mean but also what they're joining. So it's the only place I've joined that as part of the induction you've had to sit through an hour of the history of the trust.
Giving staff the positive feedback from patients	Not only have we linked [qualitative feedback] to the Wow awards so staff get recognition when they're delivering a good job but we've linked it to the NICE quality standards, to the CQC so we code it all. We also have managed to do text to phone, so we have patient voices coming in. They give consent for us to share [their feedback], so we can email them round the trust. We can use it so when people walk into induction they hear the patient voices, you know, responding to the friends and family test so you can then link it.
Identifying priority questions	What we've done is we've recently rewritten our performance report around patient experience and we've dropped an awful lot of metrics and there's about ten questions I think- there's about ten killer questions that if we nail all of those ten that will make sure that all of our values have been worked upon, and if those ten questions are good, our values must be good and therefore everything else must fall into place. So rather than chasing everything, we decide if we get those right, our values must be right and if our values are right then we must improve otherwise our values are wrong.

4.5 DISCUSSION

4.5.1 Main findings

Primary themes and sub-themes

Four primary themes were identified from staff interviews: survey methodologies, survey reports, survey data and organisation and staff factors. Sub-themes relating to each of these primary themes fell into three sentiment-related categories: barriers to using patient experience survey data, facilitators to using patient experience survey data and staff wish list items for improvement. This categorisation helped highlight the challenges faced in relation to the four primary themes as well as staff driven ideas for improvements. The second component of the interviews, the examples of improvements, illustrates the techniques used to improve patient experience through a range of approaches, not limited to using patient experience survey data.

Barriers and facilitators to the use of patient experience data

The most frequently cited barriers to using patient experience data had to do with interpreting survey results, understanding survey methodology, presentation of data in both national CQC and contractor reports, inability to link data to other sources and organisational structure. Staff feedback varied slightly when disaggregated by organisational group. Organisations whose scores had decreased cited training, organisational structure and interpreting results as barriers more often than organisations in the increased and consistent scores groups. Those whose scores had increased focused more on difficulty understanding survey methods and confusion around CQC reports, but cited knowledge of what is most important to patients as a key facilitator.

The most frequently cited facilitators were ability to link data (9 mentions), ease of survey interpretation and clarity around methodologies. In terms of a wish list for improved practice, staff desired more intuitive survey methodologies, ability to link patient experience data to other sources and more examples of best practice in patient experience improvement. More real time feedback, qualitative data and training in survey methods were also cited as wish list items (2 mentions each).

Showcase of organisations who improved their experience scores

The improvements showcased brought forward ideas for shared learning such as mapping organisational values to questions; triangulating data from multiple sources to identify trends even when data is not directly linkable; sharing feedback with staff and using "improvement maps" to gauge what questions are most important to patients (currently only provided by hired survey contractors). The underlying theme was that chasing individual questions was not as fruitful as rectifying the root causes behind negative scores. Another main theme exposed across the showcases was the importance of clinical and organisational leaders and their role in adhering to and promoting meaningful, aspirational values that support patient experience. A further related sub-theme was the desire to understand what matters most to patients, an endeavour that would require a deeper qualitative investigation into patient priorities for experience.

There was also a focus on integrating survey findings into conversations around operational development to stimulate better patient experience. Organisations found certain survey questions symptomatic of larger organisational health issues and recognised that improvement was going to take a more concerted effort than singular focus on one particular question. These examples support the idea that provision of clear information, and supplies to make ward life more enjoyable, can improve experience without the need for drastic changes to care delivery. Finally, there was support for involving staff in the process of learning from feedback, both in relaying positive feedback to staff and working with them to design collections specific to their patients.

4.5.2 Findings in relation to existing literature

While many participants cited paid-for survey contractors as providing useful analytic tools, staff did not feel that lack of funding was a chronic barrier to using patient experience data. Furthermore, even when specifically probed, staff virtually never cited finances or lack of senior-level engagement as a major barrier. These findings suggest progress in the field of patient experience, as only a decade ago, patient experience was under-prioritised by staff and within budgets (6).

The results do, however, indicate that the discussion of how to optimise survey methodology for data utility is still on-going. Staff suggested that organisational leaders tend to focus on single metrics, like the question on AIPS asking about overall experience, because they cannot understand the methods behind or the implications of other questions. Existing literature would suggest this focus is too narrow and those questions are not always reflective of the entire experience (44).

More generally, staff's stated inability to understand NPSP methodology mirrors existing findings and suggests less progress in this area (111)(171). Staff in this study called for better explanations around why the existing NPSP methods are necessary and how they could correspond to other methods used in bespoke, local feedback collections. This lack of methodological insight aligns to a problem identified by the King's Fund: often organisations do not have the statistical capacity necessary to interpret patient experience survey methods and data in the most meaningful ways (60)(194). Furthermore, staff that were well versed in survey methods indicated their desire for larger sample sizes across national surveys. While this is already being piloted in the NPSP, staff's primary motive for requesting this was to ensure that there were enough responses for data to be disaggregated by specialty (11). This concern, as discussed extensively in the previous two chapters, is in line with existing literature about data specificity (6)(5)(14).

Literature regarding organisational culture suggests that the differences observed between the increased and decreased scores groups could relate to other aspects of organisational health (8)(187)(188). For instance, organisations with decreases in scores who cited structural issues as barriers might have obstructions to the use of patient feedback that are internal, cultural or otherwise extraneous to the national system (196). Examples from the ideas staff shared around their strategies for using NPSP data to inform improvement support existing evidence and demonstrate that instilling positive staff values is central to creating the landscape and culture necessary for patient-centric improvement (183)(196).

The most resounding request, which received consensus and repetition across themes, was that of sharing best practice as a means to help organisations emulate successful use of data. Even at organisations where scores had increased, staff were very interested in learning from others. This was a compelling plea for collaboration, rather than competition, to improve experience for patients. This sentiment is relatively absent from existing research, but it aligns to literature emphasizing the importance of collaboration in creating a culture receptive to patient feedback (196).

Finally, in terms of enhanced prospects for quality improvement, staff valued the ability to link data, gather real time patient stories and draw a triangulated picture of quality within the organisation. Staff maintained a strong emphasis on the need for data to be presented in a more comprehensible way that provides benchmarking information and explains variation in experience scores across local organisations. These priorities correspond to findings from the field of PROMs which advocate researching more intuitive, linkable patient-reported metrics (163).

4.5.3 Limitations

This study only used 8 case studies, and although these were relatively diverse, it would have been beneficial to gather feedback from a broader representation. Also, it is unknown whether the organisations that improved did so strictly because they used survey data in a more effective way. The sampling strategy could also be expanded to identify more staff who come into contact with patient experience feedback. Furthermore, two interviewees declined to be recorded, meaning that their files were based on notes, which were less rich than those based on recorded speech. Relating to the topic guide, this would have benefitted from inclusion of a deliberately open question about what type of data staff found useful, however this did come through throughout conversations about NPSP data. This work would also benefit from a follow up survey to eliminate any bias created by the interviewer. Finally, staff stated that they found contractor-provided “improvement maps” valuable. In theory these maps indicate which questions are most important to patients; however, they are developed using conceptually questionable methods that do not meet the criteria necessary to inform what matters most to patients described in **Chapter 2** (10). Findings like these indicate the importance staff place on knowing what matters most to patients and should indicate a priority to the contractors who produce such maps to ensure they are methodologically sound.

4.5.4 Implications for health policy

As existing evidence suggests, engaging staff in the development of collection tools is essential to staff valuing resulting data, making sense of it and ultimately using it (163). In order for patient experience data to be an effective improvement tool, and avoid the ethical grey zone around soliciting patient input and not acting on it, feedback programmes need to make efforts to facilitate data comprehension and use. Through this research, staff have provided suggestions for how national patient experience survey data could be collected, analysed and presented to better enable it to support local quality improvement. The wish list that staff have articulated here could guide future feedback collection – along with updated evidence about patient preferences– to ensure surveys move beyond data collection and towards patient-centric improvement.

Through this study staff articulated a need for system adaptations that focus more on meeting local quality improvement needs rather than fulfilling national requirements. Specifically staff indicated a need to move towards more locally relevant metrics that explain variation and away from questions that mainly serve as national benchmarking tools. Some staff suggestions could be seen as simple adjustments to existing surveys, such as larger sample sizes, reports more appropriately pitched to the audience and revisions in survey methodologies such that they make sense to service providers (271). However, some suggestions may require national programmes to solicit and relay different kinds of feedback entirely. Findings around sharing best practice, learning from patient priorities and instilling positive cultures indicate a shift towards thinking about patient experience in a more holistic way than simply revising surveys. Staff's stated idea of linking experience data to other information represents their inclination to move towards more holistic quality improvement rather than continue to analyse and respond to a wide range of disparate, un-interoperable data. Enabling wish list items like this, as well as ideas for enhanced culture, would require a paradigm shift in patient experience feedback collection. Finally, staff suggestions also point to a need for enhanced support for cultural development to facilitate more holistic improvement planning. These suggestions from staff might be difficult for the national system to action, but given their relevance to staff, they could also be pivotal to instigating movement from data collection to data use.

Currently the paradigm around patient experience feedback is heavily rooted in large national initiatives, the NPSP and the FFT, both accompanied by a sluggish bureaucracy and political concerns (4)(140)(141). These are not capturing, or producing, what is most useful to the organisations trying to use patient experience data to improve care. This is, on the one hand, a result of compromises in the way data is collected. Listening to what staff said in this interview study could ignite a change in thinking and compel the stakeholders within the system to collect clear, linkable, digitally mature, timely information. It also reiterates findings from research about experience-based co-design which emphasizes the importance of collecting this type of feedback at a time when it can be acted upon, such as in advance of major reconfigurations like those anticipated in the NHS Strategic Transformation Plans (272). On the other hand, staff in this study focused much more on these problems as a facet of the reporting mechanisms used in national survey programmes. This indicates a need to research useful presentation strategies that clearly provide insights for improvement.

Staff ideas for enhancing data utility do not suggest abolishing national survey initiatives or the system around them. Currently these still hold the most academically robust source of patient experience data, and are likely to play a role for a long time (4). Rather, staff suggestions for improvement call for a reconciliation between high-level, national priorities and local needs. They demand modernising feedback, revamping it to be less statistically cumbersome, more timely and more versatile in terms of linkage and disaggregation. If the system is open to new approaches, these changes will help transform unused data into business intelligence insights for improving patient care.

4.6 CONCLUSIONS

Experience has joined effectiveness and safety to form the quality pyramid that has been accepted by policy makers, providers and patients (1). Patient experience survey programmes are now a staple of developed healthcare systems, however, they have not yet achieved their full potential as a conduit for patient needs and preferences into quality improvement strategy (4). The reasons for this have been extensively postulated (8)(6). This research suggests many of the barriers to using patient experience data relate to tensions between national agendas and local needs. It illuminates what staff want - and need - from the national system in order to put the data to use.

The focus on enhanced data presentation came through very strongly as did the desire for patient experience feedback to be explained in a way that is meaningful not only to analysts, but also to frontline staff. It is also clear that more needs to be done to enable data linkage so that staff can explore problems within specialities and across datasets. Building interoperable systems will become even more critical as the NHS moves towards an integrated model where multiple provider types are responsible for holding patients' records and monitoring their wellbeing across a pathway (147).

The tensions between national and local needs are real and are driving problems for data use at a local level. While **Chapter 3** revealed the importance of providing organisations a disaggregated view of their patients' concerns, the findings in this chapter have demonstrated the that a more comprehensive programme of change is needed to enhance data utility so it can be applied to quality improvement. The next chapter will explore how current patient experience data can be put to better use immediately to provide a more intuitive profile of patient experience nationally, while offering the local insights needed to understand priority areas for improvement.

CHAPTER 5

DEVELOPING A COMPOSITE SCORE FOR PATIENT EXPERIENCE: USING PATIENT EXPERIENCE DATA TO RE-INTERPRET QUALITY

5.1 INTRODUCTION

The gap between patient experience data collection and data use represents a missed opportunity (7)(8)(5)(4). Eyewitness accounts of care are going under-utilised in service improvement, and despite organisational advancements in programmes like “Greatix,” a programme designed to recognise great care, feedback about what patients consider good practice is not being relayed even to those who deserve credit for it (6). Characterising this simply as a missed opportunity, however, does not capture the entirety of the problem, nor does it get to the heart of a solution. In fact, staff in the previous chapter corroborated evidence that data under use is not just an oversight or an operational capacity issue, but also the result of system-level decisions about how national data is reported and presented (14)(37)(117)(196).

In the previous chapter, NHS staff responsible for using patient experience data articulated a desire for more intuitive survey methods and clearly reported metrics from national feedback collections. They revealed that, although they rely on multiple sources of patient feedback to determine the direction of improvement work, there is an overwhelming tendency amongst national and local leaders to focus solely on the AIPS “overall experience” score and use it for benchmarking. This trend is not only apparent in the interview feedback in the previous chapter, but also in the way politicians, commissioners and senior leaders in the NHS focus on targets, which typically take the form of single metrics, when evaluating service delivery (273). In relation to patient experience, the priority given to such targets like the “overall experience score” is arguably misguided based on evidence in other chapters (84). In order to work within the confines of a culture focused on targets, it is important to ensure that the single metrics that are rightly or wrongly prioritised are as meaningful as possible (273).

Although the “overall experience score” is a simple, seemingly intuitive metric, data from this question paints a relatively unchanging picture of organisation level patient experience from which there is little potential for learning and no indication of where to improve (12). Furthermore, it does not holistically capture patients’ experiences of care (159). This distorts understanding of quality, as overall metrics do not capture the specific problems patients have identified with their care (43)(84). Pressure to improve a single question, especially the NPSP overall metric, is unhelpful to meaningful local improvement (206).

While there is a broader argument to move away from single metrics entirely, in recognition of the fact that providers tend to focus on available single metrics, and that commissioners, regulators and senior leaders in the NHS can give priority to single metrics, it is important to ensure that these metrics are as accurate and meaningful as possible (273). Evidence demonstrates that an intuitive, conceptually simple single metric can be developed as a robust composite score, which has the potential to be more reflective of patients’ actual accounts of care than the AIPS overall score (44)(202). AIPS section scores can be used to generate this type of composite score. Section scores as, described in **Chapter 1**, can be averaged to produce a single metric that would be useful to the national system for benchmarking and also capable of unlocking the reasons for local variation if presented in line with the section scores that comprise it.

This study uses AIPS data to test whether a composite score based on multiple experience measures could offer a more meaningful single metric that is built on the actual priorities expressed by patients. It makes a case for change, advocating for the move away from the “overall experience” metric and towards a composite score and the individual data points within the composite to refocus senior leaders’ attention to a score that is built on multiple feedback points, inspire more learning and support more accurate interpretations of quality.

5.2 AIMS & OBJECTIVES

The aim of this chapter is to explore opportunities for existing NHS patient experience data to inform a new single metric that is easily interpretable for local staff and NHS leaders, linked to patient-identified improvement priorities and capable of supporting quality improvement.

Two objectives will underpin work towards this aim:

i. To compare the existing overall AIPS score to a new composite score built from AIPS section scores
ii. To determine whether the new composite score can indicate areas for learning locally and alter perceptions of quality nationally.

5.3 METHODS

5.3.1 Data source

This analysis used the 2015 return of AIPS data, the most recent AIPS data available at the time of analysis. The 2015 AIPS survey followed the same sampling and reporting procedures as described in **Chapter 1**. The AIPS survey was sent to a sample of 1,250 patients at each organisation (aside from a few very small specialist organisations that could not reach this number). 83,116 people responded, yielding a 47% response rate (274). Patients were eligible to be included in the sample if they spent one night in hospital during July 2015. Fieldwork took place between September 2015 and January 2016.

The 2015 AIPS return of data included results from 149 acute organisations in England. It is important to note that the 2015 AIPS return used in this chapter is organisation level data. All scores therefore apply to a whole acute NHS organisation, which vary in size. Partial credit scoring was used prior to receipt of the data and organisations' scores for each question range from 0 to 10 with ten being the most positive. (**Chapter 3** used a 2013 AIPS return at the patient level for the exploratory segmentation; 2013 patient level data was scored differently than 2015 organisation level data and the two should not be analysed in comparison).

This iteration of the AIPS survey contained 74 questions, most of which were scored (some were not scored as they were purely administrative) (Table 21). The scored questions formed each of the 10 sections (Table 21). Each question was scored out of 10, and each section score was derived from the average of all the questions within that section.

Table 21. Scored questions within each AIPS section

1. THE ACCIDENT & EMERGENCY DEPARTMENT
- While you were in the A&E Department, how much information about your condition or treatment was given to you?
- Were you given enough privacy when being examined or treated in the A&E Department?

2. WAITING LIST OR PLANNED ADMISSION
- How do you feel about the length of time you were on the waiting list before your admission to hospital?
- Was your admission date changed by the hospital?
- In your opinion, had the specialist you saw in hospital been given all of the necessary information about your condition or illness from the person who referred you?

3. ALL TYPES OF ADMISSION
- From the time you arrived at the hospital, did you feel that you had to wait a long time to get to a bed on a ward

4. THE HOSPITAL & WARD
- When you were first admitted to a bed on a ward, did you share a sleeping area, for example a room or bay, with patients of the opposite sex?
- After you moved to another ward (or wards), did you ever share a sleeping area, for example a room or bay, with patients of the opposite sex?
- While staying in hospital, did you ever use the same bathroom or shower area as patients of the opposite sex?
- Were you ever bothered by noise at night from other patients?
- Were you ever bothered by noise at night from hospital staff?
- In your opinion, how clean was the hospital room or ward that you were in?
- How clean were the toilets and bathrooms that you used in hospital?
- Did you feel threatened during your stay in hospital by other patients or visitors?
- Were hand-wash gels available for patients and visitors to use?
- How would you rate the hospital food?
- Were you offered a choice of food?
- Did you get enough help from staff to eat your meals?

5. DOCTORS
- When you had important questions to ask a doctor, did you get answers that you could understand?
- Did you have confidence and trust in the doctors treating you?
- Did doctors talk in front of you as if you weren’t there?

6. NURSES
- When you had important questions to ask a nurse, did you get answers that you could understand?
- Did you have confidence and trust in the nurses treating you?
- Did nurses talk in front of you as if you weren’t there?
- In your opinion, were there enough nurses on duty to care for you in hospital?

7. YOUR CARE & TREATMENT
- In your opinion, did the members of staff caring for you work well together?
- Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you?
- Were you involved as much as you wanted to be in decisions about your care and treatment?
- Did you have confidence in the decisions made about your condition or treatment?
- How much information about your condition or treatment was given to you?
- Did you find someone on the hospital staff to talk to about your worries and fears?
- Do you feel you got enough emotional support from hospital staff during your stay?
- Were you given enough privacy when discussing your condition or treatment?
- Were you given enough privacy when being examined or treated?

- Do you think the hospital staff did everything they could to help control your pain?
- How many minutes after you used the call button did it usually take before you got the help you needed?

8. OPERATIONS & PROCEDURES

- Beforehand, did a member of staff explain the risks and benefits of the operation or procedure in a way you could understand?
- Beforehand, did a member of staff explain what would be done during the operation or procedure?
- Beforehand, did a member of staff answer your questions about the operation or procedure in a way you could understand?
- Beforehand, were you told how you could expect to feel after you had the operation or procedure?
- Before the operation or procedure, did the anaesthetist or another member of staff explain how he or she would put you to sleep or control your pain in a way you could understand?
- After the operation or procedure, did a member of staff explain how the operation or procedure had gone in a way you could understand?

9. LEAVING HOSPITAL

- Did you feel you were involved in decisions about your discharge from hospital?
- Were you given enough notice about when you were going to be discharged?
- On the day you left hospital, was your discharge delayed for any reason?
- What was the MAIN reason for the delay?
- How long was the delay?
- After leaving hospital, did you get enough support from health or social care professionals to help you recover and manage your condition?
- When you transferred to another hospital or went to a nursing or residential home, was there a plan in place for continuing your care?
- Before you left hospital, were you given any written or printed information about what you should or should not do after leaving hospital?
- Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?
- Did a member of staff tell you about medication side effects to watch for when you went home?
- Were you told how to take your medication in a way you could understand?
- Were you given clear written or printed information about your medicines?
- Did a member of staff tell you about any danger signals you should watch for after you went home?
- Did hospital staff take your family or home situation into account when planning your discharge?
- Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you?
- Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?
- Did hospital staff discuss with you whether you would need any additional equipment in your home, or any adaptations made to your home, after leaving hospital?
- Did hospital staff discuss with you whether you may need any further health or social care services after leaving hospital? (e.g. services from a GP, physiotherapist or community nurse, or assistance from social services or the voluntary sector)

10. OVERALL

- Overall, did you feel you were treated with respect and dignity while you were in the hospital?
- During your time in hospital did you feel well looked after by hospital staff?
- Overall... (Please circle a number 1- 10)
- During your hospital stay, were you ever asked to give your views on the quality of your care?
- Did you see, or were you given, any information explaining how to complain to the hospital about the care you received?

5.3.2 Creating the new composite score

First, correlations between organisations' scores on the existing AIPS overall question, which reads: *Overall... (Please circle a number 1- 10)*, and their ten AIPS section scores were measured. This established a baseline for how well the AIPS overall score (which also serves as the existing benchmarking metric) related to organisations' section scores (which can specify areas for improvement). A 95% confidence level was set to understand the significance of correlations and all subsequent inference testing in the analysis.

Second, section scores were averaged to create a composite score for each organisation (Equation 2). The denominator of this calculation was usually 10, however some organisations did not have a score for every section. For instance, Section 1 - The Accident & Emergency Department, was not included for organisations that did not have emergency departments. Furthermore, Section 10, which includes the AIPS overall question, is typically broken down for analysis and reported as two separate sections: an average for all of the other questions and a single score for the overall question. This analysis uses the later to avoid including the overall sore.

Equation 2. Composite score calculation

$$\frac{(\text{Section}_1 + \text{Section}_2 ... + \text{Section}_{10})}{\text{Number of sections for which there is a score}} = \text{Composite score for organisation}$$

Organisations' resulting score was termed their "composite score." Correlations between organisations' composite score and section scores were then measured to determine if the composite score held a stronger relationship to the priority areas for improvement than the AIPS overall score. Organisations' composite score was then compared to their existing AIPS overall score. A paired sample t-test was used to determine if there was a statistically significant difference between organisations' AIPS overall scores and their composite scores.

The composite score was then presented in relation to the section scores within it to demonstrate how it could support local improvement. Finally, organisations were benchmarked using first the AIPS overall score (currently used for benchmarking) and then the new composite score to test the extent to which the composite score changed the order of existing league tables.

5.4 RESULTS

5.4.1 Correlation between single metrics and section scores

AIPS overall scores correlated with section scores at the national level (Table 22). While some of the correlations were strong, there was considerable variation on the relationship between section scores and the AIPS overall question. All correlations were significant at a 95% confidence level ($p<0.05$).

However, the new composite score held stronger positive correlations with all section scores ($p<0.05$) (Table 22).

Table 22. Correlation of organisations’ existing overall AIPS score to section scores

AIPS section	Section score	Correlation co-efficient for AIPS overall score	Sig	Correlation co-efficient for composite score	Sig
Section 1: Accident & Emergency	8.58	0.62	**0.00***	0.68	**0.00***
Section 2: Waiting list or planed admission	8.84	0.62	**0.00***	0.74	**0.00***
Section 3: All types of admission	7.86	0.82	**0.00***	0.88	**0.00***
Section 4: The hospital & ward	8.27	0.81	**0.00***	0.84	**0.00***
Section 5: Doctors	8.62	0.91	**0.00***	0.93	**0.00***
Section 6: Nurses	8.44	0.92	**0.00***	0.93	**0.00***
Section 7: Your care and treatment	7.89	0.95	**0.00***	0.96	**0.00***
Section 8: Operations & Procedures	8.48	0.69	**0.00***	0.75	**0.00***
Section 9: Leaving hospital	7.15	0.89	**0.00***	0.93	**0.00***
Section 10: Overall	5.65	0.79	**0.00***	0.82	**0.00***

* Significant at a 95% confidence level

5.4.2 Characteristics of composite score

The new composite score ranged from 7.39 - 8.82 (range=1.43), which was smaller than the AIPS overall range from 7.48 to 9.04 (range=1.56). The scores were relatively normally distributed, and all organisations with outliers for either of these two scores were specialist organisations (Figure 20).

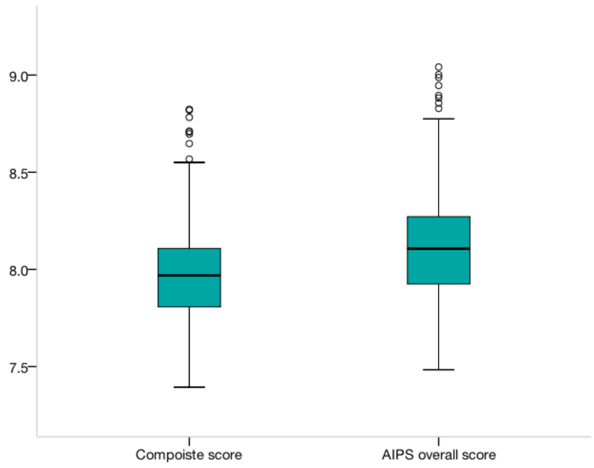


Figure 20. Stem and leaf plots for AIPS overall score and the composite score

The new composite score (M=7.99, SD= 0.27) was on average lower than the AIPS overall score (M=8.13, SD= 0.30) (Figure 21).

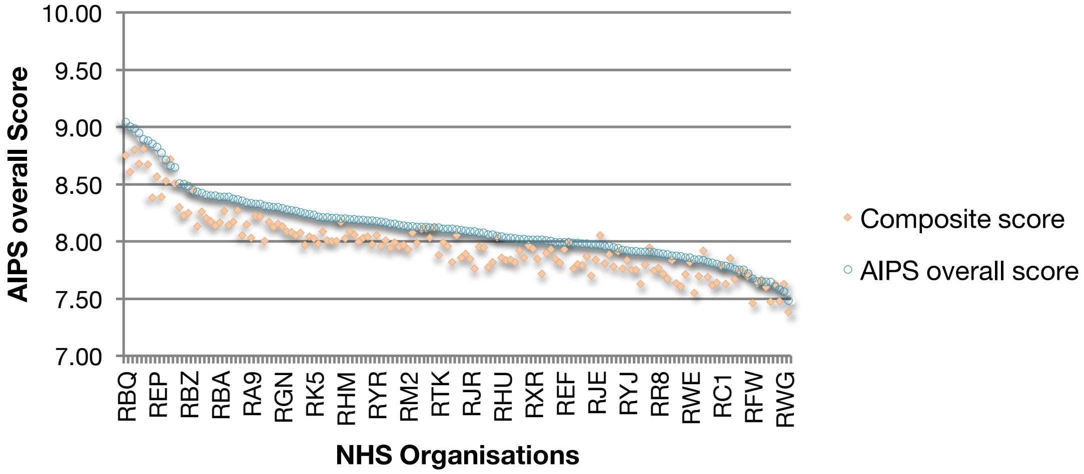


Figure 21. Difference between AIPS overall scores and composite scores

Despite relatively small differences and a strong, positive correlation, (*r* = 0.96, *p*<0.05), the difference between scores were large in the context of the NPSP results. A paired sample t-test indicated statistically significant differences between the two scores (Table 23). There was a significant average difference (t_{148}=19.13, *p*<0.05) between the two scores such that composite scores were on average 0.14 points lower than AIPS overall scores (95% CI [0.13, 0.15]).

Table 23. Paired sample t-test of difference between the AIPS overall score and the composite score

	Mean	Standard deviation	t	95% CI	Correlation	Sig.
AIPS overall score – Composite score	0.14	0.09	19.13	0.13-0.15	0.96	**0.00***

* Significant at a 95% confidence level

The maximum absolute value of any difference between the two scores was 0.47, and the average difference was 0.14. Although the average difference as a percentage of total possible score is only 1.40%, the difference as a percentage of existing AIPS overall score range is 8.97%. The difference between composite and AIPS overall scores was most pronounced in organisations that scored highly on the AIPS overall score (Figure 22).

Figure 22. Variation in the difference between the two single metric scores

5.4.3 Impact of the composite score

<u>Potential for facilitating learning</u>

Most organisations scored very highly on the AIPS overall question (Figure 23). Scores only ranged from 7.48 to 9.04. Meaning, if an organisation was in the lower quartile, it still achieved scores above 7/10 and there is no indication of what needs improving in order to achieve a higher score.

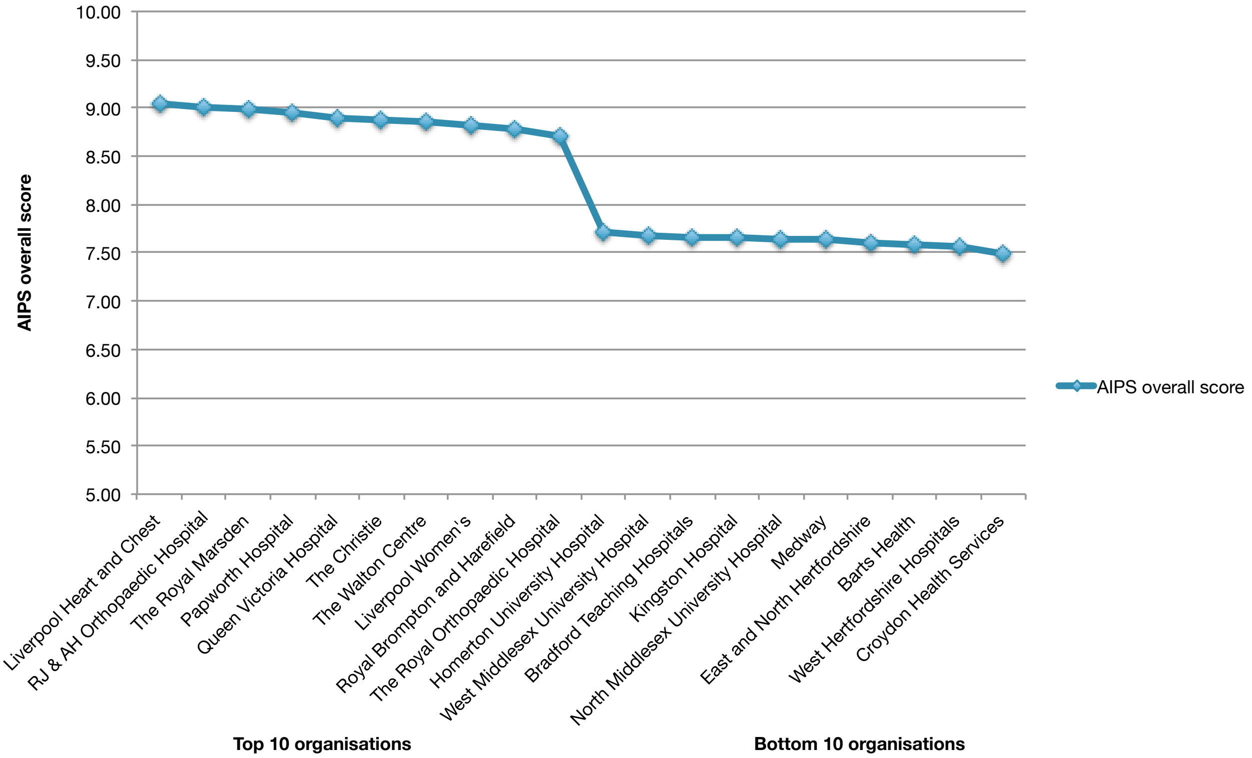


Figure 23. AIPS overall scores across organisations

Variation on the new composite score was also relatively flat across organisations, ranging from 7.38 to 8.82 (Figure 24). Because the composite score can be presented alongside its components, however, it can indicate more information about local variation. For instance, these results suggest that scores for Section 10 relating to giving feedback and knowing how to complain, as well as Section 9 relating to leaving hospital are consistently low, but they expose important local variation around which sections are most positive. Furthermore, if scores on any of the sections improve, there will be a subsequent shift in the composite score, thereby providing possible indication of where improvement has taken place.

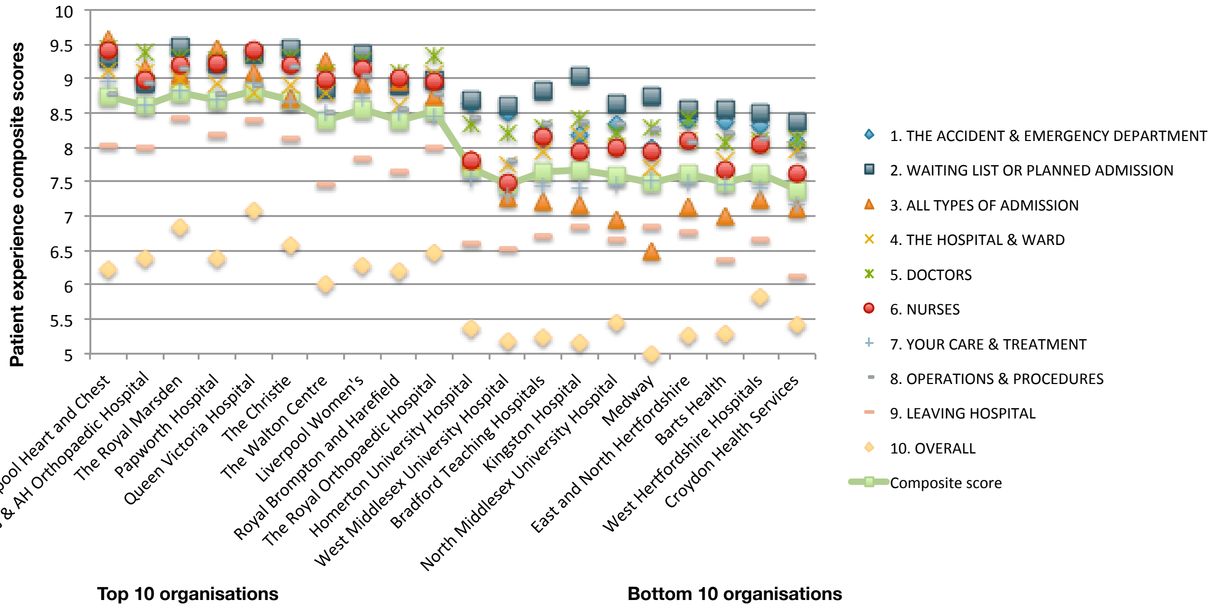


Figure 24. Composite score and corresponding section scores across organisations

National impact

On average, organisations shifted 10.86 positions in a national league table of 149 acute organisations when using the composite score as compared to the AIPS overall score. For example, RCF and RNS moved 56 and 38 positions up a national league table when using the composite metrics and RJF moved 35 positions down, a result that demonstrated the limitations of benchmarking league tables.

Figure 25 demonstrates changes within the top and bottom ten organisations (organisations as measured by the AIPS overall score), which get the most attention in benchmarking tables.

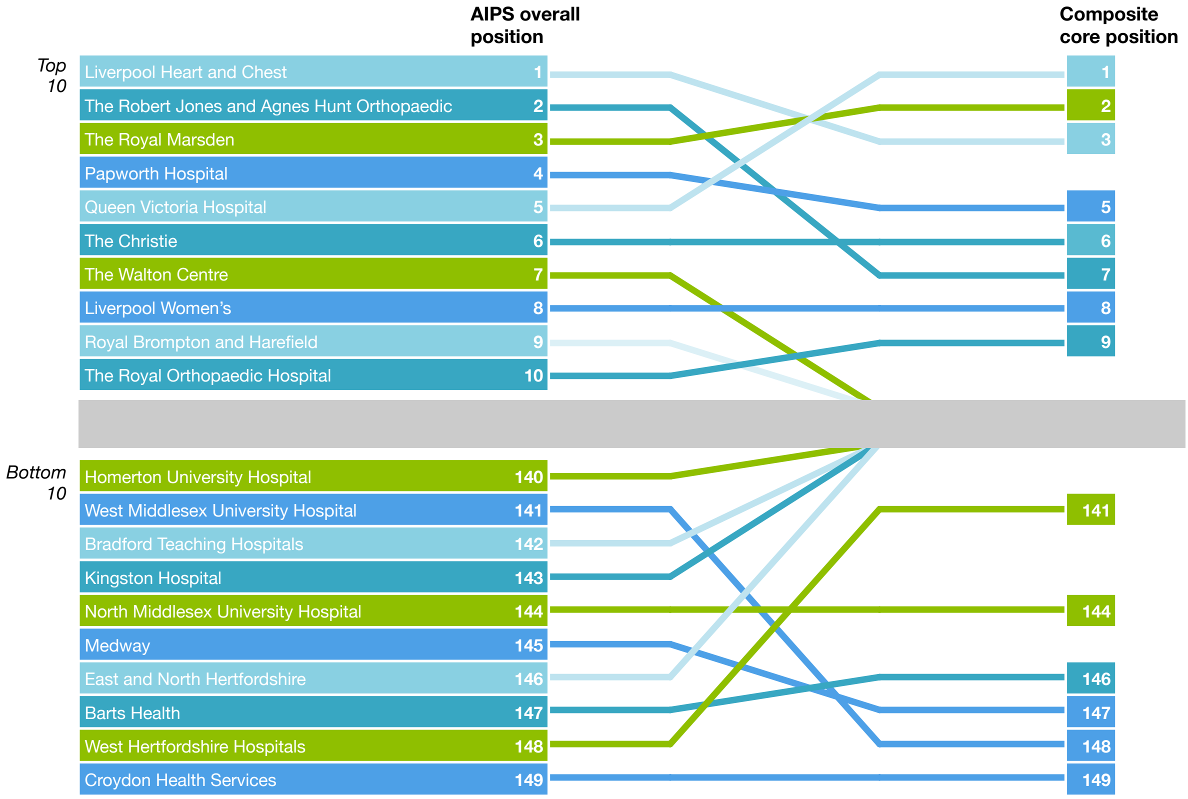


Figure 25. Movement in national patient experience benchmarking as determined by AIPS overall score and composite score

5.5 DISCUSSION

5.5.1 Statement of results

At a national level, organisations' AIPS overall score positively correlated with each of their section scores, but there was considerable variability amongst the strength of these correlations. Organisations' new composite score held stronger correlations with each of their section scores.

Organisations' results for both the AIPS overall score and the newly created composite score were very positive and presented a relatively undifferentiated picture of patient experience. However, organisations' composite scores, which encompassed a much wider array of patient-reported measures, demonstrated a slightly lower result on average: composite score (M=7.99, SD= 0.27), AIPS overall score (M=8.13, SD= 0.30). On average, organisations' scores decreased by 1.40%. A paired sample t-test confirmed a significant average difference between organisations' AIPS overall score and their composite score ($p<0.05$). The difference appears marginal, but, again, as a percentage of the existing range of AIPS overall scores, organisations' dropped by an average of 8.97%. This is a large shift, given that most AIPS overall scores rarely change by a single percentage point year on year (12)(173). While section scores and overall scores tended to correlate at the organisation level, they do not necessarily correlate at the patient level.

In terms of the impact that the composite could have on local quality improvement, it is important to emphasise the composite score itself does not provide the intelligence necessary to generate improvement that the metrics within it can. It is a conceptually simple single metric, designed to be palatable for those seeking a definitive metric on patient experience, but because it is built on the more granular components of patient experience, it could enable more insight into the source of a positive or negative experience score. Because the composite score accounts for multiple section scores, it can be meaningfully presented with its corresponding section scores to provide more insight into the source of variation and which aspects of care could be priorities for local improvement. Furthermore, at a national level, organisations shifted, on average, over ten positions in a national league table when using the composite score as opposed to the

AIPS overall score. On a descriptive level, this could change the system’s understanding of organisational benchmarking and call into question the relevance of using benchmarking procedures that are so volatile (Figure 25).

5.5.2 Findings in relation to existing literature

Using patient experience at a local level

In line with existing literature and survey results, patients’ feedback is incontrovertibly expressing that on the whole, patients have at least a moderately positive experience (12). Regardless of survey biases or feedback tendencies, the consistency of positive results across different measures is an important testament to the quality of acute services in the NHS according to patients. It supports existing evidence about the success of the NHS as an internationally acclaimed health system for patients (275). These positive results should contextualise the following discussion and serve as a reminder that this analysis aims to improve the use of existing patient experience feedback rather than expose slightly lower levels of experience.

Firstly, the composite score does not require advanced understanding of statistical and survey methods to understand, as it is a simple average of section scores. This is arguably helpful at the local level for data comprehension but also at the national level where there is an evidence trend towards prioritising single targets (273). Currently, the AIPS overall scores requires a much more advanced understanding, especially when it is presented to organisations and their staff in terms of “expected ranges” (as illustrated and described in **Chapter 1**) (10)(146).

Secondly, despite their overall positivity and correlation, the significant differences between the two metrics invite deeper inquiry into what is driving the proportion of scores that are not as positive and how to improve them. The composite score, arguably, offers a better use of NPSP than the AIPS overall score as it can be presented in line with information about priorities areas for improvement, a feature that staff consider useful (6). The composite score unlocks variation in experience scores for organisations in a way that exiting measures cannot. As an average of the components of experience across the pathway, the composite score affords organisations a practical single score, but it also explains what areas of care are contributing to that score. If the composite is low, for instance, it is possible to look to the section scores to ascertain what is accounting for the difference to guide investment and improvements.

According to existing literature, the composite score is likely to produce more accurate information, as it is not the result of a single question, which has been proven to elicit inflated responses (44)(84). Research suggests that the AIPS overall score captures an emotive response, which is not necessarily in response to the quality of care patients receive, but reflective of their loyalty to the service or their inclination to be thankful for the care they received (44)(159). This is of very little value to understanding quality, let alone using data to improve care (84). Most importantly, if problem areas are addressed successfully, the composite score will likely reflect that change because it summarises all aspects of experience, where the AIPS overall score does not (202).

Using patient experience at a national level

Previous literature has identified that a simple benchmarking metric to identify success in patient experience, and flag when change is necessary, is valuable and desired by national leaders (199)(202). This is not necessarily beneficial to gaining a nuanced, granular view of experience for quality improvement. However, if NHS leaders will continue to seek a definitive metric, a single metric based on multiple aspects of experience, the composite score represents a statistically robust single metric, palpable to both the greater system and staff who use experience data regularly.

As discussed in patient survey literature, patient experience cannot be captured in one question and multiple indicators are required to uphold a holistic, multidimensional view of experience (45)(74)(78)(201). Not only do organisations' overall patient experience scores change when using this metric, they change positions in benchmarking tables, meaning that the current interpretation of top-scoring organisations could be challenged (146). The extent of changes observed to benchmarking tables not only highlights differences in the two scores. It corroborates existing literature that benchmarking based on patient experience can create artificial differences between organisations, and more sophisticated analysis is needed to understand national distribution of best and worst patient experience (168)

The composite score takes the first step towards a single patient experience metric that does not neglect individual feedback points that patients give in their surveys, but can still provide a conceptually simple metric desired by NHS leaders.

5.5.3 Limitations

The methods used to create the composite score gave more weight to Sections 1, 2 and 3 as they had fewer questions than the other sections. However, without knowledge of what was most important to patients, no weighting was applied to the individual sections. Had these sections been weighted based on the priority given to each of the components, it could have been more reflective of patient priorities for improvement. However, given time restrictions, this piece of qualitative work was out of the scope of attempting to better use existing data.

Although this study represents a practical step towards improving the use of patient experience data, it does not go far enough to test how it would be used in actual hospital setting. More is needed to create a toolbox of metrics within organisations so that relevant NHS staff are presented with this composite metric as well as an easy to follow delineation of individual section metrics. Moreover, the composite score still requires further investigation into what is driving the lowest section scores. This does not, however, detract from how the composite score could be used at the local and national level to integrate a single patient experience metric that is more comprehensive and therefore, likely to be more accurate.

5.5.4 Implications for health policy

The composite score has potential to relieve some of the controversies around a single metric. It maintains the statistical richness of the NPSP while introducing the simplicity of the FFT. For staff, it provides a more useful evaluation that does not carry the same risk of inflation as the AIPS overall score and avoids the need for complicated statistical procedures to understand quality.

Presenting experience information in this way is an enhanced use of existing experience data and could support staff to drive quality improvements from patient experience feedback. Ideally it could also contribute to a better national understanding of experience and the source of variation across organisations. Using the data in this way not only allows for a better understanding of quality, it mediates concerns around the problems inherent in the existing metrics. The next step is to triangulate this composite score with other quality indicators and organisational data to better understand the context in which positive patient experience is achieved and identify the drivers that maximise it.

5.6 CONCLUSIONS

The NHS makes a commendable effort to collect a range of patient experience feedback, but the national collection of this information has not transformed into the national use of it for quality improvement (5)(4). NHS staff as well as other leaders in the NHS and commissioning and regulating organisations desire patient experience data that is less cumbersome than the NPSP reports, but also more informative and reflective of experience than simple overall metrics. Section scores on the AIPS, which account for all questions across the patient pathway, can be used to create a comprehensive composite metric. This composite score is significantly lower on average than the AIPS overall score. The difference suggests that the existing overall metrics are failing to capture problem areas. This new composite score is the first step to creating a measure that is better reflective of quality. In order to practically move this measure from a theoretically beneficial use of existing patient experience data, to a score that can facilitate quality improvement in the NHS, it is necessary to analyse the composite score in line with the factors that might drive patient experience. In the following chapters, the composite metric will be used to draw statistically meaningful lines between organisations with the most positive and negative patient experience and applied in sophisticated analyses to identify organisational factors that drive experience.

CHAPTER 6

USING PATIENT EXPERIENCE DATA TO SEGMENT ORGANISATIONS & IDENTIFY THE PREDICTORS OF PATIENT EXPERIENCE

6.1 INTRODUCTION

As demonstrated in the previous chapter, existing data can be used to create a patient experience composite score that satisfies the health system's appetite for a single benchmarking metric. Likewise, this composite score is intrinsically linked to NPSP sections scores, so it can be presented alongside specific measures of experience that offer local insight into where improvements are needed. The extent of local variation in patient experience that becomes apparent when using section scores reinforces the need to determine what organisational factors drive that variation (196).

Extensive evidence has been put forth about the role of care pathway and organisational features in driving patient experience (276). For instance, wait times, limited budgets, substandard hotel factors and staff shortages have all been implicated as factors responsible for driving negative experience (1)(167)(202)(207)(208)(209). However, these relationships have not been fully explored, in part because patient experience data lacks the interoperability necessary to be linked to other organisational data (163). In light of this, it is necessary to develop analytic techniques to better depict and explain the variation of patient experience across organisations.

This chapter will use the composite score developed in the previous chapter as a clustering variable to segment the provider landscape based on patient experience. Applying this technique will generate a data-driven typology of organisations. It will ideally yield groups of organisations with similarities in their experience scores that are more meaningful than the small, and often insignificant differences, observed in benchmarking league tables (**Chapter 5**). The resulting groups will offer a more meaningful grouping of providers than current organisational classifications, which are primarily based on size.

Finally, it will allow for a more precise mapping of best practice in patient experience across the country.

Once these clusters are defined, it will be possible to explore the characteristics of clusters exhibiting positive patient experience. In order to use patient experience data more effectively as a tool for quality improvement, it is necessary to integrate it with other organisational metrics that could impact experience. Including data on such characteristics in a multi-linear regression could indicate which are significant predictors of patient experience. Together these outputs will provide a road map for organisations to bolster the characteristics associated with better experience and learn from similar organisations. The result of this exercise should promote improvement of problematic characteristics where they are within the organisations' control, and learning from others' solutions when they are intrinsic or unable to be changed. Ultimately, it will separate rumour from fact around what predicts positive experience and direct organisations' focus to the root causes of patients' negativity.

6.2 AIMS & OBJECTIVES

The aim of this study was to identify the organisational and care pathway factors associated with variations in patient experience, and explore which ones predict patient experience at the organisation level, in order to inform local quality improvement.

This requires four objectives:

i. To explore whether homogenous groups of organisations exist based on patient experience scores
ii. To identify the organisational and care pathway features associated with positive patient experience and establish which are significant predictors of experience
iii. To explore the characteristics of organisations that received positive patient experience scores despite not having the typical characteristics
iv. To analyse how these care pathway and organisational features could be leveraged for organisational quality improvement.

6.3 METHODS

6.3.1 Data source

The same 2015 organisation level AIPS dataset used in the previous chapter was used for this analysis. The composite score (an average of all AIPS section scores) that was created in the previous chapter (**Chapter 5**) was added to this dataset.

A framework of organisational, care pathway and patient demographic features that might influence experience was created. Features were then classified as relating to either care pathways, the organisation itself or patient demographics, in order to analyse a wide range of relevant explanatory variables. All features were selected based on existing evidence of what is likely to influence patient experience, discussed earlier.

Topics from the literature were quantified using publically available metrics reported annually at the organisation level for all acute NHS organisations. The primary datasets holding these metrics were the CQC Intelligent Monitoring Report, The Health and Social Care Information Centre (HSCIC) (now NHS Digital) Estates Returns, HSCIC Workforce Statistics, The National Staff Survey (NSS), The English Indices of Deprivation and AIPS (224)(277)(278)(279). All metrics were taken from 2015 in order to correspond with the most current publically available AIPS data; however, some variables were measured at different points throughout the year (Table 24).

SPSS statistical package was used to perform a TwoStep Cluster analysis (full technique outlined in **Chapter 3**) and identify previously unknown clusters of organisations based on their patient experience.

Table 24. Variables and their sources

Category	Variable	Source	Unit and method of measurement
Outcome variable	Patient experience	The National Inpatient Survey	Composite score
Pathway	Patients waiting over 6 weeks for a diagnostic test	CQC Intelligence Monitoring	Number of patients waiting over 6 weeks / Total number of patients waiting
Pathway	Mean length of stay of survey respondents	The National Inpatient Survey	Average nights spent in hospital of survey respondents
Pathway	The number of patients not treated within 28 days of last minute cancellation due to non-clinical reason	CQC Intelligence Monitoring	Number of patients not treated within 28 days/ Total number of patients cancelled for non clinical reasons in two month time period
Pathway	Total emergency admissions	CQC Intelligence Monitoring	Total number of patients admitted via any emergency route in a month
Pathway	Proportion of survey respondents who received urgent/unplanned care	The National Inpatient Survey	Proportion of 2015 AIPS responders
Pathway	Number of patients spending over 4 hours from decision to admit to admission	CQC Intelligence Monitoring	Number of patients spending over 4 hours in A&E department from arrival to discharge or transfer to admission as a proportion of the total number attending the A&E per 3 months
Organisational	The proportion of staff who would recommend the organisation as a place to work or receive treatment	National Staff Survey (NSS)	Proportion of respondents to the 2015 NSS return
Organisational	Proportion of patients who received all the secondary prevention medications for which they were eligible	CQC Intelligence Monitoring	Number of / Patients eligible for secondary prevention medication per year
Organisational	Support to clinical staff	HSCIC Workforce Statistics	The number of nursing assistants, nursing auxiliaries, nursery nurses, healthcare assistants, porters,

			medical secretaries, trainees, general support workers, clerical & administrative staff and maintenance & works staff specifically identified as supporting clinical staff, and scientific, therapeutic and technical staff, trainee ambulance personnel as well as clerical & administrative staff and maintenance & works staff specifically identified as supporting clinical staff (279).
Organisational	Total number of staff employed (WTE)	HSCIC Workforce Statistics	The total authorised establishment of whole time equivalent staff (WTE), inclusive of clinical and non-clinical staff, employed by the NHS Trust, either directly or through contracts or Service Level Agreements with another organisation, that enabled the NHS Trust to carry out all its duties during the reporting year. Excludes very short- term temporary contract staff employed to undertake building and upgrading work. Includes all management, supervisors, trade staff, administrative support staff, EBME staff and staff associated with residential units (278)
Organisational	Total soft FM (Hotel Services) costs	HSCIC Estates Returns Information Collection (ERIC)	Total annual revenue cost of the Soft FM (Hotel Services) services. Include all materials and equipment necessary to provide the Soft FM services together with costs associated with relevant Directors' time, management, supervisors, trade staff and administrative support employed by the trust and through Contract or Service Level Agreement with another organisation (full list available (280))
Organisational	Number of sites - General acute hospital	HSCIC Workforce Statistics	Number of sites that provide a range of inpatient medical care and other related services for surgery, acute medical conditions or injuries (usually for a short term illness or condition) (280).
Organisational	Mortality rates for conditions normally associated with a very low rate of mortality	CQC Intelligence Monitoring (provided by Dr Foster)	Rate of deaths per year (full list of conditions included available (277))
Organisational	Total capital investment	HSCIC ERIC	The sum of capital investment for new building, improving existing buildings and equipment (280).

Organisational	Percentage of estates and hotel services contracted out	HSCIC ERIC	The percentage of hard FM (estates) and soft FM (hotel services) that are contracted out. Inclusive of equipment maintenance, EBME work, PPM work, repairs, management and manpower resources that have been contracted out to non-NHS organisations including PFI and NHS Property Services (280)
Patient demographics	Proportion of survey respondents who were 66+ years old	The National Inpatient Survey	Proportion of 2015 AIPS responders
Patient demographics	Proportion of survey respondents who were female	The National Inpatient Survey	Proportion of 2015 AIPS responders
Patient demographics	Index of Multiple Deprivation Rank	English Indices of Deprivation	The Index of Multiple Deprivation ranks every small area (Lower-layer Super Output Areas, based on the 2011 Census) in England from 1 (most deprived area) to 32,844 (least deprived area). This variable includes the rank for the small area in which the hospital is located (281).

6.3.2 Clustering

A TwoStep Cluster analysis was conducted using patient experience data for 149 acute organisations in England using the composite patient experience score (**Chapter 5**).

Profiles were then created to see how organisational characteristics varied across patient experience clusters. These profiles were created for each cluster twice, once including specialist organisations and once excluding them. This was because specialist organisations, which cater to very specific conditions and patients had much different characteristics than standard organisations, meaning their information skewed the profiles for each cluster. The clusters and their profiles were then explored to identify any outliers or instances where organisations achieved a high patient experience despite not having the characteristics typically associated with positive patient experience. Finally, clusters, and the organisations within them, were mapped across the country and by Strategic Health Authority (SHA), as it was the only geographic variable available within the dataset.

A one-way ANOVA was used to test whether the clusters were significantly different in terms of all dependent variables. A Bonferroni adjustment was used to account for multiple comparisons. ((APPENDIX D) contains the full results of this testing). Mean scores for each of the variables were then normalised and used to visualise differences in cluster profiles.

6.3.3 Multi-linear regression modelling

A multi-linear regression model was then created to test which variables were significant in predicting patient experience at an organisation level. Data was filtered for non-specialist acute organisations only, as specialist organisations had substantially different characteristics than standard organisations, relatively narrow clinical remits and historically elevated levels of experience (146). Thirteen organisations were excluded based on this filtering. These organisations were excluded in order to understand the relationship between characteristics of non-specialist organisations (which account for the vast majority of acute organisations in the country) and patient experience.

All remaining 136 acute organisations were included in the analysis. Organisations' composite patient experience score was used as the outcome variable and tested for normal distribution using Shapiro-Wilks test. The same variables used to create cluster profiles were used as independent (predictor) variables in the regression analysis (Table 24). All variables were continuous or categorical and assumptions were tested for a multi-linear regression model.

First, univariate regression was undertaken to determine if care pathway, organisational and patient demographic variables correlated with organisation level patient experience. Second, variables that did share a significant correlation with experience were then tested for multi-collinearity. Third, variables were removed if they held a correlation of over r=0.70 to any other variables in the model. Fourth, remaining variables were incorporated into a multi-linear regression model in order to determine the relative importance of each. Fifth, a linear relationship between the two variables was assessed by plotting the regression standardised residuals against the regression standardised predicted value (Figure 31)(282).

Finally, given the result of the regression, which heavily pointed to staff experience as a key factor in driving patient experience, a final exploratory multi-linear regression model using the same assumptions was conducted to better understand the predictors of staff experience. Staff experience was measured using the continuous variable for the proportion of staff responding to the NSS who would recommend the organisation as a place to work. Predictor variables were taken from the key findings about communication, leadership and culture from the same survey.

A 95% confidence level was set for all analyses.

6.3.4 Analysis procedure

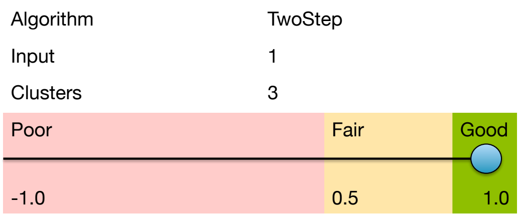
The regression results were then interpreted to better understand the predictors of positive patient and staff experience respectively. The significant predictor variables were considered with respect to the level of control organisations had to improve or amend them. Staff experience predictors were also analysed within the context of cultural improvement and how that could enhance scores and have a residual positive impact on patient experience. Variables that did not prove to be significant were also discussed, as some had been previously thought to be highly important in the quest to improve both patient and staff experiences. Finally, cluster profiles based on normalised scores were redrawn using only the significant predictors of experience. A cluster visual info-graphic was also designed in order to promote easy interpretation of what drives patient experience at the organisation level.

6.4 RESULTS

6.4.1 TwoStep Cluster analysis results

The TwoStep Cluster analysis of acute providers, which included all 149 organisations (specialist and non-specialist), yielded three significantly different groups of organisations based on experience scores. These can broadly be categorised as high, middling and low patient experience.

As demonstrated in Figure 26, there were more organisations in the clusters with low and middling patient experience than in the cluster with high patient experience: High (n=12), Middling (n=71) and Low (n=65). A one-way ANOVA accounting for multiple comparisons demonstrated that each of these three clusters had significantly different means for patient experience (High: M=8.63, SD=0.15; Middling: M=8.09, SD=0.15; Low: M=7.77, SD=0.15) ($p<0.05$) (**Error! Reference source not found.**). The high experience cluster accounted for 76.9% of specialist organisations.



Algorithm	TwoStep
Input	1
Clusters	3

Figure 26. Accuracy of the TwoStep model in its ability to classify organisations

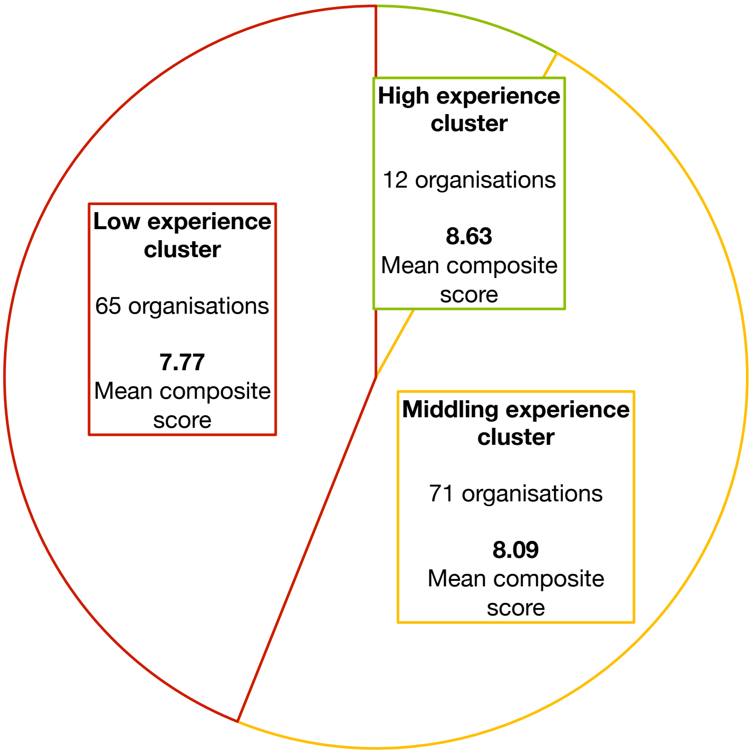


Figure 27. Description of clusters of organisations based on experience scores

In comparison to both the low and middling patient experience cluster, the high patient experience cluster had a significantly lower proportion of survey respondents who went through emergency care, lower total emergency admissions, lower total acute hospital sites and less support to clinical staff (*p*<0.05). This group also had significantly higher proportion of survey respondents over 66 years old and more staff who would recommend the organisation as a place to work (*p*<0.05) (
Figure 28). Organisations in the high patient experience cluster were also associated with lower total sub-contracting costs and other rather unexpected characteristics such as lower total number of staff and lower total spending on hotel features and estates, although these were not significant (APPENDIX D).

When specialist organisations were excluded, the final cluster profiles were different (
Figure 28). When filtering for non-specialist organisations only, the high patient experience cluster still had a significantly lower proportion of survey respondents who were admitted via emergency routes, but it also had significantly more support to clinical staff (*p*<0.05) than both of the other two clusters. In this analysis, the high experience cluster also had a greater proportion of staff who would recommend the organisation as a place to work than the low patient experience cluster (*p*<0.05). The high patient experience cluster was also associated with higher levels of total staff, lower deprivation, lower total spend on hotel features and estates, as well as lower rates of sub-contracting services and shorter wait times for emergency patients and diagnostic testing (
Figure 28), but these relationships were not significant (APPENDIX D). These characteristics were also prominent in the middling cluster and least apparent in the low experience cluster. In terms of demographic characteristics, there were no significant trends in terms of age and gender (APPENDIX D). These profiles are depicted in
Figure 28.

There were also outliers present in the results. RTF fell into the high experience cluster despite a high proportion of survey respondents admitted via an emergency route. RTR and REM also managed a middling rate of experience with a very low affluence level, low estate costs and a relatively high number of acute hospital sites. RNZ also achieved this rate of patient experience despite less support to clinical staff (**Error! Reference source not found.**).

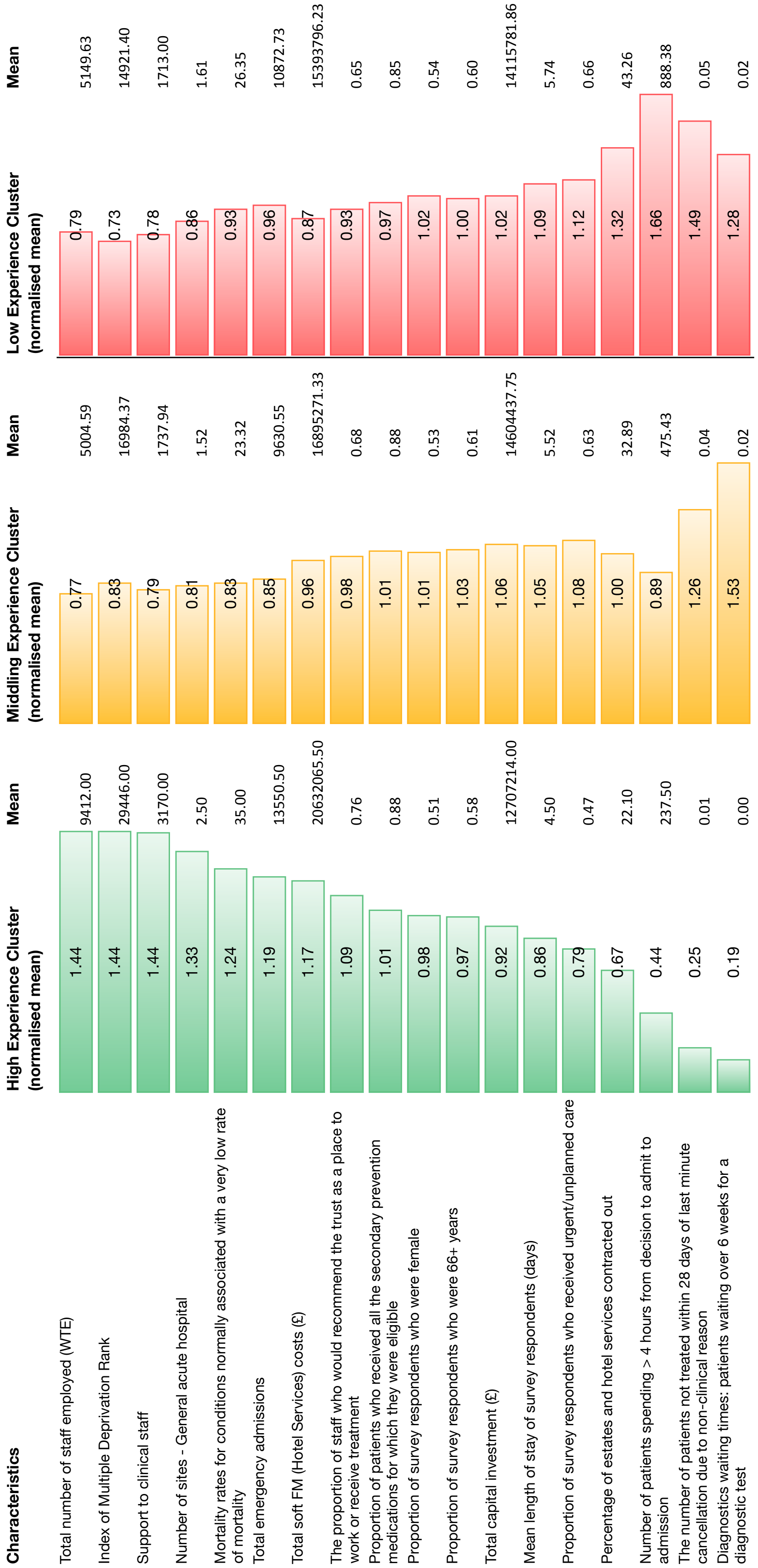


Figure 28. Cluster profiles based on normalised scores for all pathway, organisational and patient demographic variables

6.4.2 Patient experience mapped geographically

Most organisations within the high patient experience cluster were located outside of London, and those within the low patient experience cluster were highly concentrated in London.

Table 25. Distribution of non-specialist organisations across SHAs by cluster

Strategic Health Authority	High patient experience cluster	Middling patient experience cluster	Low patient experience cluster	Total
East Midlands	0	4	5	9
East of England	0	7	9	16
London	0	4	13	17
North East	2	5	1	8
North West	0	12	11	23
South Central	0	4	4	8
South East Coast	0	5	6	11
South West	0	9	7	16
West Midlands	0	6	8	14
Yorkshire and the Humber	0	7	6	13

In terms of SHA, London had the worst patient experience (M=7.85, SD=0.33) and the North East (M=8.16, SD=0.22) and North West (M=8.09, SD=0.30) had the best. The difference in experience composite scores between London and the other two groups was significant ($p<0.05$), however the difference in cluster distribution was not significant.

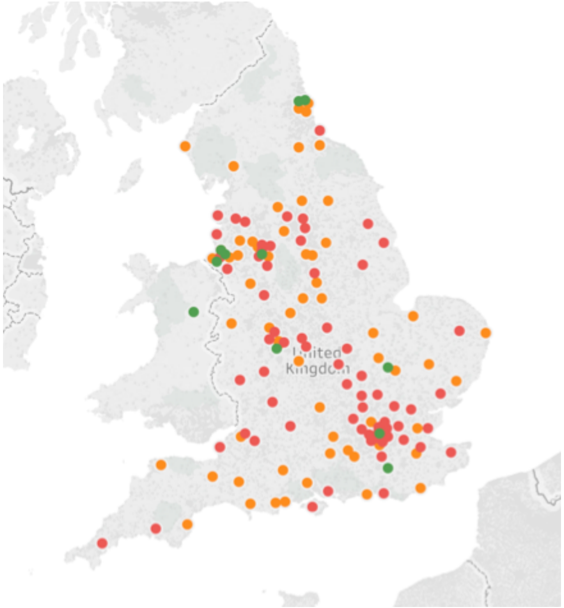
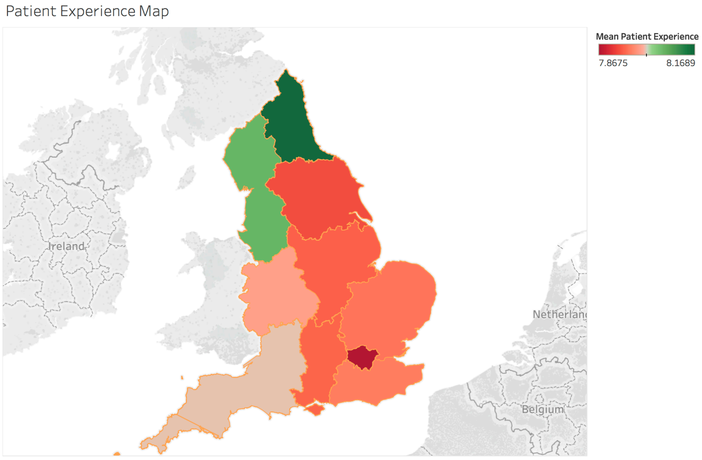


Figure 29. Map of distribution of patient experience across England by cluster (including specialists)



Map based on average of Longitude and average of Latitude. Color shows sum of Mean Patient Experience. Details are shown for PolygonID and SubPolygonID.

Figure 30. Map of patient experience by Strategic Health Authority (including specialists)

6.4.3 Univariate analysis & assumption testing

Because the high experience cluster was so small, a multi-linear regression analysis helped understand the relative importance of each variable in terms of its impact on organisation level patient experience. The continuous composite score of experience was found to be normally distributed using a Shapiro-Wilks test ($p<0.59$, as a non-significant result indicates normal distribution).

Seven of the 18 predictor variables did not correlate to patient experience in univariate analyses and were therefore excluded from the model. A final predictor variable held a strong correlation ($r>0.70$) with another predictor variable and was excluded from the model to avoid multi-collinearity. Ten predictor variables were included in the final multi-linear regression model (Table 26).

Table 26. Variables considered and their correlations to experience

Category	Variable	Correlations to patient experience	Included in final model
Outcome variable	Patient experience	1	Dependent variable
Pathway	Patients waiting over 6 weeks for a diagnostic test	0.03	Yes
Pathway	Mean length of stay of survey respondents	-0.12	Yes
Pathway	The number of patients not treated within 28 days of last minute cancellation due to non-clinical reason	-0.13	Yes
Pathway	Total emergency admissions	-0.14	No
Pathway	Proportion of survey respondents who received urgent/unplanned care	-0.30	Yes
Pathway	Number of patients spending > 4 hours from decision to admit to admission	-0.31	Yes
Organisational	The proportion of staff who would recommend the trust as a place to work or receive treatment	0.42	Yes
Organisational	Proportion of patients who received all the secondary prevention medications for which they were eligible	0.190	Yes
Organisational	Support to clinical staff	0.12	Yes
Organisational	Total number of staff employed (WTE)	0.04	No
Organisational	Total soft FM (Hotel Services) costs	-0.00	No
Organisational	Number of sites - General acute hospital	-0.02	No
Organisational	Mortality rates for conditions normally associated with a very low rate of mortality	-0.09	No
Organisational	Total capital investment	-0.14	No
Organisational	Percentage of estates and hotel services contracted out	-0.20	Yes
Patient demographics	Proportion of survey respondents who were 66+ years	0.090	No
Patient demographics	Proportion of survey respondents who were female	-0.06	No
Patient demographics	Index of Multiple Deprivation Rank	0.19	Yes

6.4.4 Multi-linear regression

A multi-linear regression was calculated to predict patient experience based on the ten care pathway, organisational and patient demographic factors. A significant regression equation was found (F[10,108] = 6.214, $p < 0.05$), with an R^2 of 0.37.

Two variables were significant in predicting a rise in patient experience: Amount of support to clinical staff (Beta=0.22, p=0.02) and the proportion of staff who would recommend the trust as a place to work or receive treatment (Beta=0.26, p=0.01). Two variables were significant in predicting a decline in patient experience: Number of patients spending over 4 hours from decision to admit to admission (Beta=-1.99, p=0.03) and the percentage of estates and hotel services contracted out (Beta=-0.23, p=0.01) (Table 27).

Table 27. Predictors of organisation-level patient experience scores at non-specialist acute NHS organisations

Independent variables	Unstandardised coefficients		Standardised coefficients	t	Sig	Correlations		
	B	Std. Error	Beta			Zero - order	Partial	Part
(Constant)	7.54	0.36		21.05	0.00*			
Number of patients spending over 4 hours from decision to admit to admission	**0.00**	**0.00**	**-0.20**	**-2.17**	**0.03***	**-0.32**	**-0.21**	**-0.17**
Proportion of patients who received all the secondary prevention medications for which they were eligible	0.10	0.13	0.06	0.77	0.44	0.21	0.07	0.06
Percentage of estates and hotel services contracted out	**0.00**	**0.00**	**-0.23**	**-2.84**	**0.01***	**-0.19**	**-0.26**	**-0.22**
Index of Multiple Deprivation Rank	0.00	0.00	0.15	1.91	0.06	0.19	0.18	0.15
Proportion of survey respondents who received urgent/unplanned care	0.00	0.00	-0.18	-1.85	0.07	-0.32	-0.18	-0.14
Mean length of stay of survey respondents	-0.02	0.02	-0.07	-0.89	0.38	-0.14	-0.09	-0.07
The proportion of staff who would recommend the trust as a place to work or receive treatment	**0.94**	**0.33**	**0.26**	**2.89**	**0.01***	**0.41**	**0.27**	**0.22**
Support to clinical staff	**0.00**	**0.00**	**0.22**	**2.32**	**0.02***	**0.14**	**0.22**	**0.18**
Total capital investment	0.00	0.00	-0.07	-0.86	0.39	-0.13	-0.08	-0.07
The number of patients not treated within 28 days of last minute cancellation due to non-clinical reason	-0.20	0.26	-0.06	-0.76	0.45	-0.12	-0.07	-0.06

The regression model demonstrated a linear relationship between the outcome variable and predictor variables as seen in the probability-probability plot (Figure 31). Crooks distance was between 0.00-0.08; it did not fall outside of 1, meaning there were no outlying data points influencing the equation.

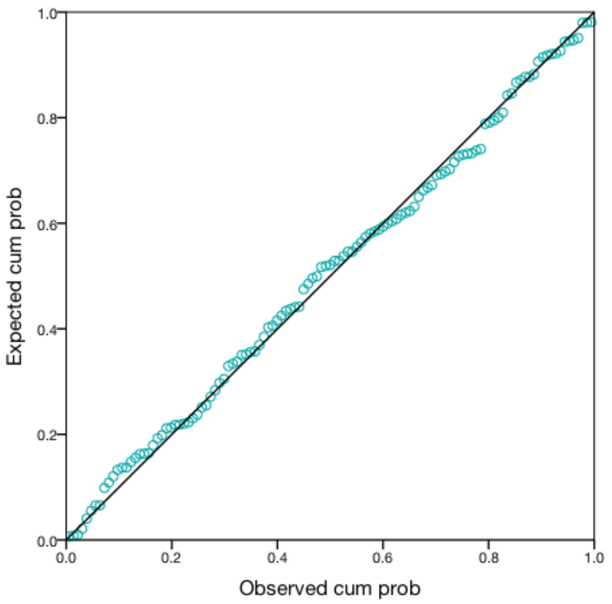


Figure 31. Probability-probability chart for patient experience regression

A significant regression equation was also found regarding staff experience. Staff recommending their organisation as a place to work or receive treatment could be predicted from key questions on the NSS (F[3,144] = 132.17, $p < 0.05$), with an R^2 of 0.73. Although this was conducted on an exploratory basis, assumptions for a valid multi-linear regression were met. Staff recommending their organisation as a place to work was normally distributed using a Shapiro-Wilks test (*p*=0.37) and the predictor variables correlated with staff experience, but did not exhibit multi-collinearity.

Three variables were significant in predicting a rise in staff experience: The proportion of staff reporting good communication between senior management and staff (Beta = 0.47, *p*=0.00), the proportion of staff reporting receiving support from immediate managers (Beta=0.20, *p*=0.01) and the proportion of staff who stated that the incident reporting procedure was fair and effective (Beta=0.28, *p*=0.00) (Table 28). This equation also demonstrated a linear relationship between the outcome and predictor variables (Figure 32) and Crooks distance was between 0.00-0.10.

Table 28. Predictors of staff recommending the organisation as a place to work or receive treatment

	Unstandardised Coefficients		**Standardised Coefficients**	**t**	**Sig.**	**Correlations**		
	B	Std. Error	Beta			Zero-order	Partial	Part
(Constant)	-0.28	0.19		-2.36	0.019			
The proportion of staff reporting good communication between senior management and staff	**0.47**	**0.07**	**0.47**	**6.40**	**0.00***	**0.82**	**0.47**	**0.28**
The proportion of staff reported receiving support from immediate managers	**0.47**	**0.17**	**0.20**	**2.84**	**0.01***	**0.74**	**0.23**	**0.12**
The proportion of staff who stated that the incident reporting procedure was fair and effective	**0.77**	**0.18**	**0.28**	**4.35**	**0.00***	**0.74**	**0.34**	**0.19**

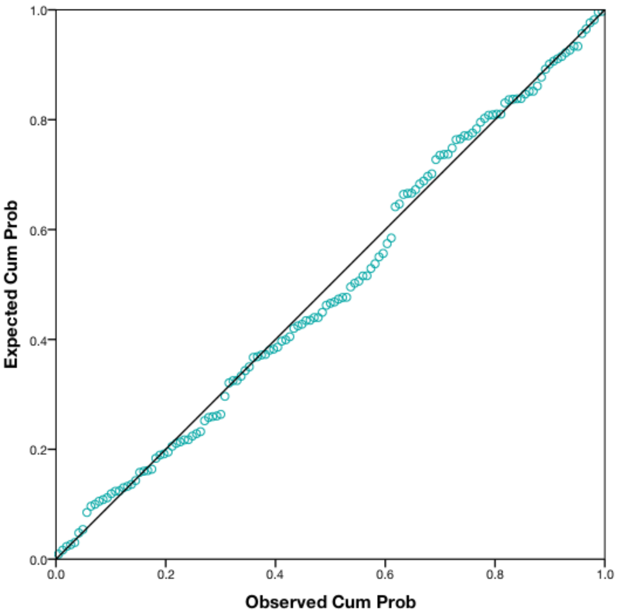


Figure 32. Probability-probability chart for staff experience regression

6.4.5 Cluster re-interpretation

Some variables were associated with positive patient experience in the initial cluster analysis, but were not significant predictors of patient experience. Figure 33 depicts the same clusters listing only significant predictors of experience in the profile. In order to use these results for quality improvement, an info-graphic was also created to visualise the information (Figure 34).

Figure 33. Cluster profiles based on normalised scores for significant pathway and organisational variables

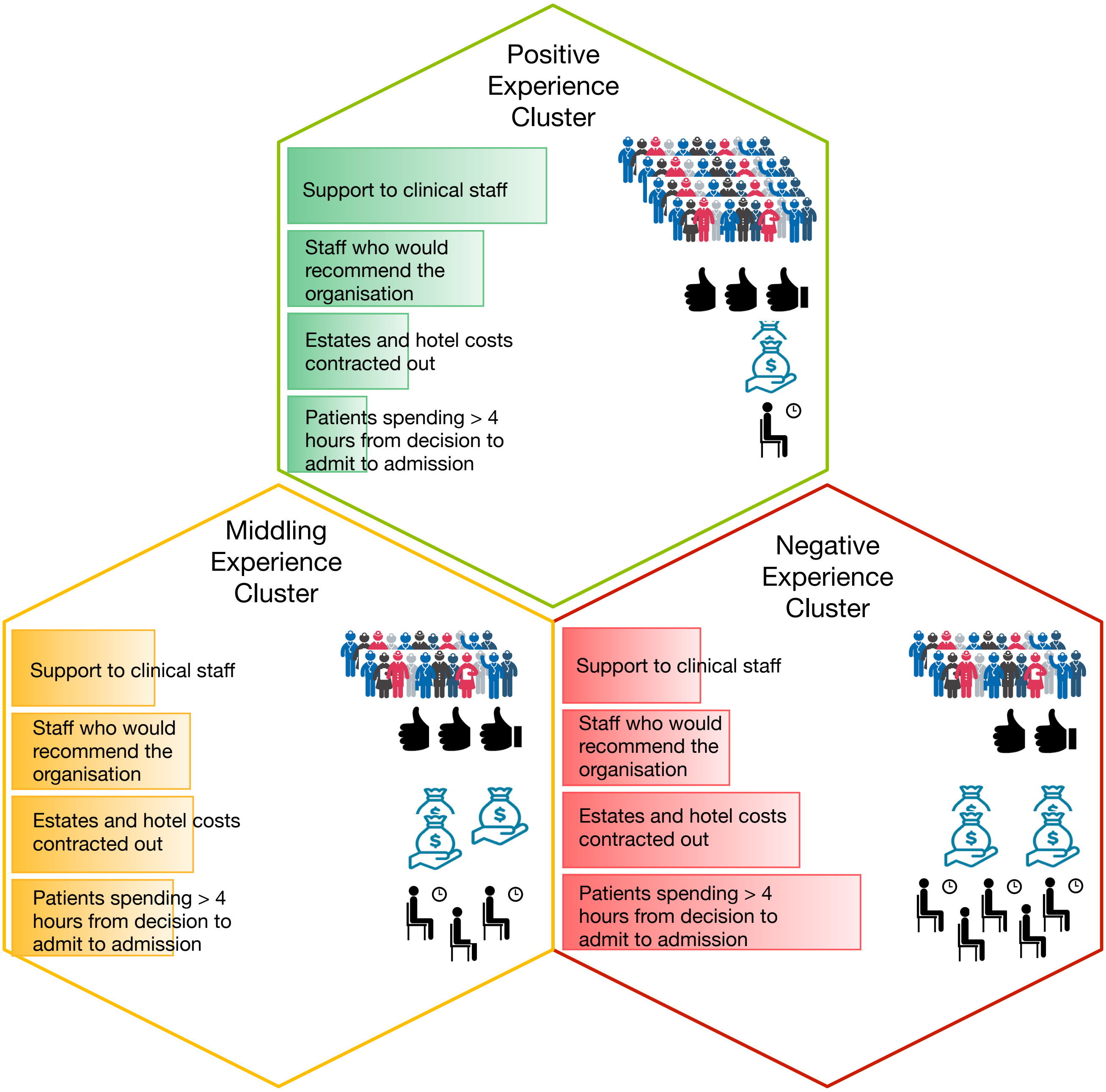


Figure 34. Visualisation of organisational clusters and the drivers of positive patient experience

6.5 DISCUSSION

These analyses demonstrated that even the organisations with the lowest experience had very high average patient experience scores and not a single acute NHS organisation had a composite score below 7/10. There is cause for celebration in these results, and the need to analyse them further does not originate from a need to reprimand organisations for poor experience. Rather, it stems from an interest in whether the variation that does exist is significant, and what drives that variation, in order to learn and improve.

6.5.1 Main findings

Cluster analysis findings

When a composite metric of patient experience derived from all AIPS section scores was used as the sole clustering variable, three distinct groups emerged: high, middling and low patient experience (High: M=8.63, SD=0.15; Middling: M=8.09, SD=0.15; Low: M=7.77, SD=0.15). The difference between mean patient experience scores was significant across all groups ($p<0.05$). The high experience cluster was the smallest and included the greatest concentration of specialist organisations.

When specialist organisations were excluded, the high cluster only included two organisations. Both of these had significantly more staff, more support to clinicians, fewer people waiting over 4 hours in accident and emergency departments and more staff who would recommend the organisation as a place to work than the middling and low experience clusters ($p<0.05$). The high and middling cluster also had lower rates of sub-contracting of services, a higher proportion of survey respondents entering through emergency routes, more affluent populations and higher hotel factors spending than the low patient experience cluster, although these relationships were not significant. Geographical differences were apparent, such that organisations within the high patient experience cluster tended to exist outside of London, with the highest concentration in the north of the country.

Some successful organisations were outliers in terms of their profile, as they did not exhibit the typical characteristics of organisations in the high and middling patient experience clusters. These provide examples of organisations that achieved positive patient experience despite their absence of commonly associated characteristics.

Regression analysis results

The results of the multi-linear regression demonstrated that some of these care pathway and organisational factors were in fact significant predictors of patient experience at the organisation level.

The variables that predicted a rise in experience related primarily to staff experience and the amount of support clinical staff received. The variables associated with lower patient experience were waiting times and the value of estates and hotel services contracted out to external companies. These findings helped refine cluster profiles to focus on the characteristics predictive of positive experience.

When staff experience was further explored, staff-reported measures of positive communication with senior managers and direct line managers, as well as fair and effective incident reporting systems, all predicted higher staff experience (as measured by rates of staff recommending the organisation as a place to work).

6.5.2 Findings in relation to existing literature

Drivers of patient experience

The results from the cluster analysis establish that there are significant differences in terms of experience across organisations, a fact that is distorted in current literature which focuses on the flat, unchanging nature of patient experience scores (12). However, these findings do support evidence that existing benchmarking should be conducted in a more statistically meaningful way (168).

Compared to other studies and common perceptions of patient experience, this study calls into question the role of hotel factors and demographic characteristics in driving patient experience. Studies outside the field of patient experience often conflate satisfaction and experience and promote the idea that experience relates to factors that are irrelevant to care, like the availability of luxury food items (283). While many hotel factors are important and helpful, more focused literature on what matters most to patients clearly demonstrates aspects like communication, involvement and information as holding primacy for patients rather than aesthetic factors (83)(84)(194). The results of this study corroborate such messages by demonstrating that experience, in its totality, is predicted by care pathway and organisational factors that can be measured and improved.

Currently there is also concern amongst clinicians around how much demographic factors are likely to influence patient experience (171). Certain demographic factors have been shown to influence scores: women and ethnic minorities have been shown to report lower levels of experience, while older patients have tended to report high levels of experience (152)(153). As a result, these characteristics have become a scapegoat for poor experience feedback at the organisation level. However, this study concludes that, at an organisation level, neither deprivation, gender nor age drive composite experience scores.

Rather than hotel or demographic factors, this analysis suggests that patient experience is driven by pathway factors, like high proportions of people waiting over four hours from decision to admission. This conclusion resonates with existing findings about wait times and emergency care experience, but goes further to suggest that these factors are important regardless of hotel factors and estates budgets (202).

Finally, this study concludes that organisational features like positive staff experience, support to clinical staff and low rates of external contracting for estates and hotel services drive patient experience. The relationship between positive staff experience and positive patient experience has been established before; however, it has not accounted for this range of other factors, which are commonly thought to influence patient experience (1). The relationship between external contracting and patient experience does not have a substantive evidence base and opens up an important line of inquiry for future research. The findings around external contracting and support to clinical staff are, however, particularly important to patient experience. Existing literature from the patient perspective indicates that patients appreciate when nurses as well as other staff groups take time to listen, provide informal support and care for their holistic needs (284). Often these staff members are not just nurses, but include cleaners, porters and ancillary staff, all of which are staff groups that are regularly externally contracted; evidence also suggests that these groups of staff recognise their own role in delivering important relational elements of care (285). Anecdotal evidence exists whereby patients have expressed concerns about agency staff and their ability to carry out the responsibilities of care (285). More research is needed in this area to clarify the impact of external contracting on the softer, relational aspects of care that these staff groups provide.

It is important to note, however, that “hotel factors” can be a misleading term. These results do not suggest that the features that make a hotel stay pleasant do not also make a hospital stay pleasant; rather, they indicate that when accounting for many variables, total spending on aesthetic or comfort services does not improve overall experience. From a quality improvement perspective, it does not suggest disregard for certain hotel factors, but encourages improvement of patient experience without demanding more money to be spent on these types of services.

The role of staff culture

The results of the multi-linear regression on predictors of patient experience give legitimacy to the notion that cultivating positive staff culture could have an important, if not essential, impact on quality (183). The exploratory analysis of drivers of staff experience, likewise, corroborates a growing body of evidence around the importance of organisational culture, outlining that the more relational and procedural aspects of working life have a significant impact on staff experience. Effectively reducing blame and increasing cooperation requires bringing clinicians and managers into a conversation about best practice in incident reporting in order to avoid the perception of a bureaucratic task, as well as implementing fair repercussions for wilful disruption or negligence (42)(43)(44). This harkens back to early evidence around patient safety and effectiveness, demonstrating that adversarial communication, lack of role clarity and poor training, increase the risk of error and harm (31)(286). It has become clear through extensive research that “no blame” culture combined with adequate time and training inspires more honest and accurate incident reporting, a central feature of positive hospital culture (41).

An improved use of patient experience data would involve a strategy to nurture the most influential organisational drivers of patient experience. As a result, systemic change of patient experience requires deeper inquiry into what drives staff culture and how to improve it. As other studies have stipulated, this includes a more targeted investigation into leadership, communication and management to understand how organisations can develop a culture that supports positive patient experience (196).

Extensive literature offers concrete ways to improve communication between managers and their team and how to embed positive communication into working relationships (183)(287)(288). The WHO has also created guidelines for implementing incident reporting systems that are fair and effective for staff (289). Vincent and colleagues have even created an evidence-based framework to identify threats to positive culture, like undue workload and inappropriate staff skill mix, so that organisations can mitigate them and embed culture improvement as a concrete feature in improvement strategy (290). These can be explored as a means to identify areas for cultural improvement that would, according to these results, support improvement of patient experience.

6.5.3 Limitations

This analysis is limited by the data available, in the sense that the most recent patient experience data available is from 2015 and that it has not included previous years' data, meaning it does not account for organisations that have low experience but made significant improvements. It would also be useful to work with some of the higher cluster organisations to understand whether their success is driven by their use of patient experience feedback in quality improvement plans, and if so, how they have gone about this. Regarding the composite score, there are many other available data sources that could provide indicators of organisation level patient and staff experience, and it is important to note that these could change clustering parameters (61)(141). These limitations would be important to address in future research, but do not interfere with the ability to use these clusters for better benchmarking and shared learning, especially from successful organisations lacking the usual characteristics.

The multi-linear regression analysis on predictors of patient experience aimed to understand what features of the health service, and the patients within in it, can predict patient experience at an organisation level. The answer is a complex, multi-dimensional list of factors and confounds that could all, at any point in time, influence experience without a concrete pattern. Due to the sheer volume of variables that could influence experience, many of which relate to individual circumstances and cannot be measured retrospectively, there are limitations inherent in any study that aims to determine what drives patient feedback on an aggregate level. However, the inquiry beyond highly personal factors is valid, as it unearths patterns that can guide quality improvement and debunk myths about what features are most important to invest in to improve quality. Future research is required to further investigate the directionality of these findings to understand the influence of positive patient experience on things like staff experience. Additionally, further research into findings around external contracting and staff support would have significantly enhanced the implications of the regression analysis.

Furthermore, many staffing variables are reported as totals rather than rates per patient, meaning that they could relate more to the size of the organisation than the nature of its staffing. These numbers also do not capture staff skill mix or patient case-mix, which is likely to be relevant.

While the framework of predictor variables was designed to include as many relevant care pathway and organisational characteristics as possible, experience is likely determined by more cultural features that are not routinely measured or publically available. Many of the metrics in this framework are likely proxies for aspects of culture, however more exact metrics would have been useful. There are also confounds around organisational culture, such as external targets and political pressures, which are not accounted for in this analysis. These limitations apply to both the analysis on patient experience and staff experience.

6.5.4 Implications for health policy

The results of the cluster analysis demonstrate which acute NHS organisations were the most successful in terms of delivering patient experience and performing well on national patient experience feedback collections. It depicts which organisations have the best patient experience in a more specific way than is currently available, and provides a more patient-centric classification system than existing ones based on size and structure (168).

This typology of organisations based on patient experience provides a more creative and potentially more useful way to understand organisations and their priority areas for quality improvement. Its also helps visualise which organisations are performing the best, and makes this division only where groups are statistically different in terms of their patient experience scores. This classification provides new insight into variation and exposes how few organisations sit at the top tier of patient experience. However, by including organisational characteristics, it does not set those organisations at the top aside; rather it reveals how many organisations have been able to attain high or middling experience without excessive estates budgets or particularly affluent populations. Hopefully this picture of experience will inspire shared learning from similar organisations instead of learned helplessness.

Organisations will be able to reflect on what characteristics are within their control to change, and which ones are engrained, structural realities that cannot be altered. For those characteristics that are associated with poor patient experience, but cannot be changed, it is possible through this typology to identify organisations with similar characteristics that have performed well on patient experience. Showcasing these examples is beneficial to staff, as staff demonstrated an appetite for positive examples when discussing what would enhance their ability to use patient experience data (**Chapter 4**). This also places an onus on organisations and commissioners, as it disavows any attempt to explain away poor experience based on deprivation, geography or other typical scapegoats.

Furthermore, these results have implications in terms of designing patient-centric service delivery. For example, these findings point out the success of specialist organisations in achieving high rates of experience. It is worth considering the success of specialist organisations' small, precise model and the value a tailored approach might have for quality improvement within normal services. Understanding the implications of this model will become more relevant to policy makers and commissioners as the NHS moves towards greater centralisation of specialities (147). This idea echoes the importance of achieving a more disaggregated understanding of patient needs and driving improvement based on those needs as covered in **Chapter 3** (117).

Multi-linear regressions on patient and staff experience

The results of the regression analysis do not simply state that a friendly staff environment helps make patients happy and comfortable. This would be a trivialisation of patient experience scores. The patient experience scores used in this analysis account for how well-informed thousands of patients feel in hospital, whether or not patients and their carers are appropriately involved in decisions and the extent to which patients receive critical education about their treatment plan (73)(78). In fact, these results suggest that eliminating entrenched problematic cultures - the type of cultures that prohibit constructive communication and effective, blame-free incident reporting - is essential to delivering care that is appropriate, informative and capable of supporting patients to adhere to the most effective pathway.

Hotel features, and the budgets to obtain them, often considered the crux of patient experience, do not share a significant correlation with patient experience and are of limited consequence when accounting for clinical support and the general wellbeing of staff. The policy implication for this is strong: it is not to say that these factors are not important, but rather to say these factors should not syphon off resources from staffing and clinical support in order to meet external demands.

To a larger extent, patient experience is driven by pathway factors; the proportion of patients waiting over four hours from decision to admission significantly predicted lower experience. The relationship between long waits and lower experience deserves further attention in quality improvement initiatives. Wait times in A&E are often the result limited bed availability due to delays in transfer or discharge, a fact the compels a closer investigation of how well both the health and social care systems are equipped to shift patients out of acute care (291). Furthermore, the association between poor experience and long waits and emergency visits could also relate to the nature of the conditions that people present with as many patients leave A&E before being seen (292).

The challenge is dispelling myths that experience is driven by money and hotel factors. Moreover the ambition needs to be prioritising these features, such as culture, staffing support and even sub-contracting of services, that are not always considered the heart of quality. These results suggest that improving quality for patients requires investigating deeper into the organisational features, especially staff culture that pervade the hospital experience, care pathways and clinical outcomes. Delving into the intricacies of staff environment, the communication they receive from management and the fairness and effectiveness of procedures by which they operate is likely to improve staff experience and deliver an impact to the patients they treat (293). Those patients are then more likely equipped to be active, educated and ready to embark on an effective patient journey.

6.6 CONCLUSION

The current paradigm in healthcare improvement revolves heavily around patient-centricity, co-design and canvasing the opinion of users on all major decisions (2)(147). This reflects an important evolution in care models and has already inspired the systematic collection of patient experience feedback in many countries, through many avenues and across many disciplines. However, the overwhelming trend is that this feedback has not been integrated into improvement strategy to drive change (4). The result is that patient voices are heard but not listened to.

This is problematic not only for patients who might be frustrated with their feedback falling on deaf ears, but also for NHS staff who have, over the past decade, grown in their enthusiasm to use patient experience data (171). Surveys and other collection methods can be criticised for hindering the process from data collection to data use, but improving these processes is not the only solution.

Improving the use of patient experience data requires more work than simply looking at the negative results to survey questions. It requires understanding the constitution of provider organisations and the system within which they operate (196). This is first about classifying organisations in a patient-centric way based on experience and examining what organisational features relate to high performance on patient experience. Secondly, it involves determining what organisational features are statistically significant predictors of patient experience.

Grouping organisations based on their patient experience scores is one way to differentiate organisations in a way that is meaningful to patients. It provides a topology from which it is possible to gauge what organisational characteristics are associated with the most positive patient experience. Most practically, however, it allows organisations to identify other structurally similar organisations and learn from their examples.

The results provide a practical map for improvement but also a theoretical challenge to what are commonly considered the most important features associated with patient experience. It demonstrates that improving patient experience is about creating the organisational culture necessary to support safe, effective delivery of care.

It is not a vast departure form existing literature to find that long wait times can detract from patient experience or that support to clinical staff could bolster patient experience, but these results provide an evidence base that policy makers can no longer afford to ignore (1)(202). The results demonstrate that achieving higher patient experience through organisational change does not require an entire overhaul of infrastructure; rather, this can be done through improving aspects of organisational culture. The next chapter will depict work with a real life acute organisation to build on these results and take a closer look at how culture can be improved to create a more supportive environment for patient-centric quality improvement.

CHAPTER 7

USING STAFF FEEDBACK TO DRIVE CULTURAL IMPROVEMENT AND POSITIVE PATIENT EXPERIENCE

7.1 INTRODUCTION

Chapters 1- 6 demonstrate *how* to improve the usefulness and use of patient experience feedback, but they do not explore the operational nuances of what that would look like in a real NHS organisation. The next step, therefore, is to build on the previous chapters' findings and explore their relevance within an actual acute hospitals' improvement process. This first involves gathering more insights on the organisational features that are paramount to improving experience, and then augmenting organisational readiness to use experience data.

Findings from the previous chapter demonstrate the centrality of certain organisational features, like staff culture, to promoting a positive patient experience. They support existing evidence that holistic improvement of patient experience begins with cultivating a staff culture characterised by positive communication and collaboration (214). The previous chapter highlighted that a rise in patient experience could be predicted by a rise in the proportion of staff who would recommend the organisation as a place to work. This finding was explored in depth, and three things were found to predict a higher proportion of staff recommending the organisation: The proportion of staff reporting good communication between senior management and staff, the proportion of staff reporting receiving support from immediate managers and the proportion of staff who stated that the incident reporting procedure was fair and effective. These findings quantify previous observations presented in the Patient Feedback Response Framework, stating that collaborative organisational culture is a prerequisite to using patient experience feedback for improvement (196). Accordingly, systemic improvement of patient experience data use requires enhancing organisations' cultural readiness to respond (8)(6)(196). Although cultural readiness to respond to patient experience data is complex and determined by many factors, as discussed in **Chapter 1**, many tools exist to gather certain cultural metrics. These tools capture certain aspects of organisational culture, and while limited, they can help organisational diagnose their culture and factors which impact organisational readiness to drive patient-centric change (217).

This chapter focuses on measuring culture within one NHS organisation, Imperial College Healthcare NHS Trust (ICHT), in an attempt to systematically improve quality and solidify their organisational readiness to use patient experience feedback for improvement. The research was based on a translational approach, and therefore conducted with academic rigour, but guided by the needs of the organisation. The decision to work with ICHT was pragmatically determined based on the proximity and availability of the site and their interest in holistic cultural improvement. Selecting an organisation based on these criteria limited the type of organisations that could be involved, and learning from ICHT should be taken as a case study in improvement.

The work used a collaborative approach with an embedded researcher working within the structure of the Medical Director's office and the ICHT's Quality Improvement team. Given the needs of ICHT, and direction given by the Trust Board, measurement of culture focused on *safety culture* rather than overall culture. This distinction presented a challenge as it offered a narrower interpretation of culture than might normally be applied when diagnosing culture and the factors that impact ability to improve based on patient feedback. However, as outlined in **Chapter 1**, the tenets of safety culture, and the metrics used to capture them, are indicative of the overall cultural attributes necessary to support patient-centric change (219). These tenets include things like, effective coordination between teams, encouragement and psychological safety to learn from mistakes and effective use of staff feedback, which are also features of patient-centric services with the culture necessary to initiate improvements based on patient survey data (294)(295)(196). Safety culture relates to organisational process and internal communication routes, which impact the way patients receive care, specifically in terms of coordination (296). In an effort to improve experience for both staff and patients, ICHT developed a nuanced approach to understanding and measuring safety culture and devised a programme of action to improve it.

Exploring staff safety culture might seem like a departure from objectives of this research. While this was a practical decision, and it would have been useful to investigate other aspects of culture pertinent to patient care, it presents a realistic approach towards holistic quality improvement. Improving the local use of patient experience survey data will not be successful if research only focuses on improving the quality and presentation of data (196). It is clear from the definition of patient experience in **Chapter 1** that organisational culture cannot be neglected in any work around patient experience: patient experience is “the sum of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care” (47). Furthermore, the chapters up until this point, including feedback from frontline staff, have articulated that improving the use of patient experience feedback through any means first requires a positive staff culture, receptive to patient feedback (196).

A systemic path to improvement starts by leveraging the predictors of positive patient experience and targeting deeper problems, including staff culture, that could be driving poor experience or perpetuating the inability to act on patient feedback.

7.1.1 Imperial College Healthcare Trust

ICHT is a large acute teaching Trust in Northwest London. The organisation has five primary sites: St Mary’s Hospital, Charing Cross Hospital, Hammersmith Hospital, Queen Charlotte & Chelsea Hospital and The Western Eye Hospital. It also includes a variety of renal satellite sites. The organisation has over 10,500 employees and nearly 200,000 inpatient contacts every year.

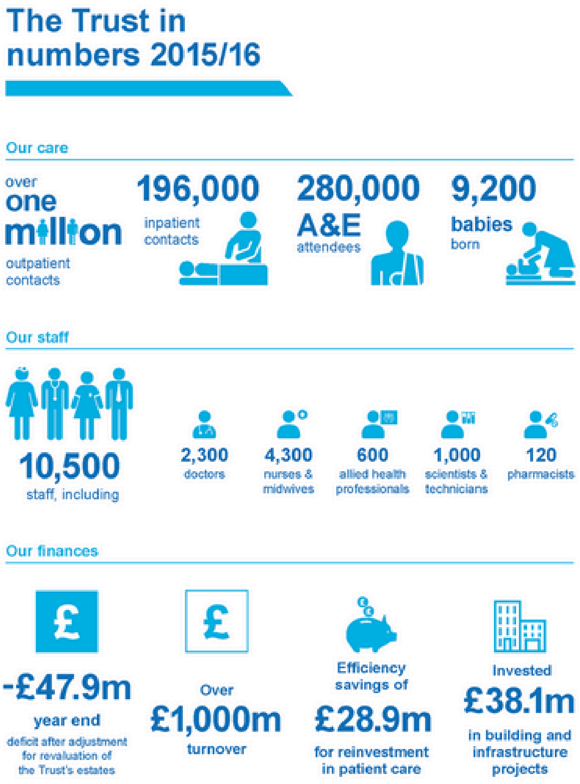


Figure 35. ICHT Profile[3]

The hospitals within ICHT have long histories as pioneering institutions, boasting many accolades and achievements like Fleming's discovery of penicillin 1928 (297). However, in recent years the organisation has recognised cause for concern in terms of care quality. In 2016 ICHT experienced 184 serious safety incidents, as compared to only 128 in 2015, a 43.8% increase (298). Further to that, patient experience scores faltered on the 2015 AIPS in sections such as nursing care, information giving, and emotional support (146). The organisation was also one of the lowest in the country for scores on the NCPES, the survey discussed in **Chapter 3**. Over time, staff have also reported a limited ability to use patient experience feedback constructively and have not demonstrated improvements to key AIPS questions (**Chapter 4**) over the past five years (299).

Initial inquiry into these problems indicated that sub-optimal staff culture, specifically around communication and collaboration in stressful environments, might be a culprit for problematic staff experience. Senior leaders suspected that these cultural challenges

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[3] Image available at https://www.imperial.nhs.uk/about-us/who-we-are

impact patient experience and staff ability to use patient feedback for improvement, but they were limited in ability to measure such a trend.

7.1.2 Existing ICHT staff culture data

The NSS, which is conducted annually did, however, expose some concerns around safety culture. ICHT had a very poor response rate in 2015 before the commencement of this work (299). This indicated to senior management that staff engagement was not at optimal levels and that this was contributing to difficulty in getting staff to champion quality improvements. Specifically, staff exhibited concerns around senior management and a range of organisational factors relating to safety. These results varied across staff groups: concerns about incident reporting were more pronounced in clinical staff groups, feelings about collaboration were poor for all levels of nursing staff and both consultants and allied health professionals demonstrated dissatisfaction in terms of morale (Table 29).

(Scores were given 1-100 with 100 representing the *most negative* responses. Green indicates significantly better results than the ICHT average and red indicates significantly lower results than the ICHT average).

Table 29. National Staff Survey results ICHT (on questions relevant to safety culture)

	Admin & Clerical	Senior Manager	Nursing (Qualified)	Nursing (Unqualified)	Scientific & Technical (Qualified)	Doctor (Consultant)	Allied Health Professional (Qualified)
Organisational Factors							
Would not recommend organisation as place to work	26	13	8	14	32	28	33
Dissatisfied with extent organisation values my work	33	28	19	43	41	50	69
Felt unwell due to work related stress in last 12 months	40	34	44	40	26	47	47
Not enough staff at organisation to do my job properly	34	31	39	64	64	80	59
Senior management							
Harassment, bullying or abuse from managers	16	6	19	31	21	28	19
Felt pressure from manager to come to work despite not feeling well enough	23	33	25	*	42	*	*
Communication between senior management and staff is not effective	21	25	29	20	40	47	76
Senior managers do not act on staff feedback	26	19	28	20	45	37	71
Senior managers do not try to involve staff in important decisions	31	38	29	27	45	37	71
Errors and near misses							
In last month, saw errors/near misses/incidents that could hurt staff	6	13	20	15	17	28	19
Staff not given feedback about changes made in response to reported errors	12	19	14	14	16	58	20
Last experience of physical violence not reported	*	*	18	*	*	*	*
In last month, saw errors/near misses/incidents that could hurt patients	14	10	36	15	33	65	63
Colleagues							
Felt pressure from colleagues to come to work despite not feeling well enough	11	11	25	*	25	*	*
Harassment, bullying or abuse from other colleagues	20	6	27	36	28	12	19

As depicted in the quality triangle (**Chapter 1**), patient experience, patient safety and clinical effectiveness are all required to deliver a quality service. The NSS data at ICHT revealed problems relevant to each of these domains that might be bolstered by an improved staff culture. With the quality triangle in mind, a meaningful approach towards improving the use of patient experience feedback required a systemic change that supported all domains of quality. Long-term improvement of patient experience needed to look towards the practical, measurable aspects of staff culture to create an environment for holistic quality improvement and eventual uptake of suggestions for better use of data (196).

7.1.3 Translational strategy for improving quality for patients and staff

From an organisational perspective, any quality improvement programme had to fall within ICHT budget constraints and meet a range of objectives that had already been set prior to commencement of this project. A key mandate of the ICHT Medical Director's office was to investigate and improve safety culture. Safety culture, discussed in **Chapter 1**, is defined as "The product of individual and group values, attitudes, perceptions, competencies, and patterns of behaviour that determine the commitment to, and the style and proficiency of, an organization's health and safety management" (216). Additionally, the focus of the work had to satisfy external pressures from regulators and commissioners to demonstrate quick success and live up to expectations of the ICHT Board and frontline staff.

On the other hand, from an evidence-based research perspective, a systemic approach to changing how organisations respond to patient experience feedback had to revolve around improving the organisational factors that drive patient experience. **Chapter 6** indicated that staff experience predicts a rise in patient experience and, in turn, staff experience is driven by effective communication, meaningful incident reporting systems and support from managers. While this evidence points to the importance of culture overall, the results about what drives staff experience in **Chapter 6** align with the role of safety culture specifically in improving quality. Therefore, although the focus on safety culture, rather than total organisational culture, was set by the organisation, it was still highly relevant to the objectives of this work.

Together these priorities provided a strong justification for a programme of work designed to improve safety culture in order to bolster poor quality indicators - including patient experience - and organisational ability to change them. This required an iterative series of objectives that sought augmented evidence to justify further action, beginning with specified organisational priorities. Phase one of this strategy began with a targeted inquiry into safety culture in operating theatres where many of the organisations' serious incidents occurred. Building on the qualitative work in operating theatres, the second phase then included establishing a quantitative baseline of safety culture across the organisation, complete with evidence-based scoring and presentation. The third phase then involved the Medical Director's office orchestrating a series of collaborative listening events to understand how staff could take forward some of the findings from the first two phases. The fourth and final stage is on-going: the organisation is working with researchers to incorporate and evaluate new policies, with the long-term aim of enhancing staff culture and improving how patient experience can be received and acted upon.

7.1.4 Safety Attitudes Questionnaire

The phase with the most empirical work, phase 2, required identifying and administering a tool to capture safety culture and analysing the results. ICHT decided to undertake a survey, which would yield very detailed feedback about safety culture. This was important to the Medical Director's Office and Quality Improvement team because it would provide a barometer of safety culture at the organisation. The SAQ mentioned in **Chapter 1** was selected. While diagnostic in nature, the SAQ is an internationally validated tool that includes a dynamic set of metrics on safety culture, which can be used to measure the effectiveness of future safety interventions and render a temperature check of the organisation as a whole.

The SAQ has been developed to apply concrete metrics to each component of safety culture. The SAQ was designed by researchers in the United States to align with the widely used Intensive Care Unity Management Attitudes Questionnaire, which itself was derived from the Flight Management Attitudes Questionnaire, popular in the aviation industry (219). While the SAQ retained many concepts included on these original questionnaires, additional concepts were added in accordance with established patient safety frameworks like Vincent's framework for analysing risk and Donabedian's conceptual model for assessing quality (290). The finalised questionnaire was adapted for pilot testing in a range of healthcare settings with minimal changes to content. The SAQ was then piloted extensively in the USA, UK and New Zealand. It was successfully pilot tested in 106 ICUs in the UK (219). All data received from the pilots was rigorously analysed to ensure the tool was valid and reliable, a process referred to as psychometric testing. This included tests of scale reliability, item factor loadings, inter-factor correlations (219). All evidence demonstrated that the SAQ is psychometrically sound and capable of generating valid, reliable data on safety attitudes. Since then, the SAQ has been administered in many settings in the USA, but also in Albania, Denmark, Australia, Canada and many more (300)(301).

Furthermore, the SAQ could be rolled out to all employees and results could be broken down using segmentation techniques to allow for nuanced insights about different issues effecting staff groups.

7.2 AIMS & OBJECTIVES

The aim of this project was to design and implement a translational research programme to measure, and eventually shift, organisational culture in order to create a safe, positive staff environment receptive to patient feedback. The objectives to achieve this were iterative:

i. To gain in-depth staff feedback about safety culture, including communication and collaboration, in an area where serious incidents had occurred
ii. To achieve baseline safety culture scores, accounting for communication and ability to drive change, across the entire organisation
iii. To work with staff to devise a programme for improving culture and therefore ability to use patient feedback
iv. To implement and evaluate improvements in a continuous way.

7.3 METHODS

7.3.1 Phase 1: In-depth feedback from theatre staff

In order to gain an in-depth knowledge of the factors effecting safety culture in the most high risk areas, an interview study was conducted with operating theatre staff. All theatre staff, regardless of job or grade, were recruited to participate in semi-structured qualitative interviews about the factors affecting safety in the theatre environment. Information about participating in an interview was relayed to all theatre staff via theatre leads.

Topic guides were developed based on the key topics affecting safety culture in the literature and tested with theatre staff in advance of the study (APPENDIX E). The interviews were conducted in the theatre environments and recorded for transcription. Transcripts were double coded and a thematic analysis was carried out on the resulting data. The main themes were organised using the McKinsey 7S Framework (302), which outlined the components of organisational change. This allowed researchers to align the contents of each theme to one or multiple components of change:

<u>Example Theme Mapping to 7S Framework</u>
Skills and training: Lack of training was reported as a major concern, resulting in the lack of appropriate skill mix, and a lack of confidence around patient handover. This can be improved by a formal skills assessment, protected time for training and a procedure for ensuring bank staff have the requisite training.

The strategy for change involved using the 7S Framework to identify problems and match them with an actionable solution. Responses to the validated SAQ discussed below will, in future, be used as a pre-post test for each solution derived from the 7S Framework (290).

7.3.2 Phase 2: SAQ rollout

Following the in-depth qualitative work, a more systematic approach was taken to achieve a baseline of safety culture across the whole organisation. The SAQ was conducted in ICHT between 12th October 2016 and 10th January 2017. All staff, regardless of job role or contract type were invited to complete the SAQ. The survey link was sent to 8,664 staff email addresses via an email from the safety culture team. Email addresses of staff who were bank or agency staff, had left the organisation or were on long-term leave were then removed, giving a denominator of 8,353. Two reminder emails were sent at four weekly intervals. Responses were also obtained in person using iPads at meetings attended by the team, through three In Brief stories, and through links to the survey in the team's email footers. In addition, the divisional managers were asked to encourage their teams to complete the survey through weekly reminders at the Medical Director's incident review panel.

The SAQ included 33 statements about safety culture to which respondents could agree or disagree, as well as 6 demographic questions focusing on job characteristics. All safety statements and demographic questions were mandatory, meaning that respondents could not skip over any of them. The 33 safety statements were all presented on a Likert scale with the options including:

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree
- N/A

SAQ scoring

Partial credit scoring, the scoring system used in the NSS and NPSP that has proven to be highly reliable, was employed to highlight areas of success and areas for improvement (143). This scoring system helped observe the extent of staff's positivity towards each of the safety attitudes. Strong agreement represented very positive attitudes, while agreement represented generally positive attitudes. Both strong disagreement and disagreement represented no positivity, and therefore indicated room for improvement. This procedure also made sure that neutral responses were not misrepresented as middling levels of positivity. Moreover, a traditional 1-5 scoring approach was not used because that would have falsely inflated neutral and negative responses.

Responses to the 33 safety statements were scored such that a numeric value was applied to each response on the Likert scale. Out of the 33 statements, 26 were worded positively; meaning that responding, "Agree" or "Strongly Agree" indicated a positive view of safety culture.

For instance a statement like, "*I experience good collaboration with the doctors where I work*" is positively worded, and agreement with it demonstrates positivity towards this aspect of safety culture. For these 26 statements, coding was applied such that the most agreement got the highest score and disagreement received a 0. These scores were applied to positively worded statements:

- Strongly Agree = 10
- Agree = 5
- Neutral = No score
- Disagree = 0
- Strongly Disagree = 0
- N/A = No score

The 7 remaining statements were negatively worded; meaning that agreement with them actually indicated something negative about safety culture. For instance, "*It is difficult to discuss errors where I work*" is a negatively worded statement and only disagreement with it would suggest positivity towards this aspect of safety culture. Such statements were scored using the reverse pattern, and are presented in blue in the results. This ensures that high scores only indicate positivity.

- Strongly Agree = 0
- Agree = 0
- Neutral = No score

- Disagree = 5
- Strongly Disagree = 10
- N/A = No score

SAQ data analysis

Once all data was scored, the dataset contained a unique pseudonymised identifier for each respondent, as well as 6 demographic variables and 33 scored responses to the safety statements. The dataset was then input to SPSS to perform analysis.

Averages were taken for each question at the organisation level, which enabled a view of where the entire organisation was doing best and where it needed improvement. SAQ results were also broken down and compared by staff group (as determined by staff type classifications used on the NSS), hospital site, division and directorate.

Data for each of these comparisons was then put back into Excel to clearly demonstrate the variation in scores. Conditional formatting was used purely as a visual tool to depict where areas of positivity were in each staff group, hospital site, division and directorate. This formatting helped visualise trends and pick out areas of success or concern amongst many data points. Statements with scores less than 5 were identified at the organisation, and each comparative level, as areas for improvement. This is because a score of less than 5 indicated that the average respondent did not respond positively. Themes were drawn out for the organisation level, as well as each of the comparison levels to understand what requires improvement and what could be showcased as success.

Thematic analysis of the SAQ has historically been conducted using seven dimensions (teamwork climate, job satisfaction, perceptions of management, safety climate, working conditions and stress recognition). Whilst the organisation could still conduct a thematic analysis using these dimensions, staff felt that some of these dimensions did not directly relate to aspects of the organisation’s safety culture. Instead they thought it would be useful to attempt an analysis of the SAQ results using the MaPSaF domains, which have a clearer relationship to actionable elements of the organisation’s existing action plans. The MaPSaF was then used as a tool for grouping questions and creating themed scores.

The MaPSaF is a well recognised tool that is used to assess the maturity of safety culture within teams (303).

The MaPSaF included ten “domains” of safety culture:

- Commitment to overall continuous improvement
- Priority given to safety
- System errors and individual responsibility
- Recording incidents and best practice
- Evaluating incidents and best practice
- Learning and effecting change
- Communication about safety issues
- Personnel management and safety issues
- Staff education and training
- Team working

During this process it was considered useful to add an eleventh domain to capture the feedback received around the theme of leadership and safety, a priority topic for the Medical Director’s office. As a result, the SAQ questions were mapped to the dimensions of the MaPSaF, (including the eleventh dimension of “leadership and safety culture”). Averages for each group were then taken at the organisation, staff group, divisional and directorate level.

Data disaggregation and theming (as suggested in previous chapters) was used to facilitate data comprehension and improvement planning.

7.3.3 Phase 3: Listening events & identifying areas for improvement

Following the SAQ and analysis of it, priority areas were identified. The Medical Director’s office in collaboration with the Quality Improvement team and researchers designed opportunities for staff to convene to discuss the reasons for the results and ideas to learn from them. These events were referred to as listening events, which took the form of workshops. Staff followed a specified series of questions starting from comprehending the problem, moving towards prioritising issues and developing short, medium and long-term solutions.

The Quality Improvement team recorded staff contributions to the listening events and developed word clouds to describe the prominence of themes discussed during the sessions.

7.3.4 Phase 4: Driving improvements

The results of each phase were considered collectively and used to drive short-term and long-term goals, some of which have already materialised with measurable improvements. Others have been designed and will be integrated into long-term improvement plans at ICHT.

7.4 RESULTS

7.4.1 Phase 1: In-depth theatre staff feedback results

A total of 21 interviews were conducted across the three main ICHT hospital sites involving 13 nurses, 4 doctors, 3 health care assistants and one member of clerical staff.

The main findings surrounded ineffective coordination and communication between and within teams:

> *“Coordination is difficult because we are across multiple sites. Not as cohesive as it could be” (Doctor)*
>
> *“The fact that HDU beds are spread out everywhere and that critical care is not run as a single service doesn’t help” (Nurse)*
>
> *“Doctors and nurses aren’t on the same page around discharge even in one unit. It’s not seen as the doctors problem, it’s the nurses that need to sort it out” (Nurse)*

There was also a sense that safety was a priority, but whether or not it could be achieved depended on the staffing or skill mix of any particular team.

> *"Even when everyone worries [about] safety, it feels as though the shortage of staff is worsening and the workload is increasing" (Nurse)*
>
> *"Staffing levels on the wards are seen as a particular issue for receiving patients and causing delayed discharges and other safety problems" (Nurse)*
>
> *"We [are] keeping patients in ICU because of staff skill mix on wards" (Anonymous)*

These as well as the other findings were then mapped using the 7S Framework to identify organisational priorities (Table 30) (302). The first column of Table 32 presents the seven aspects of the framework, the second column highlights main findings in relation to each aspect of the framework and the third column lists possible opportunities that were identified to rectify problems relating to each aspect.

Table 30. Theatre interview findings in 7S Framework (302)

7s Framework	Key issues	Opportunities
Strategic Priorities	• Change and investment is too often reactive; based on an incident or who shouts the loudest • *"Safety is one of the most complicated problems of our time in the theatres … and we try to make a five minute video... That's not really a serious effort to change such a complicated thing."* • *"If the way that changes are being made was a bit better then the resistance of the staff would be a bit less"*	• Proactive investment planning to avoid reactive decision-making
Structures	• Lack of clarity about roles, responsibilities and ownership within organisational structures • *"They think it's our problem … but if you don't start it's not my problem. If your list overruns it's not my problem. Well, actually, it is everybody's problem*"	• Define escalation procedures and opportunities for clear accountability framework • Recognition that there is need for individual accountability within teams
Systems and Process	• WHO checklist great to have but there is a risk that is can become automated • Some of the policies are out of date and systematically need to be updated • Availability and quality of equipment is a major contributor to safety incidents • *"We have a serious problem in the equipment... We've been using the same instruments for the last 10, 15 years, okay. And I can tell you… about 70% [of incidents] are related to the faulty equipment"*	• Develop solutions focused on commitment rather than just compliance • Develop or utilise robust asset register and a process of updating equipment
Shared values & priorities	• Need for strong and unrelenting patient-centred values • Apathy due to perceived inability to change • *"In consultant led service, there is a reluctance to change"*	• Follow through on actions and provide feedback mechanism
Skills & training	• Perceived lack of training for theatre staff • Inappropriate skill mix can result in not having the right staff for right patients • *"Our first priority is the patient...make sure that their dignity is being looked after … they comfortable and times that*	• MDT training opportunities and plan for developing a balanced skill mix • Assertiveness training for confidence building

	they can’t really talk because when they are under the anaesthesia...we are like their eyes and their feelings as well, so you look out to see that they are comfortable”	
Staff	• Rotating staff – elective and emergency – affects confidence and teamwork • Staff retention issues and impact of locum/agency staff • All leads to “uncertainty” and “increased anxiety” • *“We’re always rotating and hardly ever– or most of us do not- have the same people working together. Sometimes we come together as a brilliant team.”*	• Plan to make theatres a “great place to work”
Style, communication & relationships	• Generally, theatre environment has excellent teamwork, although there are pockets where this is not the case e.g. poor MDT communication • Leadership perceived as not listening, feedback not timely and decision not transparent. • Communication can become “hit and miss” • *“So a lot of the time the staff are talking here as well, but there’s no serious effort to listen to them”* • *“We don’t hear any feedback from the last few months that we’ve been talking about all these problems that we don’t get feedbacks from them.”*	• Develop mechanism for timely feedback and transparent decision making • Develop framework for cascading information in a consistent way to staff

7.4.2 Phase 2: SAQ results

The SAQ was completed by 1580 ICHT employees at six sites (renal satellite sites have been combined for the purposes of this survey) across all divisions and directorates. The final response rate was 1580/8353 (19%). Figure 36 shows the volume of responses received over the course of the survey.

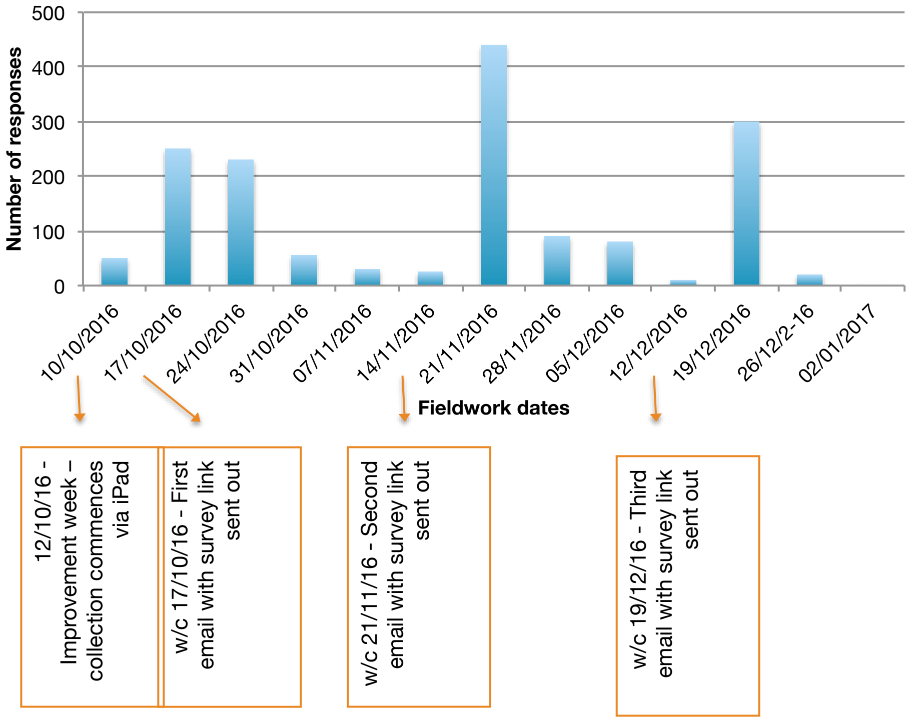


Figure 36. Response volume over time and fieldwork milestones

The SAQ results to the 33 questions are descriptive and indicate how people across the organisation felt about certain aspects of safety culture. They also enabled descriptive comparisons of how different groups felt (i.e. staff groups, sites, divisions and directorates).

It is important to note that the three statements that received the least positivity were not necessarily reflections of the organisational culture. These statements were personal, and agreement or disagreement with them did not necessarily relate to the organisational culture. For instance, "*I am less effective at work when fatigued*" is a negatively worded question, which was reverse scored. Agreement with it therefore indicated negativity. However, ICHT staff decided it was fair to assume that any employee could agree with this statement regardless of their organisations’ safety culture. This decision did not have any empirical backing, so rather than remove the three questions that fell into this category, they were presented in the results with a thick black line above them to indicate their separation from the diagnostic proses. They were, however, removed from staff group, site, division and directorate averages.

Organisational results

As an organisation, 20 out of the 30 statements included in diagnostic analysis received a score above 5, equating to agreement or strong agreement. As Table 31 demonstrates, there is a strong sense of organisation-wide positivity towards overall job satisfaction, being able to ask questions and encouraged to report incidents. However, there were 10 statements indicating a need for improvement. Generally, the organisation level priorities revolved around communication/information giving, support and training, senior management, how problem staff are handled and feelings of safe staffing.

Table 31. Trust level SAQ results

Question	Mean
13. I like my job	6.77
15. I am proud to work where I do	6.60
7. I know the proper channels to direct questions regarding patient safety where I work	6.46
10. I am encouraged by my colleagues to report any patient safety concerns I may have	6.38
3. It is easy for staff here to ask questions when there is something that they do not understand	6.35
28. I experience good collaboration with nurses where I work	6.19
5. I would feel safe being treated here as a patient	6.14
6. Clinical errors are handled appropriately where I work	6.08
14. This is a good place to work	6.02
1. Where I work, it is difficult to speak up if I perceive a problem with patient care	5.96
12. My suggestions about safety would be acted upon if I expressed them to my line manager	5.88
29. I experience good collaboration with doctors where I work	5.79
20. My line manager supports my daily efforts	5.76
2. Disagreements are resolved appropriately where I work (i.e. not who is right, but what is best for the patient)	5.63
27. Trainees/Students in my area of work are adequately supervised	5.60
4. The staff here work together as a well-coordinated team	5.56
8. I receive appropriate feedback about my performance	5.38
21. Senior leaders don't knowingly compromise patient safety	5.32
9. It is difficult to discuss errors where I work	5.21
11. The culture where I work makes it easy to learn from the errors of others	5.13
24. I get adequate & timely information about events that might affect my work, from my line manager	4.99
26. This organisation does a good job of training new staff	4.73
22. Senior leaders are doing a good job	4.64
31. I have support I need from other staff to care for patients	4.23
32. All the necessary information for diagnostic and therapeutic decisions is routinely available to me	4.01
16. Morale is high where I work	3.71
23. Problem staff are dealt with constructively in our organisation	3.14

33. Fatigue impairs my performance during emergency situations (e.g. emergency resuscitation, seizure)	3.00
25. Where I work the levels of staffing are sufficient to handle the number of patients	2.55
30. Communication breakdowns that lead to delays in delivery of care are common	2.50
19. I am more likely to make errors in tense or hostile situations	1.30
17. When my workload becomes excessive, my performance is impaired	1.29
18. I am less effective at work when fatigued	0.67

At each comparative level (staff group, site, division, directorate) the scores were displayed in order of the organisation level results to expose that the organisation level patterns were not always consistent to all staff and areas, and action planning would need to be devolved.

Staff group results

Eight out of 13 staff groups had an average score above 5. This means that on average, these groups demonstrated positivity about safety culture:

1. Admin & Clerical
2. Allied Health Professionals (unregistered)
3. Consultant Doctors
4. Maintenance/Ancillary
5. Nursing/Midwifery (unregistered)
6. Nursing/Midwifery (registered)
7. Science & Technical (unregistered)
8. Senior Managers

The other five groups indicated less positivity:

1. Allied Health Professional (registered)
2. Doctor (Career grade - associate specialist or specialty doctor)
3. Doctor (training grade)
4. Pharmacist
5. Scientific and Technical (registered)

As Table 32 demonstrates, the average scores of these five staff groups were still relatively positive (i.e. all are greater than 4), and there was variation when looking across the individual questions. In response to some questions, where the organisation-level results show negativity, certain staff groups demonstrate a more encouraging sentiment.

Senior managers and unregistered nurses, for example, exhibited more positivity around information, training and support than other groups, while nurses, senior managers and unregistered allied health professionals demonstrated the highest morale and general workplace positivity. However, communication was consistently low across staff groups.

Perceptions of morale received negative scores from consultants and registered scientific and technical staff. Doctors, pharmacists and registered allied health professionals also perceived staffing levels very negatively and career grade doctors offered very negative feedback on team coordination. Training grade doctors were more positive about coordination but were on average the only group that did not feel encouraged to report safety incidents and found it difficult to speak up about safety. Admin and clerical staff also exhibited concerns about discussing errors and maintenance staff showed much more positivity on all questions, however they were a very small group and relatively removed from most safety issues (only 0.8% of the overall sample).

Table 32. Staff group SAQ results (next page)

Which of the following best describes your role or profession?	Admin & Clerical	Allied Health Professional (registered)	Allied Health Professional (unregistered)	Doctor	Consultant	Doctor - training grade	Maintenance/Ancillary	Nursing/Midwifery (registered)	Nursing/Midwifery	Pharmacist	Scientific & Technical	Scientific & Technical	Sr. Manager
Percentage of respondent profile	20.6%	11.3%	6.1%	1%	7.3%	2.2%	0.8%	32.4%	6.6%	1.3%	3.5%	1.5%	5.4%
Staff group average	5.00	4.84	5.44	4.82	5.03	4.71	6.76	5.20	6.02	4.96	4.85	5.52	5.65
13. I like my job	6.17	6.44	7.33	6.43	6.73	6.43	7.73	6.92	7.64	7.06	5.77	5.38	7.58
15. I am proud to work where I do	6.22	6.02	7.40	6.54	6.49	6.48	7.50	6.68	7.32	7.19	5.74	6.00	7.12
7. I know the proper channels to direct questions regarding patient safety where I work	5.78	6.40	5.71	5.71	6.81	5.19	7.78	6.61	7.47	6.88	6.25	7.00	7.03
10. I am encouraged by my colleagues to report any patient safety concerns I may have	6.11	6.30	6.45	5.77	6.46	4.52	6.88	6.44	6.75	7.50	6.22	5.36	6.93
3. It is easy for staff here to ask questions when there is something that they do not understand	5.92	6.57	6.30	5.71	6.41	5.83	7.27	6.38	6.93	6.88	6.16	7.00	6.41
28. I experience good collaboration with nurses where I work	5.80	5.39	5.85	6.67	7.37	7.31	7.50	6.09	6.60	6.25	5.00	7.00	6.85
5. I would feel safe being treated here as a patient	5.93	5.67	6.19	5.00	6.05	5.63	7.78	6.28	6.65	5.33	6.00	6.15	6.69
6. Clinical errors are handled appropriately where I work	6.10	5.83	6.36	5.00	5.97	5.23	7.00	6.12	6.60	5.38	5.98	5.83	6.22
14. This is a good place to work	5.71	5.41	6.45	6.15	5.96	6.04	8.89	6.02	7.32	6.76	4.43	5.42	6.46
1. Where I work, it is difficult to speak up if I perceive a problem with patient care	5.72	5.54	5.89	5.00	6.56	4.35	8.33	5.91	6.24	5.59	5.97	5.77	7.30
12. My suggestions about safety would be acted upon if I expressed them to my line manager	5.31	5.79	6.04	5.00	5.54	5.00	6.82	5.99	6.30	6.18	6.15	6.15	6.94
29. I experience good collaboration with doctors where I work	5.90	5.28	5.49	7.08	7.05	7.04	5.00	5.49	5.82	5.36	5.33	6.11	6.09
20. My line manager supports my daily efforts	5.63	5.27	5.89	5.00	5.78	4.64	6.82	5.80	6.15	6.18	5.91	5.38	6.72
2. Disagreements are resolved appropriately where I work (i.e. not who is right, but what is best for the patient)	5.57	5.20	5.71	5.42	5.56	4.78	6.43	5.59	6.45	5.67	5.30	6.54	6.21
27. Trainees/Students in my area of work are adequately supervised	5.38	5.63	6.25	5.00	6.18	4.60	9.00	5.40	5.97	5.00	5.00	5.00	5.78
4. The staff here work together as a well-coordinated team	5.24	5.30	5.94	3.89	5.93	5.54	6.36	5.65	6.45	5.67	5.71	4.64	4.85
8. I receive appropriate feedback about my performance	5.19	5.57	5.49	5.00	5.12	3.75	6.82	5.42	5.63	6.00	5.26	5.77	5.51
21. Senior leaders don't knowingly compromise patient safety	5.50	5.15	4.02	5.00	5.29	6.00	5.50	4.95	5.82	4.64	5.71	7.22	7.00
9. It is difficult to discuss errors where I work	4.87	5.04	5.07	4.58	5.45	4.13	7.50	5.10	5.84	5.67	5.71	6.25	5.68
11. The culture where I work makes it easy to learn from the errors of others	5.20	4.84	5.71	4.55	4.89	3.86	6.67	5.26	5.83	4.29	4.72	6.00	4.27
24. I get adequate & timely information about events that might affect my work, from my line manager	4.65	4.88	5.41	5.56	4.25	3.33	6.50	5.07	5.35	5.00	5.97	5.36	5.68
26. This organisation does a good job of training new staff	4.60	5.09	5.43	3.89	3.15	3.33	6.11	4.84	6.14	4.58	3.43	5.50	4.24
22. Senior leaders are doing a good job	4.55	4.16	5.43	3.57	4.10	5.40	7.50	4.41	5.62	4.09	3.54	6.25	5.45
31. I have support I need from other staff to care for patients	3.94	3.50	4.53	3.18	3.65	4.20	5.00	4.40	5.53	3.13	4.29	5.00	5.00
32. All the necessary information for diagnostic and therapeutic decisions is routinely available to me	4.20	3.21	4.69	4.58	3.87	3.15	7.50	3.93	5.69	2.50	4.00	5.00	5.36

16. Morale is high where I work	3.38	2.72	5.31	4.44	1.99	4.09	7.50	4.00	5.87	4.17	1.62	2.69	3.90
23. Problem staff are dealt with constructively in our organisation	3.10	2.23	4.13	4.00	2.07	3.57	5.71	3.09	5.09	2.50	2.86	3.33	2.67
33. Fatigue impairs my performance during emergency situations (e.g. emergency resuscitation, seizure)	2.61	2.83	3.25	3.18	2.71	2.22	3.33	2.95	4.33	1.67	3.57	5.00	3.21
25. Where I work the levels of staffing are sufficient to handle the number of patients	3.03	1.97	3.13	1.50	1.35	2.50	7.00	2.65	3.23	0.00	1.18	4.00	3.87
30. Communication breakdowns that lead to delays in delivery of care are common	2.56	1.94	2.26	2.08	2.19	3.10	3.00	2.48	3.87	1.67	2.69	3.50	2.50
[redacted]													
19. I am more likely to make errors in tense or hostile situations	1.55	0.83	2.18	0.56	0.54	0.19	3.75	1.19	2.46	0.29	0.77	1.54	2.11
17. When my workload becomes excessive, my performance is impaired	2.00	0.65	1.83	0.83	0.39	0.36	0.56	1.17	2.42	1.07	0.88	3.08	1.60
18. I am less effective at work when fatigued	1.27	0.17	1.36	0.00	0.21	0.17	1.36	0.56	1.43	0.00	0.36	0.83	0.24

Site level results

All sites besides Queen Charlotte and Chelsea received average scores above 5. These include Charing Cross, combined renal sites, Hammersmith, St. Mary's and the Western Eye. At the site level, scores broadly followed the same pattern as organisation level results, with some interesting variation on certain questions.

Staff at the Western Eye found it more difficult to raise questions than other sites. However, the Western Eye had very positive attitudes towards senior leaders.
Staff at Queen Charlotte and the Western Eye did not think their suggestions about safety would be acted upon and did not think that disagreements were resolved appropriately. The combined renal sites had poor perceptions of senior leadership. However, communication was still low across sites aside form the combined renal sites (Table 33).

Table 33. Site level SAQ results

Which site do you spend most time at?	Charing Cross Hospital	Combined Renal Sites	Hammersmith Hospital	Queen Charlotte's and Chelsea	St. Mary's Hospital	Western Eye Hospital
Percentage of respondent profile	31.7%	3%	21%	4.9%	38%	1.30%
Site Average	5.10	5.14	5.25	4.70	5.31	5.03
13. I like my job	6.64	6.81	6.86	6.41	6.87	6.88
15. I am proud to work where I do	6.41	6.25	6.69	6.53	6.77	5.88
7. I know the proper channels to direct questions regarding patient safety where I work	6.50	6.45	6.37	6.00	6.54	6.56
10. I am encouraged by my colleagues to report any patient safety concerns I may have	6.18	6.91	6.28	6.25	6.54	7.14
3. It is easy for staff here to ask questions when there is something that they do not understand	6.17	6.11	6.54	6.44	6.46	4.71
28. I experience good collaboration with nurses where I work	6.13	5.50	6.21	5.82	6.34	6.00
5. I would feel safe being treated here as a patient	5.83	6.17	6.29	6.17	6.27	6.79
6. Clinical errors are handled appropriately where I work	5.95	6.49	6.36	5.00	6.10	6.88
14. This is a good place to work	5.87	6.54	6.07	5.88	6.07	7.00
1. Where I work, it is difficult to speak up if I perceive a problem with patient care	5.73	5.77	5.93	5.34	6.26	6.00
12. My suggestions about safety would be acted upon if I expressed them to my line manager	5.71	6.09	5.89	4.81	6.18	4.67
29. I experience good collaboration with doctors where I work	5.75	5.25	5.93	5.78	5.81	5.00
20. My line manager supports my daily efforts	5.57	5.38	5.67	5.10	6.07	5.71
2. Disagreements are resolved appropriately where I work (i.e. not who is right, but what is best for the patient)	5.78	5.57	5.58	4.80	5.69	4.67
27. Trainees/Students in my area of work are adequately supervised	5.59	5.38	5.64	5.09	5.65	6.36
4. The staff here work together as a well-coordinated team	5.38	5.74	5.59	5.00	5.80	4.41
8. I receive appropriate feedback about my performance	5.19	5.17	5.43	3.94	5.67	5.88
21. Senior leaders don't knowingly compromise patient safety	5.41	3.82	4.91	5.23	5.50	6.25
9. It is difficult to discuss errors where I work	5.32	5.78	5.12	4.25	5.25	5.00
11. The culture where I work makes it easy to learn from the errors of others	4.95	6.17	4.98	4.07	5.43	5.00
24. I get adequate & timely information about events that might affect my work, from my line manager	5.05	4.81	4.86	3.93	5.21	4.00
26. This organisation does a good job of training new staff	4.61	4.00	5.31	4.25	4.69	3.18
22. Senior leaders are doing a good job	4.57	3.10	4.66	3.45	4.89	6.25
31. I have support I need from other staff to care for	4.08	5.00	4.18	4.72	4.25	4.29

patients						
32. All the necessary information for diagnostic and therapeutic decisions is routinely available to me	3.85	4.76	4.18	4.30	3.99	3.33
16. Morale is high where I work	3.79	3.52	3.69	2.58	3.88	2.50
23. Problem staff are dealt with constructively in our organisation	3.19	3.91	3.21	2.44	3.05	4.29
33. Fatigue impairs my performance during emergency situations (e.g. emergency resuscitation, seizure)	3.11	1.36	3.09	3.59	2.94	2.78
25. Where I work the levels of staffing are sufficient to handle the number of patients	2.30	2.04	2.96	1.33	2.85	1.56
30. Communication breakdowns that lead to delays in delivery of care are common	2.25	4.20	2.90	2.45	2.37	1.82
19. I am more likely to make errors in tense or hostile situations	1.32	1.15	1.39	1.14	1.29	0.94
17. When my workload becomes excessive, my performance is impaired	1.16	2.14	1.50	1.61	1.24	0.29
18. I am less effective at work when fatigued	0.56	1.25	0.78	0.61	0.68	0.63

Division level results

All divisions had an overall average score over 5 and results followed the same basic pattern as the organisation with a few minor variations.

The Corporate division responded higher than the average in perceptions of clinical errors and disagreements being handled appropriately, support from line managers, perceptions of senior leaders, perceptions of staffing levels and morale. Medicine & integrated care and Surgery, Cancer & Cardiovascular Sciences had negative perceptions of senior leaders knowingly compromising safety. Medicine & integrated care received high scores in sections relating to emergency or unplanned care. Women's & Children's were more negative than average about trainee supervision and whether or not they received appropriate feedback and information. Most starkly, Women's & Children's had very negative perceptions of problem staff being dealt with effectively (Table 34).

Table 34. Division level SAQ results

What division do you work in?	Corporate	Medicine & Integrated Care	Surgery, Cancer & Cardiovascular	Women's, Children's & Clinical Support
Percentage of respondent profile	15.90%	33.90%	28.20%	22%
Division Average	5.43	5.15	5.13	5.16
13. I like my job	6.98	6.76	6.85	6.53
15. I am proud to work where I do	6.85	6.55	6.43	6.73
7. I know the proper channels to direct questions regarding patient safety where I work	6.27	6.42	6.47	6.63
10. I am encouraged by my colleagues to report any patient safety concerns I may have	6.62	6.35	6.19	6.50
3. It is easy for staff here to ask questions when there is something that they do not understand	6.21	6.33	6.24	6.62
28. I experience good collaboration with nurses where I work	6.43	6.08	6.23	6.20
5. I would feel safe being treated here as a patient	6.08	6.00	6.16	6.38
6. Clinical errors are handled appropriately where I work	5.77	6.03	6.14	6.20
14. This is a good place to work	6.25	5.95	6.12	5.84
1. Where I work, it is difficult to speak up if I perceive a problem with patient care	6.62	5.82	5.86	5.92
12. My suggestions about safety would be acted upon if I expressed them to my line manager	6.37	5.88	5.72	5.73
29. I experience good collaboration with doctors where I work	5.72	5.95	5.56	5.90
20. My line manager supports my daily efforts	6.74	5.49	5.55	5.72
2. Disagreements are resolved appropriately where I work (i.e. not who is right, but what is best for the patient)	6.14	5.70	5.34	5.60
27. Trainees/Students in my area of work are adequately supervised	5.57	5.74	5.69	5.29
4. The staff here work together as a well-coordinated team	5.32	5.55	5.64	5.64
8. I receive appropriate feedback about my performance	5.75	5.45	5.13	5.31
21. Senior leaders don't knowingly compromise patient safety	6.63	4.95	4.81	5.54
9. It is difficult to discuss errors where I work	5.43	5.32	5.14	4.96
11. The culture where I work makes it easy to learn from the errors of others	5.06	5.10	5.25	5.04
24. I get adequate & timely information about events that might affect my work, from my line manager	5.70	4.90	4.91	4.71
26. This organisation does a good job of training new staff	4.79	4.86	4.64	4.63
22. Senior leaders are doing a good job	5.33	4.44	4.57	4.52
31. I have support I need from other staff to care for patients	3.82	4.16	4.40	4.25
32. All the necessary information for diagnostic and therapeutic decisions is routinely available to me	3.80	4.00	4.12	3.95
16. Morale is high where I work	4.23	3.67	3.77	3.36
23. Problem staff are dealt with constructively in our	3.17	3.35	3.32	2.56

organisation				
33. Fatigue impairs my performance during emergency situations (e.g. emergency resuscitation, seizure)	3.45	2.85	3.03	3.11
25. Where I work the levels of staffing are sufficient to handle the number of patients	3.83	2.36	2.49	2.41
30. Communication breakdowns that lead to delays in delivery of care are common	2.07	2.55	2.24	2.95
19. I am more likely to make errors in tense or hostile situations	1.83	1.35	1.27	0.93
17. When my workload becomes excessive, my performance is impaired	1.80	1.19	1.19	1.24
18. I am less effective at work when fatigued	0.64	0.77	0.67	0.55

Directorate level results

Given that variation across divisions was limited, and results broadly mirrored those of the organisation, not every question required examining at the more granular directorate level. Furthermore, the respondent numbers for each directorate were very small and cannot necessarily provide a good indication of the overall directorate, or a useful comparison to others.

The most useful approach to learning from directorate level results was to identify areas of outlying negativity and positivity so that specific actions could be explored in response.

Table 35. Directorate level results

Directorate	Potential areas for learning	Potential areas for improvement
Corporate	• ICT and Nursing directorates around being able to speak up	• Chief Financial Officer's office around knowing where to channel questions about safety and around training new staff • Cross directorate around trainee supervision • Medical Director's office around perceptions of communication
Medicine & Integrated Care	• Urgent Care & Emergency Medicine around staff coordination and learning from the errors • Specialist Medicine and Cross directorate in speaking up about problems	• Clinical research facility around support and information • Cross directorate around clinical errors being handled appropriately, trainees being supervised and communication • Integrated care around nurse collaboration • Renal around perceptions of senior leaders • Therapies around support and information • Urgent Care & Emergency Medicine around fatigue and staffing levels
Women's & Children's	• Cross directorate around being encouraged to report errors and being able to speak up when there is a problem • Outpatients around knowing the channels to report errors Pharmacy around line management	• Cross directorate around suggestions about safety, receiving timely feedback, training for new staff, dealing with problem staff and staffing levels • Imaging around perceptions of senior leaders knowingly compromising safety, problem staff being dealt with effectively and perceptions of staffing levels • Maternity around problem staff and staffing levels • Outpatients around support and having all the necessary information • Pathology around support, morale and problem staff • Pharmacy around perceptions of staffing levels
Surgery, Cancer & Cardiovascular	• Cross directorate team for being able to speak up • Clinical haematology for training • Ophthalmology for perceptions of senior leaders and in trauma for morale	• Cardiac around perceptions of senior leaders compromising safety • Critical care around fatigue • Cross directorate around learning from errors and receiving necessary information • General surgery around perceptions of senior leaders compromising safety and communication • Oncology and Ophthalmology around being able to speak up, communication and staffing levels • Specialist surgery around problem staff and staffing levels • Theatres/anaesthesia around problem staff, staffing and communication

MaPSaF

When grouping SAQ questions by the MaPSaF domains, it was clear that learning and effecting change received the most positive results (score of 5.81) while leadership and communication received more negative results (score of 4.30 and 3.85 respectively) at the organisation level.

Table 36. Organisational MaPSaF theming results

MaPSaF Domain	Question	Section Score
Learning and effecting change	1. Where I work, it is difficult to speak up if I perceive a problem with patient care	5.81
	3. It is easy for staff here to ask questions when there is something that they do not understand	
	6. Clinical errors are handled appropriately where I work	
	7. I know the proper channels to direct questions regarding patient safety where I work	
	11. The culture where I work makes it easy to learn from the errors of others	
Team working	4. The staff here work together as a well-coordinated team	5.31
	28. I experience good collaboration with nurses where I work	
	29. I experience good collaboration with doctors where I work	
	31. I have support I need from other staff to care for patients	
Personnel management and safety issues (leadership)	20. My line manager supports my daily efforts	5.27
	23. Problem staff are dealt with constructively in our organisation	
Personnel management and safety issues	2. Disagreements are resolved appropriately where I work (i.e. not who is right, but what is best for the patient)	
	8. I receive appropriate feedback about my performance	
	13. I like my job	
	14. This is a good place to work	
	15. I am proud to work where I do	
	16. Morale is high where I work	
Staff education and training	26. This organisation does a good job of training new staff	5.04
	27. Trainees/Students in my area of work are adequately supervised	
System errors and individual responsibility	12. My suggestions about safety would be acted upon if I expressed them to my line manager	5.03
	17. When my workload becomes excessive, my performance is impaired	
	19. I am more likely to make errors in tense or hostile situations	
	18. I am less effective at work when fatigued	
	33. Fatigue impairs my performance during emergency situations (e.g. emergency resuscitation)	
Priority given to safety (leadership)	21. Senior leaders don't knowingly compromise patient safety	4.98
	22. Senior leaders are doing a good job	
	25. Where I work the levels of staffing are sufficient to handle the number of patients	
Priority given to safety	5. I would feel safe being treated here as a patient	
	9. It is difficult to discuss errors where I work	
	10. I am encouraged by my colleagues to report any patient safety concerns I may have	

Leadership Cross-sectional	21. Senior leaders don't knowingly compromise patient safety 22. Senior leaders are doing a good job 25. Where I work the levels of staffing are sufficient to handle the number of patients 24. I get adequate & timely information about events that might affect my work, from my line manager 20. My line manager supports my daily efforts 23. Problem staff are dealt with constructively in our organisation	4.30
Communication about safety issues (leadership) **Communication about safety issues**	24. I get adequate & timely information about events that might affect my work, from my line manager 30. Communication breakdowns that lead to delays in delivery of care are common 32. All the necessary information for diagnostic and therapeutic decisions is routinely available to me	3.85

7.4.3 Phase 3: Listening events feedback

Eight listening events were held with an attendance from 10-25 staff members at each.

During the listening events, staff discussed their ideals for a mature safety culture and developed personal and organisation level priorities for cultural improvement. Staff focused on gaining senior level support for driving individual and team based improvements and emphasised the importance of learning from incidents.

Ideas for improvement were very specific to the organisation and local operational procedures. Examples were as follows:

- Establish local safety culture champions
- Improve signage and "wayfinding" on the institutional Intranet
- Remove old information from the intranet
- Strategic plan to communicate local safety improvement to the whole organisation
- CEO communications other than generic emails about serious incidents

Figure 37. Word cloud depicting staff priorities for improved culture

7.5.4 Cumulative results: Materialised improvements

ICHT successfully implemented policy changes in response to the findings. Below is a list of initial changes based on research recommendations:

- Initiated new policy that ensures theatre teams do not start work without a brief
- Improved NSS response rate from 33% in 2015 to 42% in 2016, and improved overall staff engagement from 3.71 to 3.80 out of 5, placing ICHT at the National average (299)
- Work to roll out “Greatix’s” recognition for speaking up about safety
- Importance of positive staff culture included in the new Headstart leadership module for staff preparing for their first management role
- Establishment of the Incident Reporting Reference Group to better engage clinical colleagues and the Patient Safety Translational Research Centre (PSTRC) in improving our incident reporting

While most of the short-term improvements have been focused on directly improving safety culture, they emphasise positive communication and collaboration, which are necessary attributes for organisational quality improvement and use of patient feedback.

7.5 DISCUSSION

7.5.1 Statement of results

Interviews

The interview study revealed challenges to safety culture including ineffective communication amongst teams, concerns around skill mix of theatre teams and feelings that providing safe care depended on the staffing of any particular team.

SAQ

The breakdown of SAQ results helped identify problem areas and particular success. It also revealed that the patterns exhibited at the organisation level were broadly the same across different staff groups, sites, divisions and directorates.

Outliers to the organisational trend were important because they indicated very specific improvement priorities. For instance feelings of effective coordination amongst career grade doctors were considerably lower than the organisational average and other grades of doctors. Also, feelings of receiving adequate feedback were much lower for trainee doctors than any other group. More generally, results for registered groups of staff (nurses, technical and scientific staff) were notably lower than those of unregistered staff from the same groups. This trend may be attributable to registered staff having a greater knowledge of, and investment in, any existing cultural problems. On a positive note, however, outliers also provided examples from which to learn and improve. The Emergency Department and Urgent Care Division received better scores across questions than the organisational average. This finding offers an important area for learning for other challenging care environments, as well as a pillar of positivity amid substantial negative press about emergency care (304).

These results indicated that rather than individual questions being significantly better or worse in certain areas, that whole themes required work across the organisation. The use of the MaPSaF to group the individual metrics was effective in demonstrating the areas that required the most attention rather than cherry picking questions. The primary themes that needed attention related to communication and leadership. The MaPSaF highlighted that while staff demonstrated concerns in communication, actually their perceived ability to drive change was much more positive.

Listening events & improvements

The main findings from the listening also related to communication and better mechanisms for shared learning. Although the listening events formed a core part of the engagement around the culture work, very few concrete findings emerged other than how many were held, how many attended and what was discussed.

However, these events allowed action plans to be led and owned by individual divisions and directorates rather than parachuted in from the corporate level. Feedback from the meetings was used to inform immediate actions for policy revisions and will contribute to evidence-based, long-term culture change initiatives at ICHT. Part of the translational value to this work has been the organisations' ability to implement change based on research findings in a timely and locally-led way.

7.5.2 Findings in relation to existing literature

In the case of ICHT, these results demonstrate that communication and leadership were the most negatively perceived elements of staff culture and therefore potentially areas that have contributed to the inability to drive improvement from patient feedback. This observation is consistent with other literature suggesting that these are necessary components of a positive staff culture, receptive to patient feedback (183)(196). However, findings revealed that ICHT staff perceived the ability to drive change relatively positively. This invites more investigation into why staff felt positively about driving change and if that perception applies specifically to driving change from patient experience feedback.

Regarding the change process used in this study, a themed approach to cultural improvement facilitated by the MaPSaF and listening events, helped avoid the perception that senior management was issuing a perfunctory action plan, and engender trust that there was a long-term plan to improve the maturity of culture (217)(305). The strategy received communal participation in all three phases of work demonstrated by a relatively high survey response rate (as compared to other local staff surveys) and strong participation in interviews and listening events. This supports existing findings that a collaborative approach to cultural improvement is most helpful when it is not top-down or bottom-up, but collaborative based on collective feedback (188).

Furthermore, as evidenced throughout previous chapters, the idea of “question chasing” in order to improve patient experience scores is typically not a useful approach in terms of generating a holistically better experience for patients (206). The problem with question chasing is that it does not account for patterns that might be evident in the data, and, crucially, it does not promote learning from other areas of good performance (206). In this study, and in previous examples, better experience is achieved through a more concerted effort targeting an underlying trend that might be bringing down multiple questions.

Most importantly, this study corroborates findings that collaborative organisational cultures are a necessary pre-requisite to improving the use of patient experience feedback (187)(188)(196). Moreover, it provides a blueprint for how to begin to cultivate that culture.

7.5.3 Limitations

The primary limitation of this work was that it was based on a translational improvement programme rather than a strict research methodology. This meant that the focus was on safety culture rather than organisational culture in its entirety, which would have been preferable given the context of other chapters. Given that **Chapter 6** specifically pointed to the role of staff factors in predicting patient experience, it would be helpful for future research to work with multiple organisations to diagnose and improve culture with explicit relevance to how improving culture can stimulate changes in response to patient feedback. Furthermore, with regard to the translational strategy, while the SAQ phase was academically robust, future work to measure improvement in ICHT safety culture will need to account for the fact that the other two phases of the work did not adhere to the same academic rigour.

With regard to the SAQ phase, the most important barrier to extrapolating from results is the extent of neutral responses. Although neutral responses were deliberately removed to examine the extent of positivity and negativity, in some cases there were a very high number of neutral responses, making the denominator for the average scores very low. For example, when questions received many neutral or non-response answers, the average for those questions would only be based on a small group of people. This is especially important for staff group results where certain groups are already proportionally small, like maintenance staff. This group only had 13 people to begin with; consequently, if some gave neutral responses, the positivity (which is high in most places) might only be based on a few people. It is also important to note that groups like maintenance staff may be very removed from safety issues, so they might not have the same type of attitudes towards aspects of safety culture. This is important but cannot be determined from these results. Most importantly with regard to the SAQ, the metrics are not all sufficiently relevant to patient experience. The metrics are relevant to staff experience and the intention of this chapter was to create a baseline of staff culture that can be improved as a lever to bolster patient experience. However, it would have been useful to have employed a tool more specifically designed to capture staff empathy and relational ability that are critical to delivering patient experience.

The scoring used was intended to be helpful from a quality improvement perspective; however, it proved difficult to understand in some cases. In future iterations it would be prudent to use the existing SAQ scoring as well as partial credit scoring to identify problems to satisfy the needs of frontline staff who prefer a more traditional scoring system. The analysis would also be enhanced if triangulated with other sources of quality information. This process is currently underway within ICHT.

Finally, there is a limitation in data interpretation, as most results are presented in league tables. As discussed extensively through other chapters, league tables are descriptive and do not test the statistical difference between scores. This means that positions within a league table are not necessarily statistically meaningful (168). While limiting, the SAQ was intended to be diagnostic and descriptive to indicate areas in need of improvement. Statistical testing will become more important as interventions to improve scores are measured and evaluated.

7.5.4 Improvement strategy and next steps

This improvement exercise unearthed many more questions than it answered about why certain scores are negative, how to improve them and who is responsible for doing so. This can seem daunting to an organisation needing to make improvements quickly to satisfy regulators, commissioners and other external demands. However, the windows of insight these findings have opened cannot be ignored. They provide a relevant starting point for improving culture and organisational readiness to drive improvements based on patient experience feedback.

The scores to the individual questions serve as a diagnostic guide for improvement; however, further investigation into the sentiment behind the responses and real-life examples have also proven important for generating improvements. Leaders within the Medical Director's office are now working with staff in different directorates to develop explanations for why communication has been compromised in different parts of the organisation. This will help identify any existing protocols or practice that infringe upon effective communication. The on-going strategy allows staff to take ownership of actual improvement tasks designed to yield quick, incremental changes throughout a more long-term change process. For instance, ICHT are now embarking on a series of next steps to take forward the actions decided throughout these three phases and triangulate findings. In the first instance this relates to a targeted programme around communication, but it also includes wide-ranging programmes around local priorities like staffing perceptions, safety to speak up amongst clinicians and concerns around incident reporting. This requires deliberate attempts to relate the work back to improving based on patient feedback, which has involved the integration of more work with lay partners and involvement of experts in bridging the patient perspective on safety with that of healthcare professionals.

This process, in line with the iterative objectives, includes the continual collection of new information. The organisation will continue to collect metrics from future iterations of the SAQ, the NSS and AIPS. It will also keep qualitative logs regarding whether or not short-term goals have been achieved. This will help evidence over time how small shifts have corresponded to changes in cultural metrics. It will then be possible to determine if cultural shifts have also been concurrent with a greater ability to use patient experience feedback for quality improvement.

Further to that, appetite has grown across the North West London Academic Health Science Network for rolling the SAQ out on a larger scale to support improvement programmes in other organisations. A wider roll out would also support more effective benchmarking and learning: the more organisations involved, the more opportunities for translational learning and comparative assessments. This is especially true for highly specialised directorates that might learn best from the reflections of similar directorates at other organisations that would be familiar with the challenges of their specialty. Finally, this scale up would make it possible to identify a statistical relationship between positive shifts in culture and effective local uses of patient experience feedback.

In the future it will be important to use the tool to measure complex cultural interventions and fill a current gap in available metrics to quantify elements of organisational culture. There is scope to move the SAQ from providing helpful descriptive results towards exploiting it to generate predictive key performance indicators (KPIs). ICHT's pioneering approach has been a commendable way of making systemic improvements to bolster culture and, eventually, leverage the opportunities for patient-centric quality improvement that come with positive staff culture.

7.6 CONCLUSIONS

Improving the usefulness and use of patient experience feedback does not stop at rectifying problems within the collection and presentation of the data as explored in **Chapters 2-6**. Fundamentally, it involves building on the evidence around what drives patient experience and using a multitude of data sources to make systemic improvements to factors that are accountable for low patient experience. As staff explained in **Chapter 4**, this takes expertise to triangulate and understand data and requires a well-resourced and energised team responsible for quality improvement (6). Further to that, however, it demands an organisational mind-set that is not fixated on immediate gratification and score increases, but rather geared towards investment that will deliver long-term change over a period of time (196).

ICHT has been an exemplar organisation in this respect. Even though their patient experience data pointed to many challenges, the team took responsibility and instituted a plan to learn more about one of the single most important drivers of patient experience – staff culture. Not only did this get set in motion, the organisation utilised data expertise to break down the data in ways that **Chapters 2-6** have suggested are best to yield digestible information for improvement. Finally, the team engaged many different types of staff in this process in order to bolster response rates and galvanise support for the upcoming interventions. Further to that the organisation analysed their staff culture metrics to identify what might be affecting a more negative culture and preventing the process of data-driven, patient-centric change. Although the results were complex and demanded a long-term programme of work to bolster communication and leadership, the organisation embarked on its first steps and implemented a series of short-term goals in order to facilitate better communication around safety incidents. This is a first step, but a necessary one in order to promote the type of organisation amenable to communication and eventually patient-centric change.

The process from identifying a challenging culture, to systematically diagnosing it, to improving it to being able to leverage it as a platform from which to drive patient-centric change takes much more time than that provided within the scope of this study.

However, the benefits of a more open and collaborative culture at ICHT will ideally be objectively clear in future iterations of the SAQ, NSS and, ideally, AIPS.

The experience of ICHT in rolling out this programme does not provide a simple model for improving the local use of nationally collected patient experience data. This is because improving the local use of patient experience feedback cannot be simplistically modelled. On top of requiring better quality of data from the national system, being amenable and able to enact change desired by patients requires a specific organisational culture. Achieving that culture relies on a complex series incremental changes and a concerted effort towards more safe, open and collaborative culture.

CHAPTER 8

CONCLUSIONS & RECOMMENDATIONS FOR IMPROVING THE USEFULNESS AND USE OF PATIENT EXPERIENCE FEEDBACK

8.1. OVERVIEW OF FINDINGS

The previous chapter explored the practical actions necessary to build a positive staff culture capable of enacting patient-centric change locally. By showcasing the journey of one acute NHS organisation, it demonstrated the complexity to this task and highlighted the importance of communication and collaboration to enhancing culture. Cumulatively, the empirical findings from this research demonstrate how policy makers and local leaders within providing organisations can improve the usefulness and use of patient experience feedback. In order to guide action in this direction, these findings have been solidified into recommendations for policy and practice.

8.1.1 Review of research framework

The empirical findings, and the research techniques used to achieve them, originate from the research framework presented in **Chapter 1** (Figure 5). This framework was developed based on the narrative review, which identified six evidence gaps that needed to be addressed in order to fully understand how to improve the usefulness and use of patient experience feedback:

1. Need to interrogate the evidence surrounding what matters to patients
2. Need to identify how patient priorities vary across groups
3. Need to understand how the national system around patient surveys is supporting local providers' needs
4. Need to develop a robust composite metric that explains local variation and national quality
5. Need to understand what pathway and organisational factors predict experience
6. Need to use organisational levers practically to improve experience

As the framework sets out, a specific chapter was designated to address each evidence gap. The following sections outline the results from each chapter that are most critical to bridging these gaps and producing recommendations.

8.1.2 Key findings for improving the usefulness of patient experience feedback

The first empirical chapter, **Chapter 2**, demonstrates through a systematic review of literature that the evidence about what matters to patients is not as patient-centric as it could be. In order to rectify this situation and augment the level of direct patient input into what is known about patient priorities, it will be important to involve patients in more meaningful ways and structure feedback tools so that they allow for patient-driven rankings and more granular breakdowns of different groups' priorities. Moreover, the findings from **Chapter 2** suggest a need to refresh what is asked to patients, specifically investigating differences between patient groups.

Results from **Chapter 3** reveal that segmentation via cluster analysis is a useful methodological tool for disaggregating patient survey data and making it more useful to providers. Furthermore, when applied on a target population it demonstrates that certain patient groups do exist with differing needs and areas of concern for patient experience. While this work clarifies the breakdown of patient groups and associated needs for urological cancer care, this type of analytic breakdown should be accessible to other services.

Feedback from relevant NHS professionals in **Chapter 4** highlights current shortcomings in national survey methodologies. It draws attention to where those procedures are not intuitive or helpful to driving local quality improvement. Their collective insights about the barriers to using survey data, and their wish list for improvement, provide a roadmap for the system around patient feedback to improve utility for the frontline. These findings also emphasise the importance of sharing best practice around improving patient experience; while the showcases of best practice in **Chapter 4** provide an initial attempt at sharing, staff expressed the need for a publically available national repository of good patient experience practice.

8.1.3 Findings related to improving the use of patient experience feedback

While the first three empirical chapters focused on improving the usefulness of patient experience feedback from structured surveys through interrogating the evidence base, applying novel analytic techniques and gathering frontline suggestions, the final three focused on improving the actual use of this data for benchmarking, learning and improving.

Chapter 5 used existing patient experience feedback to create a composite score to facilitate national benchmarking that is more reflective of the entire patient experience and can be meaningfully presented with information relevant for local improvement.

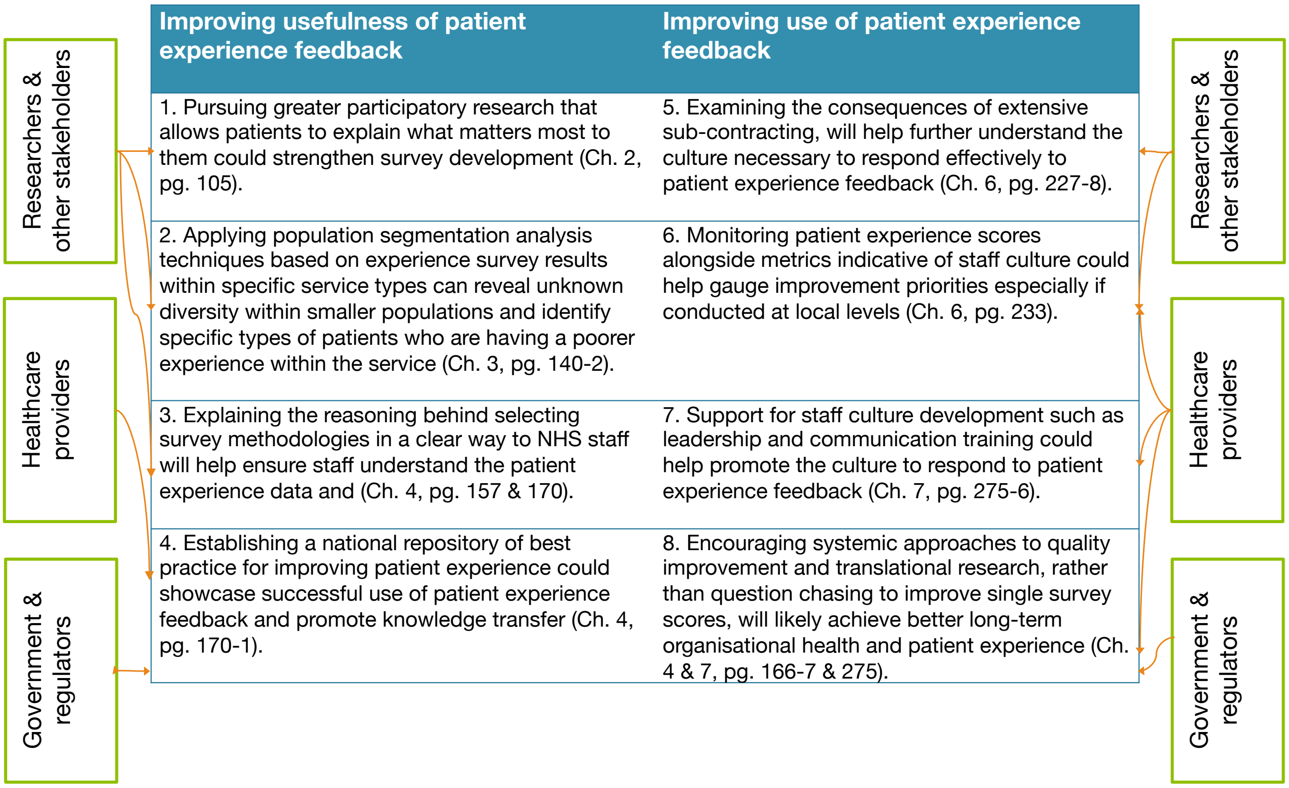
Following that, **Chapter 6** used patient experience data to expose different clusters of organisations based on their experience, demonstrating regional variations in experience. Diving deeper into these trends, **Chapter 6** also used patient experience data alongside other metrics to determine the care pathway and organisational drivers of experience. These findings articulate for the first time what factors are most significant in producing higher and lower rates of patient experience. They indicate that positive patient experience hinges on organisations, and the system around them, investing in staff support and culture.

Finally, **Chapter 7** demonstrates how one organisation began a systemic journey toward enhanced quality, including improved patient experience, by holistically measuring and improving staff culture. The results point heavily to roles of senior leaders and organisational development in order to achieve the attributes of safe culture that are necessary to promote an environment that is receptive and responsive to patient feedback.

8.2 RECOMMENDATIONS FOR IMPROVING THE USEFULNESS AND USE OF PATIENT EXPERIENCE FEEDBACK

All of the findings above contain translational elements, meaning they are pertinent to policy and practice, and can be acted upon practically. The translational elements have been configured into 14 recommendations. While these recommendations are relevant to all actors within the health system, they have been classified according to who would hold primary responsibility. These classifications include government organisations, regulators, healthcare providers, researchers and other stakeholders like survey contractors.

8.2.1 Recommendations



Improving usefulness of patient experience feedback	Improving use of patient experience feedback
1. Pursuing greater participatory research that allows patients to explain what matters most to them could strengthen survey development (Ch. 2, pg. 105).	5. Examining the consequences of extensive sub-contracting, will help further understand the culture necessary to respond effectively to patient experience feedback (Ch. 6, pg. 227-8).
2. Applying population segmentation analysis techniques based on experience survey results within specific service types can reveal unknown diversity within smaller populations and identify specific types of patients who are having a poorer experience within the service (Ch. 3, pg. 140-2).	6. Monitoring patient experience scores alongside metrics indicative of staff culture could help gauge improvement priorities especially if conducted at local levels (Ch. 6, pg. 233).
3. Explaining the reasoning behind selecting survey methodologies in a clear way to NHS staff will help ensure staff understand the patient experience data and (Ch. 4, pg. 157 & 170).	7. Support for staff culture development such as leadership and communication training could help promote the culture to respond to patient experience feedback (Ch. 7, pg. 275-6).
4. Establishing a national repository of best practice for improving patient experience could showcase successful use of patient experience feedback and promote knowledge transfer (Ch. 4, pg. 170-1).	8. Encouraging systemic approaches to quality improvement and translational research, rather than question chasing to improve single survey scores, will likely achieve better long-term organisational health and patient experience (Ch. 4 & 7, pg. 166-7 & 275).

Figure 38. Recommendations and responsibilities

8.3 RESEARCH FINDINGS AND THE CONTEXT OF QUALITY IMPROVEMENT

In terms of improving the usefulness of patient experience feedback, many of the recommendations fall within the remit of government agencies and regulators. This is due to the fact that in the NHS these actors control the key levers of national feedback collections (306). As data becomes more useful, and the movement towards enhanced data use evolves, the burden of these recommendations will likely become more evenly distributed. Responsibility will then fall to researchers, other stakeholders (like survey coordination centres and contractors) and providing organisations. In order to translate research findings into practice, however, it will be crucial for the main actors to work across the system to achieve each recommendation.

These recommendations are designed to be quickly actionable and are not envisaged to cost burdensome amounts of money. In terms of cost and feasibility, the recommendations concerning *usefulness* focus on existing analytic techniques, which could be applied with minimal new costs (10). While some of the qualitative research recommended would necessitate more resource, it is likely that these costs can be covered by funding currently earmarked for the NPSP, if emphasis is shifted from implementing surveys to conducting preliminary research (271). In terms of recommendations concerning *use*, the findings from this research centre on improved benchmarking and integrating patient experience data into systemic change strategies. These would require investment in interoperable systems to integrate all relevant quality data and most importantly in leadership development. However, these costs should be considered within the evidence of their potential to transform cultures and generate improvement for staff and patients (307).

These recommendations are generic and do not necessarily recognise the few organisations already taking forward certain aspects of them. Translational and applied research programmes across the NHS are already promoting the fundamentals of some of these recommendations (308). These recommendations echo the national sentiment of visible patient-centric agendas as well as many more discrete local initiatives (147)(151)(228). The novelty of these recommendations, however, lies in their specificity to improving the usefulness and use of patient experience feedback.

8.4 UNANSWERED QUESTIONS

Although technical limitations to each component of this research have been presented sequentially, there are overarching restrictions that have resulted in unanswered questions and limit the scope of the above policy recommendations.

Firstly, one primary restriction is the fact that the vast majority of improvement work around patient experience is conducted locally and does not exist within the public domain (151)(193). These projects would have been useful to include in the systematic review of what matters to patients. It compels further research to identify whether or not local initiatives to understand what matters most to patients have taken place and what their long-term impact has been.

Secondly, this work focuses on patient experience data from structured national surveys. As discussed, this is only one source of patient feedback, and it is important to explore the role of unstructured feedback in terms of its utility for improvement. As expressed by staff members in Chapter 4, often free text qualitative sources provide richer, more compelling details that can stimulate action towards improvement in a way that structured data cannot. Studies about this type of 'soft intelligence,' as Martin et al describe it, explain that organisational intelligence that is not in the form of metrics holds value intuitively for NHS managers; however, the way it is often interpreted can diminish its value to the improvement process (309). Their work describes a similar pattern to what occurs with structured patient feedback: there is agreement that it is necessary and potentially useful, but there is not yet consensus on how best to collect it and learn from it (309). A next step would be to explore ways to use both sources of data in a more productive way towards improvement.

Thirdly, the methods applied to conduct population segmentation analysis were somewhat restricted given relatively small sample sizes. Clustering techniques are best applied to large populations, and while each analysis in this research yielded statistically significant results, there are unanswered questions as to the patient segments that exist within the population at large. Applying segmentation analysis to a larger population dataset would address this question; however, patient-level data on this scale is prohibitively difficult to access due to UK government regulations (310).

Finally, the complex nature of NHS organisations means that findings from the two chapters that worked with real life organisations (**Chapters 4** and **7**) do not account for all variation across organisations which could impact approaches to using data and driving improvements. This poses a challenge rather than a question; it demands a greater focus on translational research such that research questions are developed within the context of NHS organisations. This would help ensure researchers are cognisant of different NHS structures and the impact they have on the process of integrating findings into practice.

Although research in these areas are not complete, and in some cases still in emerging stages, advancements in these fields deserve recognition. Extensive work is being conducted into participatory research to learn more about expectations on a disaggregated level (271); feedback trials are already underway to test the suitability of new, real-time feedback mechanisms that build on the needs of staff and preferences of patients (311); and an entire field of organisational development for NHS leadership is advancing at a rapid rate with a growing focus on the importance and implications of patient experience (312).

8.5 FINAL CONCLUSIONS

As the definition of quality has gradually evolved to embrace the importance of patients' perceptions, a paradigm of patient-centricity has unfolded (2). The vision behind this paradigm is noble; it advocates that the complex array of healthcare stakeholders harmonise and align their actions and interests in support of patients. It has garnered broad interest and generated invaluable impact (38). However, reality has not mirrored the vision as well as it could.

Patient-centricity requires the system actively listening to, and adapting in response to, patient voices (5)(4)(174). Until patients are listened to, and the system makes bold steps to improve around them, patients, however active, are not leading agents of change.

Patients are experts in their lived experience of care, however, their feedback is not being used to drive improvement (5). This might be the result of a historical view of patients as secondary to the specialised experts that dominate health systems. However, as staff in this study revealed, the patient-centricity movement has gone a long way to marginalise this sentiment (**Chapter 4**).

More likely, the lag between data collection and use is symptomatic of the challenge: soliciting patient experience feedback is now commonplace, but actually rebuilding a system in response to it is daunting (111)(6). Evidence demonstrates that the common perception is still that the root causes of patients' experience are either so individual that they are impossible to measure, or so dependent on complex relationships that they would be too difficult, or not within any individuals' remit to resolve (6)(193). Adapting based on patient experience requires breaking down entrenched approaches to service delivery and overhauling traditional relationships.

This research demonstrates that the next step along the continuum (**Chapter 1**) towards embedding nationally collected patient experience feedback within local organisations for quality improvement can be achieved with system thinking and evidence-based incremental change (10). Improvements in the evidence base around what matters to patients can strengthen survey tools; and novel segmentation techniques can make patient experience data more relevant to certain types of patients and services. A national survey programme with a focus on local needs and the adoption of a single metric relevant to improvement can also support staff to use patient experience data for improvement. Finally, organisational features and staff culture can be measured and cultivated to, over time, create an organisation receptive to patient feedback and ready to drive change.

If leaders within the health system, as well as stakeholders at its periphery, can take forward the recommendations necessary to improve the usefulness and use of patient experience feedback, it will not only help reduce suffering, but begin to improve the NHS in a truly patient-centric way.

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APPENDIX A

Chapter 2 Bibliographic and scoring information for systematic review

Table 37. Chapter 2 included papers, scores and characteristics

Author		Year	Title	Sample Size	Data from	Explicit ranking	Patients rank	Population	Scope	Score	Most important
1.	Krones CJ, et al.	2006	The doctor in the patient’s perception	n=507	1	0	0	0	0	**1**	Role of doctor as paternal role
2.	Piderman KM, et al.	2013	Hospitalized young adults’ expectations of pastoral interventions	n=4,500	1	0	0	0	0	**1**	Young adults were more likely to value ethical counsel from chaplains thank older adults
3.	Huppertz JW & Smith R	2014	The Value of Patients’ Handwritten Comments on HCAHPS Surveys	n=589	1	1	0	0	0	**2**	Numerical ratings do not sufficiently capture the range of consumer experiences
4.	Doyle C et al.	2010	Understanding what matters to patients- identifying key patient perceptions of quality	n=149,000	1	1	0	0	0	**2**	Communication and trust engendered
5.	Jenkinson C et al.	2002	Patients’ experiences and satisfaction with healthcare: results of a questionnaire study of specific aspects of care	n=2,349	1	1	0	0	0	**2**	Physical comfort, emotional support and respect for patient preferences
6.	Cleary PD, et al.	2014	Are Comparisons of Patient Experiences Across Hospitals Fair? A Study in Veterans Health Administration Hospitals	n=1,858	1	0	0	1	0	**2**	None
7.	Fletcher KE, et al.	2007	Patients speak: What’s really important about bedside interactions with physician teams	n=17	1	0	0	0	1	**2**	Exchange of information, evidence of caring from their team, involvement in teaching, knowing the team members, Bedside manner
8.	Frampton SB, et al.	2013	Compassion as the foundation of patient-centered care: the importance of compassion in action	No details	1	0	0	0	1	**2**	Compassion
9.	Winsor S, et al.	2013	Experiences of patient-centredness with specialized community-based care: a systematic review and qualitative meta-synthesis	n=29	0	1	0	1	0	**2**	Understanding diagnosis, increased socialization, managing own care

10.	Shattell M, et al.	2005	‘It’s the people that make the environment good or bad’: the patient’s experience of the acute care hospital environment	n=20	1	0	0	0	1	**2**	Human-to-human contact, disconnection vs. connection, fear vs. less fear, and confinement vs. freedom
11.	Williams AM & Irurita VF	2004	Therapeutic and non-therapeutic interpersonal interactions: the patient’s perspective	n=40	1	0	0	0	1	**2**	Emotional comfort, personal control
12.	Liu SS, et al.	2010	Visualizing desirable patient healthcare experiences	n=1,800	1	1	1	0	0	**3**	Communication, empowerment, compassionate and respectful care
13.	Elliott MN, et al.	2009	Components of Care Vary in Importance for Overall Patient-Reported Experience by Type of Hospitalization	n=19,723	1	1	0	1	0	**3**	Nurse communication (Discharge information was least important); but results very significantly depending on hospital type
14.	Elliott MN, et al.	2010	Do Hospitals Rank Differently on HCAHPS for Different Patient Subgroups?	n=1,203,229	1	1	0	1	0	**3**	Nurse communication (mostly looked at overall scores)
15.	Hargreaves DS, et al.	2012	Do Young and Older Adults Have Different Health Care Priorities? Evidence From a National Survey of English Inpatients.	n=161	1	1	0	1	0	**3**	Women: respect and the skills/attitudes of their doctors Men: Effective pain control (Hospitals’ results on AIPS (total not specified))
16.	Krol MW, et al.	2015	Patient experiences of inpatient hospital care: a department matter and a hospital matter	n=15, 171	1	1	0	1	0	**3**	Communication with doctors, treatment of pain, information at discharge.
17.	Miceli P, & Clark PA.	2005	Your patient - My child - Seven priorities for improving pediatric care from the parent’s perspective	n=50,446	1	1	0	1	0	**3**	Sensitivity to the inconvenience that a child's health problems and hospitalization can cause, emotional and spiritual, response to concerns/complaints made during the child's stay, include parents in decisions about the child's treatment, improve the accommodations and comfort for visitors
18.	Schwappach & Strasmann	2007	Does location matter? A study of the public’s preferences for surgical care provision	n = 1134	1	1	0	1	0	**3**	Specialization and experience of provider, waiting times, staff continuity
19.	Sipsma H, et al.	2013	Patient experiences with inpatient care in rural China	n = 443	1	1	0	1	0	**3**	Communication with nurses’; Age was the only socio-demographic characteristic associated with overall ratings
20.	Solheim E & Garratt AM	2013	Parent experiences of inpatient paediatric care in relation to health care delivery and socio-demographic characteristics: results of a Norwegian national	n=3,308	1	1	0	1	0	**3**	Disappointment with staff, unexpected waiting, information regarding new medication, staff success in easing the child’s pain, incorrect treatment and number of previous admissions Socio-demographic

			survey								characteristics had weak or no associations with parent experiences.
21.	Coulter A & Cleary PD	2001	Patients' experiences with Hospital care in five Countries.	N= 62,925	1	1	0	1	0	**3**	Information and education, coordination of care, respect for patients' preferences, emotional support, physical comfort, involvement of family and friends, and continuity and transition were prevalent in all five countries.
22.	Digby R & Bloomer MJ	2014	People with dementia and the hospital environment: the view of patients and family carers	Patients (n=7) and carers (n=4)	1	0	0	1	1	**3**	No official ranking of important aspects of experience
23.	Clift L, et al.	2007	Adolescents' experiences of emergency admission to children's wards	n=6	1	0	0	1	1	**3**	No specific finding on what is most important
24.	Ewart L, et al.	2014	Patient- and family-centred care on an acute adult cardiac ward.	Patients (n=56) or carers (n=68)	1	0	0	1	1	**3**	Involving families and family visiting
25.	Fridh I, et al.	2015	Extensive human suffering: a point prevalence survey of patients' most distressing concerns during inpatient care	n=710	1	0	1	0	1	**3**	The suffering self, the suffering person in close relations and the suffering person in a threatening world.
26.	Garrett PW, et al.	2008	What do non-English-speaking patients value in acute care? Cultural competency from the patient's perspective: a qualitative study	n=59 (7 different groups)	1	0	0	1	1	**3**	Language facilitation, attention to specific preferences, positive engagement, information and involvement, compassionate and respectful treatment, and involvement family
27.	Henderson A, et al.	2004	Patient satisfaction: the Australian patient perspective	n=20	1	0	0	1	1	**3**	Hotel features, medical outcomes, provision of information, clinical care, comfort. (Lowest priority was participation in care)
28.	Wainer J, et al.	2012	The treatment experiences of Australian women with gynaecological cancers and how they can be improved: a qualitative study	n=25	1	0	0	1	1	**3**	Serious post-operative morbidity, coordination between the surgical team and general practitioners, management of pain
29.	Hweidi IM	2007	Jordanian patients' perception of stressors in critical care units: A questionnaire survey	n=165	1	1	1	1	0	**4**	Having tubes in nose or mouth, pain, lack of sleep, too much hospital noise and not being in control of your-self. Marital status, educational level, age, and income were the most significant characteristics that affected patients' perception of stressors.

30.	You JJ, et al.	2014	What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families	n=233 patients, n= 205 family members	1	1	1	1	0	**4**	Preferences for care in the event of life-threatening illness, values, prognosis, fears or concerns, and additional questions about goals of care
31.	Van Staa A, et al	2011	'What we want': Chronically ill adolescents' preferences and priorities for improving health care	n=965*	1	1	0	1	1	**4**	A feeling of trust, voice and choice, avoiding pain and discomfort, keeping in touch with home and being entertained (less: being hospitalized with peers, being heard)
32.	Heyland DK, et al.	2006	What matters most in end-of-life care: perceptions of seriously ill patients and their family members	n=440 patients n=160 relatives	1	1	0	1	1	**4**	Confidence in doctors, not being kept alive on life support when there is little hope of recovery, honest communication, support preparing for end of life. Significant differences in priorities were found between patients and their family members for many elements of care.
33.	Davis Y, et al.	2009	Patient and Family Member Needs During the Perioperative Period	n=68 patients and n=63 family members	1	1	1	1	1	**5**	Patients: access to pain and/or nausea management, information about the condition after surgery, respect and dignity. Family member: communication with the surgeon after the procedure, opportunities to ask questions and address concerns with hospital staff, and information about the procedure.
34.	Dougherty M	2010	Assessment of Patient and Family Needs During an Inpatient Oncology Experience	n=27 patients, n=27 carers	1	1	1	1	1	**5**	Patients: information and communication, the competence of their caregivers, cleanliness of the care environment, and adequacy of pain management. Family: most important needs were similar, with the addition of needs related to visitation and specific discharge information. (The least important needs identified by both groups related to information about the hospital setting and nursing continuity)
35.	Tsianakas V, et al.	2012	Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives, surveys or both?	Narrative: n=13, survey: n=82	1	1	1	1	1	**5**	Availability of nurses, pain relief, provision of information on treatment, possible side effects of treatment and what to do after discharge and need for support at home. (Not important: communication between departments or continuity)

* interviews n=31, peer interviews n=34 and questionnaire n=90

APPENDIX B

Chapter 3 Statistical tests

Table 38. Significance of patient experience variation in AIPS exploratory cluster analysis

ANOVA		**Mean Square**	**F**	**Sig.**
Do you feel you got enough emotional support from hospital staff during your stay?	Between Groups	34.362	61.751	**0.00***
	Within Groups	0.556		
When you had important questions to ask a nurse, did you get answers that you could understand?	Between Groups	9.994	29.831	**0.00***
	Within Groups	0.335		
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	Between Groups	10.391	38.578	**0.00***
	Within Groups	0.269		
Do you think the hospital staff did everything they could to help control your pain?	Between Groups	10.635	27.709	**0.00***
	Within Groups	0.384		
Did you have confidence and trust in the doctors treating you?	Between Groups	19.648	67.103	**0.00***
	Within Groups	0.293		
Did you find someone on the hospital staff to talk to about your worries and fears?	Between Groups	59.692	98.938	**0.00***
	Within Groups	0.603		
Did a member of staff tell you about medication side effects to watch for when you went home?	Between Groups	60.574	77.099	**0.00***
	Within Groups	0.786		

* Significant at a .05 significance level

Table 39. Significance of patient experience variation in AIPS exploratory cluster analysis adjusting for multiple comparisons

Dependant variables	Cluster	Comparison to other cluster	Mean Difference	Std. Error	Sig. (Bonferroni)	Lower (95% CI)
Do you feel you got enough emotional support from hospital staff during your stay?	1	2	.169*	**0.00***	0.13	0.2
		3	.141*	**0.00***	0.1	0.18
		4	.073*	**0.00***	0.04	0.11
	2	1	-.169*	**0.00***	-0.2	-0.13
		3	-0.028	0.492	-0.07	0.01
		4	-.096*	**0.00***	-0.14	-0.06
	3	1	-.141*	**0.00***	-0.18	-0.1
		2	0.028	0.492	-0.01	0.07
		4	-.068*	**0.00***	-0.11	-0.03
	4	1	-.073*	**0.00***	-0.11	-0.04
		2	.096*	**0.00***	0.06	0.14
		3	.068*	**0.00***	0.03	0.11
When you had important questions to ask a nurse, did you get answers that you could understand?	1	2	.077*	**0.00***	0.05	0.1
		3	.068*	**0.00***	0.04	0.09
		4	.045*	**0.00***	0.02	0.07
	2	1	-.077*	**0.00***	-0.1	-0.05
		3	-0.009	**1**	-0.04	0.02
		4	-.032*	**0.01***	-0.06	-0.01
	3	1	-.068*	**0.00***	-0.09	-0.04
		2	0.009	**1**	-0.02	0.04
		4	-0.023	0.182	-0.05	0.01
	4	1	-.045*	**0.00***	-0.07	-0.02
		2	.032*	**0.01***	0.01	0.06
		3	0.023	0.182	-0.01	0.05
Overall, did you feel you were treated with respect and dignity while you were in the hospital?	1	2	.082*	**0.00***	0.06	0.1
		3	.046*	**0.00***	0.02	0.07
		4	.026*	**0.00***	0.01	0.05
	2	1	-.082*	**0.00***	-0.1	-0.06
		3	-.036*	**0.00***	-0.06	-0.01
		4	-.056*	**0.00***	-0.08	-0.03
	3	1	-.046*	**0.00***	-0.07	-0.02
		2	.036*	**0.00***	0.01	0.06
		4	-0.02	0.162	-0.04	0
	4	1	-.026*	**0.00***	-0.05	-0.01

		2	.056*	**0.00***	0.03	0.08
		3	0.02	0.162	0	0.04
Do you think the hospital staff did everything they could to help control your pain?	1	2	.097*	**0**	0.07	0.13
		3	.072*	**0.00***	0.04	0.11
		4	.067*	**0.00***	0.04	0.1
	2	1	-.097*	**0.00***	-0.13	-0.07
		3	-0.025	0.488	-0.06	0.01
		4	-0.029	0.112	-0.06	0
	3	1	-.072*	**0.00***	-0.11	-0.04
		2	0.025	0.488	-0.01	0.06
		4	-0.005	1	-0.04	0.03
	4	1	-.067*	**0.00***	-0.1	-0.04
		2	0.029	0.112	0	0.06
		3	0.005	1	-0.03	0.04
Did you have confidence and trust in the doctors treating you?	1	2	.106*	**0.00***	0.08	0.13
		3	.079*	**0.00***	0.06	0.1
		4	.064*	**0.00***	0.04	0.08
	2	1	-.106*	**0.00***	-0.13	-0.08
		3	-.026*	**0.04***	-0.05	0
		4	-.042*	0	-0.07	-0.02
	3	1	-.079*	0	-0.1	-0.06
		2	.026*	**0.04***	0	0.05
		4	-0.015	0.658	-0.04	0.01
	4	1	-.064*	**0.00***	-0.08	-0.04
		2	.042*	**0.00***	0.02	0.07
		3	0.015	0.658	-0.01	0.04
Did you find someone on the hospital staff to talk to about your worries and fears?	1	2	.222*	**0.00***	0.18	0.26
		3	.192*	**0.00***	0.15	0.23
		4	.148*	**0.00***	0.11	0.19
	2	1	-.222*	**0.00***	-0.26	-0.18
		3	-0.03	0.475	-0.08	0.02
		4	-.074*	**0.00***	-0.12	-0.03
	3	1	-.192*	**0.00***	-0.23	-0.15
		2	0.03	0.475	-0.02	0.08
		4	-0.044	0.058	-0.09	0
	4	1	-.148*	**0.00***	-0.19	-0.11
		2	.074*	**0.00***	0.03	0.12
		3	0.044	0.058	0	0.09
Did a member of staff tell you about medication side effects to watch for when you went home?	1	2	.190*	**0.00***	0.15	0.23
		3	.222*	**0.00***	0.17	0.27

		4	.167*	**0.00***	0.12	0.21
	2	1	-.190*	**0.00***	-0.23	-0.15
		3	0.032	0.557	-0.02	0.08
		4	-0.023	1	-0.07	0.02
	3	1	-.222*	**0.00***	-0.27	-0.17
		2	-0.032	0.557	-0.08	0.02
		4	-.055*	**0.02***	-0.11	0
	4	1	-.167*	**0.00***	-0.21	-0.12
		2	0.023	1	-0.02	0.07
		3	.055*	**0.02***	0	0.11

* Significant at a .05 significance level

Table 40. Significance of demographic characteristics in cluster analysis of all urological cancer patients within NCPES

ANOVA		Mean Square	F	Sig.
Gender	Between Groups	4.01	35.74	**0.00***
	Within Groups	0.11		
Cancer type	Between Groups	37.62	4.36	**0.01***
	Within Groups	8.63		
Age	Between Groups	3051.42	26.38	**0.00***
	Within Groups	115.66		
National income quintile	Between Groups	61.49	34.15	**0.00***
	Within Groups	1.80		

* Significant at a .05 significance level

Table 41. Significance of NCPES section score variation in cluster analysis of all urological cancer patients within NCPES adjusting for multiple comparisons

Dependant variables	Cluster	Comparison to other cluster	Mean Difference	Std. Error	Sig. (Bonferroni)	Lower (95% CI)
Seeing a GP	1	2	.2998*	**0.00***	0.18	0.42
		3	1.7659*	**0.00***	1.61	1.92
	2	1	-.2998*	**0.00***	-0.42	-0.18
		3	1.4660*	**0.00***	1.33	1.60
	3	1	-1.7659*	**0.00***	-1.92	-1.61
		2	-1.4660*	**0.00***	-1.60	-1.33
Diagnostic testing	1	2	.3282*	**0.00***	0.25	0.41
		3	2.0567*	**0.00***	1.96	2.16
	2	1	-.3282*	**0.00***	-0.41	-0.25
		3	1.7285*	**0.00***	1.64	1.82
	3	1	-2.0567*	**0.00***	-2.16	-1.96
		2	-1.7285*	**0.00***	-1.82	-1.64
Finding out	1	2	.5542*	**0.00***	0.47	0.64
		3	2.5026*	**0.00***	2.39	2.61
	2	1	-.5542*	**0.00***	-0.64	-0.47
		3	1.9483*	**0.00***	1.85	2.05
	3	1	-2.5026*	**0.00***	-2.61	-2.39
		2	-1.9483*	**0.00***	-2.05	-1.85
Deciding treatment	1	2	.7882*	**0.00***	0.68	0.89
		3	3.4691*	**0.00***	3.34	3.60
	2	1	-.7882*	**0.00***	-0.89	-0.68
		3	2.6809*	**0.00***	2.56	2.80
	3	1	-3.4691*	**0.00***	-3.60	-3.34
		2	-2.6809*	**0.00***	-2.80	-2.56
Clinical nurse specialist	1	2	.3679*	**0.00***	0.28	0.46
		3	2.0966*	**0.00***	1.98	2.21
	2	1	-.3679*	**0.00***	-0.46	-0.28
		3	1.7287*	**0.00***	1.62	1.84
	3	1	-2.0966*	**0.00***	-2.21	-1.98
		2	-1.7287*	**0.00***	-1.84	-1.62
Support for people with cancer	1	2	1.0220*	**0.00***	0.87	1.17
		3	3.6756*	**0.00***	3.49	3.86
	2	1	-1.0220*	**0.00***	-1.17	-0.87
		3	2.6536*	**0.00***	2.49	2.82
	3	1	-3.6756*	**0.00***	-3.86	-3.49
		2	-2.6536*	**0.00***	-2.82	-2.49
Operations	1	2	.6161*	**0.00***	0.50	0.73
		3	2.6403*	**0.00***	2.49	2.79
	2	1	-.6161*	**0.00***	-0.73	-0.50
		3	2.0241*	**0.00***	1.90	2.15
	3	1	-2.6403*	**0.00***	-2.79	-2.49

		2	-2.0241*	**0.00***	-2.15	-1.90
Hospital doctors	1	2	.3432*	**0.00***	0.26	0.43
		3	2.4752*	**0.00***	2.37	2.58
	2	1	-.3432*	**0.00***	-0.43	-0.26
		3	2.1320*	**0.00***	2.04	2.23
	3	1	-2.4752*	**0.00***	-2.58	-2.37
		2	-2.1320*	**0.00***	-2.23	-2.04
Ward nurses	1	2	.4107*	**0.00***	0.33	0.49
		3	1.6180*	**0.00***	1.52	1.72
	2	1	-.4107*	**0.00***	-0.49	-0.33
		3	1.2073*	**0.00***	1.12	1.30
	3	1	-1.6180*	**0.00***	-1.72	-1.52
		2	-1.2073*	**0.00***	-1.30	-1.12
Hospital care	1	2	.4642*	**0.00***	0.40	0.53
		3	2.2688*	**0.00***	2.18	2.36
	2	1	-.4642*	**0.00***	-0.53	-0.40
		3	1.8046*	**0.00***	1.73	1.88
	3	1	-2.2688*	**0.00***	-2.36	-2.18
		2	-1.8046*	**0.00***	-1.88	-1.73
Home care	1	2	1.2449*	**0.00***	1.05	1.44
		3	4.5537*	**0.00***	4.32	4.79
	2	1	-1.2449*	**0.00***	-1.44	-1.05
		3	3.3088*	**0.00***	3.10	3.52
	3	1	-4.5537*	**0.00***	-4.79	-4.32
		2	-3.3088*	**0.00***	-3.52	-3.10
Hospital care as a day patient	1	2	.5907*	**0.00***	0.47	0.72
		3	3.3381*	**0.00***	3.18	3.49
	2	1	-.5907*	**0.00***	-0.72	-0.47
		3	2.7474*	**0.00***	2.61	2.88
	3	1	-3.3381*	**0.00***	-3.49	-3.18
		2	-2.7474*	**0.00***	-2.88	-2.61
Outpatient procedures	1	2	.179*	**0.00***	0.08	0.27
		3	1.043*	**0.00***	0.92	1.17
	2	1	-.179*	**0.00***	-0.27	-0.08
		3	.865*	**0.00***	0.76	0.97
	3	1	-1.043*	**0.00***	-1.17	-0.92
		2	-.865*	**0.00***	-0.97	-0.76
GP care	1	2	.4760*	**0.00***	0.37	0.58
		3	2.6259*	**0.00***	2.49	2.76
	2	1	-.4760*	**0.00***	-0.58	-0.37
		3	2.1498*	**0.00***	2.03	2.27
	3	1	-2.6259*	**0.00***	-2.76	-2.49
		2	-2.1498*	**0.00***	-2.27	-2.03

* Significant at a .05 significance level

Table 42. Significance of demographic characteristics in cluster analysis of patients within the poorest experience cluster

ANOVA		Mean Square	F	Sig.
Gender	Between Groups	1.35	8.33	**0.00***
	Within Groups	0.16		
Cancer type	Between Groups	47.07	6.52	**0.00***
	Within Groups	7.22		
Age	Between Groups	10.60	0.09	0.92
	Within Groups	121.20		
National income quintile	Between Groups	10.88	5.62	**0.00***
	Within Groups	1.94		

* Significant at a .05 significance level

Table 43. Significance of NCPES section score variation in cluster analysis of all urological cancer patients within the poorest experience cluster

Dependant variables	Cluster	Comparison to other cluster	Mean Difference	Std. Error	Sig. (Bonferroni)	Lower (95% CI)	Upper (95% CI)
Seeing a GP	1	2	-1.072*	0.35	**0.01**	-1.91	-0.24
		3	-2.676*	0.37	**0.00***	-3.55	-1.80
	2	1	1.072*	0.35	**0.01**	0.24	1.91
		3	-1.605*	0.34	**0.00***	-2.42	-0.79
	3	1	2.676*	0.37	**0.00***	1.80	3.55
		2	1.605*	0.34	**0.00***	0.79	2.42
Diagnostic testing	1	2	-2.673*	0.20	**0.00***	-3.16	-2.18
		3	-3.572*	0.21	**0.00***	-4.08	-3.06
	2	1	2.673*	0.20	**0.00***	2.18	3.16
		3	-.899*	0.20	**0.00***	-1.37	-0.42
	3	1	3.572*	0.21	**0.00***	3.06	4.08
		2	.899*	0.20	**0.00***	0.42	1.37
Finding out	1	2	-2.669*	0.21	**0.00***	-3.18	-2.15
		3	-3.844*	0.23	**0.00***	-4.38	-3.30
	2	1	2.669*	0.21	**0.00***	2.15	3.18
		3	-1.175*	0.21	**0.00***	-1.68	-0.67
	3	1	3.844*	0.23	**0.00***	3.30	4.38
		2	1.175*	0.21	**0.00***	0.67	1.68
Deciding treatment	1	2	-2.402*	0.24	**0.00***	-2.98	-1.82
		3	-4.451*	0.25	**0.00***	-5.06	-3.84
	2	1	2.402*	0.24	**0.00***	1.82	2.98
		3	-2.049*	0.24	**0.00***	-2.62	-1.48
	3	1	4.451*	0.25	**0.00***	3.84	5.06
		2	2.049*	0.24	**0.00***	1.48	2.62
Clinical nurse specialist	1	2	-2.141*	0.25	**0.00***	-2.74	-1.54
		3	-3.715*	0.26	**0.00***	-4.34	-3.08
	2	1	2.141*	0.25	**0.00***	1.54	2.74
		3	-1.573*	0.24	**0.00***	-2.16	-0.99
	3	1	3.715*	0.26	**0.00***	3.08	4.34
		2	1.573*	0.24	**0.00***	0.99	2.16
Support for people with cancer	1	2	-1.378*	0.27	**0.00***	-2.03	-0.73
		3	-5.383*	0.28	**0.00***	-6.06	-4.70
	2	1	1.378*	0.27	**0.00***	0.73	2.03
		3	-4.005*	0.26	**0.00***	-4.64	-3.37
	3	1	5.383*	0.28	**0.00***	4.70	6.06
		2	4.005*	0.26	**0.00***	3.37	4.64
Operations	1	2	-2.162*	0.19	**0.00***	-2.63	-1.69
		3	-3.673*	0.20	**0.00***	-4.16	-3.18
	2	1	2.162*	0.19	**0.00***	1.69	2.63
		3	-1.512*	0.19	**0.00***	-1.97	-1.06

	3	1	3.673*	0.20	0.00*	3.18	4.16
		2	1.512*	0.19	0.00*	1.06	1.97
Hospital doctors	1	2	-2.908*	0.18	0.00*	-3.35	-2.47
		3	-3.821*	0.19	0.00*	-4.28	-3.36
	2	1	2.908*	0.18	0.00*	2.47	3.35
		3	-.913*	0.18	0.00*	-1.34	-0.48
	3	1	3.821*	0.19	0.00*	3.36	4.28
		2	.913*	0.18	0.00*	0.48	1.34
Ward nurses	1	2	-.852*	0.16	0.00*	-1.25	-0.46
		3	-1.869*	0.17	0.00*	-2.28	-1.45
	2	1	.852*	0.16	0.00*	0.46	1.25
		3	-1.016*	0.16	0.00*	-1.40	-0.63
	3	1	1.869*	0.17	0.00*	1.45	2.28
		2	1.016*	0.16	0.00*	0.63	1.40
Hospital care	1	2	-1.753*	0.15	0.00*	-2.11	-1.40
		3	-3.004*	0.16	0.00*	-3.38	-2.63
	2	1	1.753*	0.15	0.00*	1.40	2.11
		3	-1.251*	0.14	0.00*	-1.60	-0.91
	3	1	3.004*	0.16	0.00*	2.63	3.38
		2	1.251*	0.14	0.00*	0.91	1.60
Home care	1	2	-.998*	0.31	0.00*	-1.73	-0.26
		3	-3.669*	0.32	0.00*	-4.44	-2.90
	2	1	.998*	0.31	0.00*	0.26	1.73
		3	-2.671*	0.30	0.00*	-3.39	-1.96
	3	1	3.669*	0.32	0.00*	2.90	4.44
		2	2.671*	0.30	0.00*	1.96	3.39
Hospital care as a day patient	1	2	-1.706*	0.26	0.00*	-2.33	-1.08
		3	-4.431*	0.27	0.00*	-5.09	-3.77
	2	1	1.706*	0.26	0.00*	1.08	2.33
		3	-2.726*	0.26	0.00*	-3.34	-2.11
	3	1	4.431*	0.27	0.00*	3.77	5.09
		2	2.726*	0.26	0.00*	2.11	3.34
Outpatient procedures	1	2	-3.799*	0.32	0.00*	-4.56	-3.03
		3	-2.523*	0.33	0.00*	-3.32	-1.72
	2	1	3.799*	0.32	0.00*	3.03	4.56
		3	1.276*	0.31	0.00*	0.53	2.02
	3	1	2.523*	0.33	0.00*	1.72	3.32
		2	-1.276*	0.31	0.00*	-2.02	-0.53
GP care	1	2	-2.936*	0.33	0.00*	-3.73	-2.15
		3	-2.795*	0.35	0.00*	-3.62	-1.97
	2	1	2.936*	0.33	0.00*	2.15	3.73
		3	0.14	0.32	1.00	-0.63	0.91
	3	1	2.795*	0.35	0.00*	1.97	3.62
		2	-0.14	0.32	1.00	-0.91	0.63

* Significant at a .05 significance level

Table 44. Significance of demographic characteristics in Non-Operations Clusters

ANOVA	Column2	Mean Square	F	Sig.
Gender	Between Groups	0.75	14.95	**0.00***
	Within Groups	0.05		
Cancer type	Between Groups	94.93	13.68	**0.00***
	Within Groups	6.94		
Age	Between Groups	976.69	10.48	**0.00***
	Within Groups	93.19		
National income quintile	Between Groups	2.97	1.67	0.190
	Within Groups	1.78		

* Significant at a .05 significance level

Table 45. Significance of NCPES section score variation in cluster analysis of Non-Operations urological cancer patients

Dependant variables	Cluster	Comparison to other cluster	Mean Difference	Std. Error	Sig. (Bonferroni)	Lower (95% CI)	
Seeing a GP	1	2	5.5377*	0.09	**0.00***	5.33	5.75
		3	-1.9154*	0.06	**0.00***	-2.05	-1.78
	2	1	-5.5377*	0.09	**0.00***	-5.75	-5.33
		3	-7.4532*	0.08	**0.00***	-7.64	-7.27
	3	1	1.9154*	0.06	**0.00***	1.78	2.05
		2	7.4532*	0.08	**0.00***	7.27	7.64
Diagnostic testing	1	2	-2.6538*	0.07	**0.00***	-2.82	-2.49
		3	-3.0869*	0.05	**0.00***	-3.20	-2.98
	2	1	2.6538*	0.07	**0.00***	2.49	2.82
		3	-.4331*	0.06	**0.00***	-0.58	-0.29
	3	1	3.0869*	0.05	**0.00***	2.98	3.20
		2	.4331*	0.06	**0.00***	0.29	0.58
Finding out	1	2	-3.0003*	0.08	**0.00***	-3.19	-2.81
		3	-3.4778*	0.05	**0.00***	-3.60	-3.35
	2	1	3.0003*	0.08	**0.00***	2.81	3.19
		3	-.4775*	0.07	**0.00***	-0.65	-0.31
	3	1	3.4778*	0.05	**0.00***	3.35	3.60
		2	.4775*	0.07	**0.00***	0.31	0.65
Deciding treatment	1	2	-3.1815*	0.09	**0.00***	-3.41	-2.96
		3	-4.0697*	0.06	**0.00***	-4.22	-3.92
	2	1	3.1815*	0.09	**0.00***	2.96	3.41
		3	-.8882*	0.08	**0.00***	-1.09	-0.69
	3	1	4.0697*	0.06	**0.00***	3.92	4.22
		2	.8882*	0.08	**0.00***	0.69	1.09
Support	1	2	-2.8476*	0.15	**0.00***	-3.21	-2.48
		3	-3.7996*	0.10	**0.00***	-4.04	-3.56
	2	1	2.8476*	0.15	**0.00***	2.48	3.21
		3	-.9520*	0.14	**0.00***	-1.28	-0.63
	3	1	3.7996*	0.10	**0.00***	3.56	4.04
		2	.9520*	0.14	**0.00***	0.63	1.28
Hospital care as a day patient	1	2	-1.9536*	0.13	**0.00***	-2.28	-1.63
		3	-2.4092*	0.09	**0.00***	-2.63	-2.19
	2	1	1.9536*	0.13	**0.00***	1.63	2.28
		3	-.4557*	0.12	**0.00***	-0.74	-0.17
	3	1	2.4092*	0.09	**0.00***	2.19	2.63
		2	.4557*	0.12	**0.00***	0.17	0.74
GP care	1	2	-.7168*	0.12	**0.00***	-1.01	-0.42
		3	-1.5553*	0.08	**0.00***	-1.75	-1.36

	2	1	.7168*	0.12	**0.00***	0.42	1.01
		3	-.8385*	0.11	**0.00***	-1.10	-0.58
	3	1	1.5553*	0.08	**0.00***	1.36	1.75
		2	.8385*	0.11	**0.00***	0.58	1.10

* Significant at a .05 significance level

Table 46. Significance of demographic characteristics in Operations Clusters

ANOVA		Mean Square	F	Sig.
Gender	Between Groups	5.761	41.30	**0.00***
	Within Groups	0.14		
Cancer type	Between Groups	312.284	44.43	**0.00***
	Within Groups	7.029		
Age	Between Groups	1734.616	13.61	**0.00***
	Within Groups	127.437		
National income quintile	Between Groups	11.306	6.30	**0.02***
	Within Groups	1.794		

* Significant at a .05 significance level

Table 47. Significance of NCPES section score variation in cluster analysis of Operations urological cancer patients

Dependant variables	Cluster	Comparison to other cluster	Mean Difference	Std. Error	Sig. (Bonferroni)	Lower (95% CI)	Upper (95% CI)
Seeing a GP	1	2	-.7537*	0.08	**0.00***	-0.94	-0.57
		3	-2.7534*	0.07	**0.00***	-2.93	-2.58
	2	1	.7537*	0.08	**0.00***	0.57	0.94
		3	-1.9997*	0.06	**0.00***	-2.14	-1.86
	3	1	2.7534*	0.07	**0.00***	2.58	2.93
		2	1.9997*	0.06	**0.00***	1.86	2.14
Diagnostic testing	1	2	-2.7605*	0.04	**0.00***	-2.86	-2.66
		3	-3.4253*	0.04	**0.00***	-3.52	-3.33
	2	1	2.7605*	0.04	**0.00***	2.66	2.86
		3	-.6648*	0.03	**0.00***	-0.74	-0.59
	3	1	3.4253*	0.04	**0.00***	3.33	3.52
		2	.6648*	0.03	**0.00***	0.59	0.74
Finding out	1	2	-2.7696*	0.05	**0.00***	-2.88	-2.66
		3	-4.3364*	0.04	**0.00***	-4.44	-4.23
	2	1	2.7696*	0.05	**0.00***	2.66	2.88
		3	-1.5668*	0.03	**0.00***	-1.65	-1.48
	3	1	4.3364*	0.04	**0.00***	4.23	4.44
		2	1.5668*	0.03	**0.00***	1.48	1.65
Deciding treatment	1	2	-3.8519*	0.06	**0.00***	-3.99	-3.72
		3	-5.5337*	0.05	**0.00***	-5.66	-5.41
	2	1	3.8519*	0.06	**0.00***	3.72	3.99
		3	-1.6818*	0.04	**0.00***	-1.78	-1.58
	3	1	5.5337*	0.05	**0.00***	5.41	5.66
		2	1.6818*	0.04	**0.00***	1.58	1.78
Support for people with cancer	1	2	-2.7503*	0.09	**0.00***	-2.96	-2.54
		3	-5.9834*	0.08	**0.00***	-6.18	-5.78
	2	1	2.7503*	0.09	**0.00***	2.54	2.96
		3	-3.2331*	0.07	**0.00***	-3.39	-3.08
	3	1	5.9834*	0.08	**0.00***	5.78	6.18
		2	3.2331*	0.07	**0.00***	3.08	3.39
Operations	1	2	-2.1294*	0.05	**0.00***	-2.26	-2.00
		3	-3.1244*	0.05	**0.00***	-3.25	-3.00
	2	1	2.1294*	0.05	**0.00***	2.00	2.26
		3	-.9950*	0.04	**0.00***	-1.09	-0.90
	3	1	3.1244*	0.05	**0.00***	3.00	3.25
		2	.9950*	0.04	**0.00***	0.90	1.09
Hospital doctors	1	2	-1.6505*	0.05	**0.00***	-1.77	-1.53

		3	-2.3866*	0.05	**0.00***	-2.50	-2.28
	2	1	1.6505*	0.05	**0.00***	1.53	1.77
		3	-.7362*	0.04	**0.00***	-0.83	-0.65
	3	1	2.3866*	0.05	**0.00***	2.28	2.50
		2	.7362*	0.04	**0.00***	0.65	0.83
Ward nurses	1	2	-.8494*	0.05	**0.00***	-0.96	-0.74
		3	-1.3742*	0.05	**0.00***	-1.48	-1.27
	2	1	.8494*	0.05	**0.00***	0.74	0.96
		3	-.5248*	0.04	**0.00***	-0.61	-0.44
	3	1	1.3742*	0.05	**0.00***	1.27	1.48
		2	.5248*	0.04	**0.00***	0.44	0.61
Hospital care	1	2	-1.3815*	0.04	**0.00***	-1.48	-1.28
		3	-2.0482*	0.04	**0.00***	-2.14	-1.96
	2	1	1.3815*	0.04	**0.00***	1.28	1.48
		3	-.6667*	0.03	**0.00***	-0.74	-0.59
	3	1	2.0482*	0.04	**0.00***	1.96	2.14
		2	.6667*	0.03	**0.00***	0.59	0.74
GP care	1	2	-1.4388*	0.08	**0.00***	-1.63	-1.25
		3	-2.2410*	0.07	**0.00***	-2.42	-2.06
	2	1	1.4388*	0.08	**0.00***	1.25	1.63
		3	-.8023*	0.06	**0.00***	-0.94	-0.67
	3	1	2.2410*	0.07	**0.00***	2.06	2.42
		2	.8023*	0.06	**0.00***	0.67	0.94

* Significant at a .05 significance level

APPENDIX C

Chapter 4 Staff interview topic guide

5 Minutes - Introduction:

- Our names, job roles, what we will be doing during the interview
- Interview will take 30 – 60 minutes
- Your responses will be kept confidential and your names will not be included in any reporting, nor attributed to the organisation you work for.
- Free to stop at any time or reschedule.
- Consent and consents for recorder. Note how recorder helps us transcribe the interview so we have an accurate record and we can perform a better analysis. These recordings will be deleted at the end of the project.

We are working together to better understand how to make patient experience data- specifically data from the National Inpatients Survey- more useful to quality improvement. The project is a collaborative effort between Picker Institute Europe and the Centre for Health Policy at Imperial College London, and we are looking for input from people who deal with patient experience data in their daily jobs. Insights from your experience working with the data are uniquely helpful to this project. Your feedback today will contribute to efforts to design a survey programme that works best for you in terms of data collection, analysis and presentation.

10 minutes - General discussion about topic

Can you tell us a bit about your experience with the National Inpatient Survey data and how you have been able – or not been able – to use it for quality improvement?

- Probe: novel approaches, other people mentioned in response

5 minutes - Specific inquiries about improvement

- We see you've significantly improved in XXXX, can you tell us a bit about how you did this?
    - Probe: novel approaches, key features of success (i.e. changes in management, data presentation etc.), "deliberateness" of improvement.
- {Picker team to insert questions that might be appropriate for specific organisation}
- How did you overcome any challenges related to using the data?

5 minutes - Specific inquiries about data

- Do you use inpatient experience data alongside any other patient data like safety or effectiveness?
    - Probe: What helps or hinders this?
- What other people work with you on this (i.e. clinicians, patient safety manager)?
- What improvements would you like to see to the data?
    - Probe: questions in data, timeliness of data presentation, aggregate level reporting

5 minutes – Final thoughts

- Thinking about when you have used the IP data for quality improvement, what have the main challenges been? The main drivers of success?
- Any other ideas for how to use patient experience feedback to drive improvement?

APPENDIX D

Chapter 6 Statistical tests

Table 48. ANOVA for organisational and pathway variables across provider clusters with multiple comparisons (including all organisations)

Dependant variables	Cluster	Comparison to other cluster	Mean Difference	Std. Error	Sig. (Bonferroni)	Lower (95% CI)	Upper (95% CI)
Patients waiting over 6 weeks for a diagnostic test	Low	Middling	0.00	0.00	1.00	-0.01	0.01
		High	0.01	0.01	0.19	0.00	0.03
	Middling	Low	0.00	0.00	1.00	-0.01	0.01
		High	0.02	0.01	0.06	0.00	0.04
	High	Low	-0.01	0.01	0.19	-0.03	0.00
		Middling	-0.02	0.01	0.06	-0.04	0.00
Mean length of stay of survey respondents	Low	Middling	0.22	0.19	0.76	-0.25	0.69
		High	-0.16	0.35	1.00	-1.01	0.70
	Middling	Low	-0.22	0.19	0.76	-0.69	0.25
		High	-0.38	0.35	0.86	-1.24	0.48
	High	Low	0.16	0.35	1.00	-0.70	1.01
		Middling	0.38	0.35	0.86	-0.48	1.24
The number of patients not treated within 28 days of last minute cancellation due to non-clinical reason	Low	Middling	0.01	0.01	1.00	-0.02	0.03
		High	0.03	0.02	0.41	-0.02	0.08
	Middling	Low	-0.01	0.01	1.00	-0.03	0.02
		High	0.02	0.02	0.80	-0.03	0.08
	High	Low	-0.03	0.02	0.41	-0.08	0.02
		Middling	-0.02	0.02	0.80	-0.08	0.03
Total emergency admissions	Low	Middling	1394.12	801.56	0.25	-549.38	3337.63
		High	6890.879*	1694.28	**0.00***	2782.88	10998.88
	Middling	Low	-1394.12	801.56	0.25	-3337.63	549.38
		High	5496.756*	1703.14	**0.01***	1367.26	9626.25
	High	Low	-6890.879*	1694.28	**0.00***	-10998.88	-2782.88
		Middling	-5496.756*	1703.14	**0.01***	-9626.25	-1367.26
Proportion of survey respondents who	Low	Middling	0.04	0.02	0.08	0.00	0.09

received urgent/unplanned care							
		High	40.06772%*	0.03	**0.00***	0.32	0.48
	Middling	Low	-0.04	0.02	0.08	-0.09	0.00
		High	35.81936%*	0.03	**0.00***	0.27	0.44
	High	Low	-40.06772%*	0.03	**0.00***	-0.48	-0.32
		Middling	-35.81936%*	0.03	**0.00***	-0.44	-0.27
Number of patients spending over 4 hours from decision to admit to admission	Low	Middling	427.719*	118.24	**0.00***	141.04	714.40
		High	835.983*	249.91	**0.00***	230.03	1441.93
	Middling	Low	-427.719*	118.24	**0.00***	-714.40	-141.04
		High	408.26	251.22	0.32	-200.86	1017.39
	High	Low	-835.983*	249.91	**0.00**	-1441.93	-230.03
		Middling	-408.26	251.22	0.32	-1017.39	200.86
The proportion of staff who would recommend the trust as a place to work or receive treatment	Low	Middling	-.03771*	0.01	**0.00***	-0.06	-0.02
		High	-.13143*	0.02	**0.00***	-0.17	-0.10
	Middling	Low	.03771*	0.01	**0.00***	0.02	0.06
		High	-.09372*	0.02	**0.00***	-0.13	-0.06
	High	Low	.13143*	0.02	**0.00***	0.10	0.17
		Middling	.09372*	0.02	**0.00***	0.06	0.13
Proportion of patients who received all the secondary prevention medications for which they were eligible	Low	Middling	-0.03	0.02	0.40	-0.08	0.02
		High	-0.04	0.06	1.00	-0.18	0.09
	Middling	Low	0.03	0.02	0.40	-0.02	0.08
		High	-0.01	0.06	1.00	-0.14	0.12
	High	Low	0.04	0.06	1.00	-0.09	0.18
		Middling	0.01	0.06	1.00	-0.12	0.14
Support to clinical staff	Low	Middling	-11.61	149.24	1.00	-373.25	350.03
		High	782.0062*	266.56	**0.01***	136.05	1427.96
	Middling	Low	11.61	149.24	1.00	-350.03	373.25
		High	793.6151*	267.84	**0.01***	144.55	1442.68
	High	Low	-782.0062*	266.56	**0.01***	-1427.96	-136.05
		Middling	-793.6151*	267.84	**0.01***	-1442.68	-144.55
Total number of staff employed (WTE)	Low	Middling	230.24	479.05	1.00	-930.65	1391.13
		High	2165.7451*	854.20	**0.04***	95.75	4235.74
	Middling	Low	-230.24	479.05	1.00	-1391.13	930.65
		High	1935.50	860.38	0.08	-149.46	4020.47
	High	Low	-2165.7451*	854.20	**0.04***	-4235.74	-95.75

		Middling	-1935.50	860.38	0.08	-4020.47	149.46
Total soft FM (Hotel Services) costs	Low	Middling	-852098.34	1934046.00	1.00	-5536498.25	3832301.57
		High	5195597.16	3516433.80	0.43	-3321460.97	13712655.28
	Middling	Low	852098.34	1934046.00	1.00	-3832301.57	5536498.25
		High	6047695.50	3539820.65	0.27	-2526007.28	14621398.27
	High	Low	-5195597.16	3516433.80	0.43	-13712655.28	3321460.97
		Middling	-6047695.50	3539820.65	0.27	-14621398.27	2526007.28
Number of sites - General acute hospital	Low	Middling	0.11	0.15	1.00	-0.25	0.48
		High	1.0915*	0.27	**0.00***	0.43	1.76
	Middling	Low	-0.11	0.15	1.00	-0.48	0.25
		High	.9769*	0.28	**0.00***	0.31	1.65
	High	Low	-1.0915*	0.27	**0.00***	-1.76	-0.43
		Middling	-.9769*	0.28	**0.00***	-1.65	-0.31
Mortality rates for conditions normally associated with a very low rate of mortality	Low	Middling	3.05	2.00	0.39	-1.80	7.91
		High	-8.62	8.20	0.89	-28.51	11.27
	Middling	Low	-3.05	2.00	0.39	-7.91	1.80
		High	-11.68	8.21	0.47	-31.60	8.25
	High	Low	8.62	8.20	0.89	-11.27	28.51
		Middling	11.68	8.21	0.47	-8.25	31.60
Total capital investment	Low	Middling	120901.41	2448858.92	1.00	-5810412.78	6052215.61
		High	3685823.95	4452453.70	1.00	-7098342.38	14469990.28
	Middling	Low	-120901.41	2448858.92	1.00	-6052215.61	5810412.78
		High	3564922.54	4482065.77	1.00	-7290966.36	14420811.44
	High	Low	-3685823.95	4452453.70	1.00	-14469990.28	7098342.38
		Middling	-3564922.54	4482065.77	1.00	-14420811.44	7290966.36
Percentage of estates and hotel services contracted out	Low	Middling	5444288.94	2635003.89	0.12	-937881.90	11826459.78
		High	7722721.08	4790897.81	0.33	-3881181.47	19326623.63
	Middling	Low	-5444288.94	2635003.89	0.12	-11826459.78	937881.90
		High	2278432.14	4822760.78	1.00	-9402644.82	13959509.10
	High	Low	-7722721.08	4790897.81	0.33	-19326623.63	3881181.47
		Middling	-2278432.14	4822760.78	1.00	-13959509.10	9402644.82
Proportion of survey respondents who were 66+ years	Low	Middling	-0.01	0.01	1.00	-0.04	0.02
		High	8.30763%*	0.02	**0.00***	0.03	0.14
	Middling	Low	0.01	0.01	1.00	-0.02	0.04
		High	8.92603%*	0.02	**0.00***	0.03	0.15
	High	Low	-8.30763%*	0.02	**0.00***	-0.14	-0.03
		Middling	-8.92603%*	0.02	**0.00***	-0.15	-0.03
Proportion of survey respondents who were female	Low	Middling	0.00	0.01	1.00	-0.03	0.03

		High	0.05	0.02	0.07	0.00	0.10
	Middling	Low	0.00	0.01	1.00	-0.03	0.03
		High	0.05	0.02	0.06	0.00	0.10
	High	Low	-0.05	0.02	0.07	-0.10	0.00
		Middling	-0.05	0.02	0.06	-0.10	0.00
Index of Multiple Deprivation Rank	Low	Middling	-2092.34	1481.36	0.48	-5680.30	1495.63
		High	-4261.54	2693.37	0.35	-10785.08	2262.00
	Middling	Low	2092.34	1481.36	0.48	-1495.63	5680.30
		High	-2169.21	2711.29	1.00	-8736.13	4397.72
	High	Low	4261.54	2693.37	0.35	-2262.00	10785.08
		Middling	2169.21	2711.29	1.00	-4397.72	8736.13

Table 49. ANOVA for organisational and pathway variables across provider clusters with multiple comparisons (including only non-specialist organisations)

Dependant variables	**Cluster**	**Comparison to other cluster**	**Mean Difference**	**Std. Error**	**Sig. (Bonferroni)**	**Lower (95% CI)**	**Upper (95% CI)**
Patients waiting over 6 weeks for a diagnostic test	Low	Middling	0.00	0.00	1.00	-0.01	0.01
		High	0.01	0.02	1.00	-0.03	0.06
	Middling	Low	0.00	0.00	1.00	-0.01	0.01
		High	0.02	0.02	0.94	-0.03	0.06
	High	Low	-0.01	0.02	1.00	-0.06	0.03
		Middling	-0.02	0.02	0.94	-0.06	0.03
Mean length of stay of survey respondents	Low	Middling	0.22	0.16	0.49	-0.16	0.60
		High	1.24	0.65	0.17	-0.33	2.81
	Middling	Low	-0.22	0.16	0.49	-0.60	0.16
		High	1.02	0.65	0.35	-0.55	2.60
	High	Low	-1.24	0.65	0.17	-2.81	0.33
		Middling	-1.02	0.65	0.35	-2.60	0.55
The number of patients not treated within 28 days of last minute cancellation due to non-clinical reason	Low	Middling	0.01	0.01	1.00	-0.02	0.04
		High	0.04	0.05	1.00	-0.07	0.15
	Middling	Low	-0.01	0.01	1.00	-0.04	0.02
		High	0.03	0.05	1.00	-0.08	0.15
	High	Low	-0.04	0.05	1.00	-0.15	0.07
		Middling	-0.03	0.05	1.00	-0.15	0.08
Total emergency admissions	Low	Middling	1242.18	787.99	0.35	-669.99	3154.34
		High	-2677.77	3170.68	1.00	-10371.83	5016.28
	Middling	Low	-1242.18	787.99	0.35	-3154.34	669.99
		High	-3919.95	3175.34	0.66	-11625.31	3785.41
	High	Low	2677.77	3170.68	1.00	-5016.28	10371.83
		Middling	3919.95	3175.34	0.66	-3785.41	11625.31
Proportion of survey respondents who received urgent/unplanned care	Low	Middling	0.02	0.02	0.34	-0.01	0.06
		High	19.32%*	0.06	**0.01***	0.04	0.35
	Middling	Low	-0.02	0.02	0.34	-0.06	0.01
		High	16.86%*	0.06	**0.03***	0.01	0.32
	High	Low	-0.19	0.06	**0.01***	-0.35	-0.04
		Middling	-16.85952%*	0.06	**0.03***	-0.32	-0.01
Number of patients spending over 4 hours from decision to admit to	Low	Middling	412.95*	122.39	**0.00***	115.96	709.93

admission							
		High	650.88	492.45	0.57	-544.11	1845.87
	Middling	Low	-412.945*	122.39	**0.00***	-709.93	-115.96
		High	237.93	493.17	1.00	-958.81	1434.68
	High	Low	-650.88	492.45	0.57	-1845.87	544.11
		Middling	-237.93	493.17	1.00	-1434.68	958.81
The proportion of staff who would recommend the trust as a place to work or receive treatment	Low	Middling	-.03505*	0.01	**0.00***	-0.06	-0.01
		High	-.10814*	0.04	**0.01**	-0.19	-0.02
	Middling	Low	.03505*	0.01	**0.00***	0.01	0.06
		High	-0.07	0.04	0.12	-0.16	0.01
	High	Low	.10814*	0.04	**0.01***	0.02	0.19
		Middling	0.07	0.04	0.12	-0.01	0.16
Proportion of patients who received all the secondary prevention medications for which they were eligible	Low	Middling	-0.03	0.02	0.37	-0.09	0.02
		High	-0.03	0.09	1.00	-0.24	0.18
	Middling	Low	0.03	0.02	0.37	-0.02	0.09
		High	0.00	0.09	1.00	-0.21	0.21
	High	Low	0.03	0.09	1.00	-0.18	0.24
		Middling	0.00	0.09	1.00	-0.21	0.21
Support to clinical staff	Low	Middling	-24.94	146.66	1.00	-380.74	330.87
		High	-1457.0000*	595.16	**0.05***	-2900.91	-13.09
	Middling	Low	24.94	146.66	1.00	-330.87	380.74
		High	-1432.06	595.72	**0.05***	-2877.35	13.22
	High	Low	1457.0000*	595.16	**0.05***	13.09	2900.91
		Middling	1432.06	595.72	**0.05***	-13.22	2877.35
Total number of staff employed (WTE)	Low	Middling	145.04	472.03	1.00	-1000.15	1290.22
		High	-4262.37	1913.97	0.08	-8905.88	381.13
	Middling	Low	-145.04	472.03	1.00	-1290.22	1000.15
		High	-4407.41	1916.70	0.07	-9057.53	242.71
	High	Low	4262.37	1913.97	0.08	-381.13	8905.88
		Middling	4407.41	1916.70	0.07	-242.71	9057.53
Total soft FM (Hotel Services) costs	Low	Middling	-1501475.11	1985186.12	1.00	-6315299.70	3312349.49
		High	-5238269.27	8197792.75	1.00	-25116877.10	14640338.55
	Middling	Low	1501475.11	1985186.12	1.00	-3312349.49	6315299.70
		High	-3736794.17	8210433.91	1.00	-23646055.22	16172466.89
	High	Low	5238269.27	8197792.75	1.00	-14640338.55	25116877.10
		Middling	3736794.17	8210433.91	1.00	-16172466.89	23646055.22
Number of sites -	Low	Middling	0.09	0.15	1.00	-0.27	0.45

General acute hospital		High	-0.89	0.61	0.44	-2.36	0.59
	Middling	Low	-0.09	0.15	1.00	-0.45	0.27
		High	-0.98	0.61	0.33	-2.45	0.50
	High	Low	0.89	0.61	0.44	-0.59	2.36
		Middling	0.98	0.61	0.33	-0.50	2.45
Mortality rates for conditions normally associated with a very low rate of mortality	Low	Middling	3.03	2.02	0.41	-1.86	7.92
		High	-8.65	8.23	0.89	-28.62	11.33
	Middling	Low	-3.03	2.02	0.41	-7.92	1.86
		High	-11.68	8.25	0.48	-31.68	8.32
	High	Low	8.65	8.23	0.89	-11.33	28.62
		Middling	11.68	8.25	0.48	-8.32	31.68
Total capital investment	Low	Middling	-488655.89	2548569.03	1.00	-6668612.60	5691300.82
		High	1408567.86	10524273.03	1.00	-24111459.62	26928595.34
	Middling	Low	488655.89	2548569.03	1.00	-5691300.82	6668612.60
		High	1897223.75	10540501.68	1.00	-23662156.15	27456603.64
	High	Low	-1408567.86	10524273.03	1.00	-26928595.34	24111459.62
		Middling	-1897223.75	10540501.68	1.00	-27456603.64	23662156.15
Percentage of estates and hotel services contracted out	Low	Middling	5427647.89	2728942.39	0.15	-1189691.35	12044987.12
		High	-15070972.34	11269121.78	0.55	-42397163.60	12255218.92
	Middling	Low	-5427647.89	2728942.39	0.15	-12044987.12	1189691.35
		High	-20498620.23	11286499.01	0.22	-47866949.05	6869708.59
	High	Low	15070972.34	11269121.78	0.55	-12255218.92	42397163.60
		Middling	20498620.23	11286499.01	0.22	-6869708.59	47866949.05
Proportion of survey respondents who were 66+ years	Low	Middling	-0.02	0.01	0.50	-0.04	0.01
		High	0.02	0.05	1.00	-0.09	0.13
	Middling	Low	0.02	0.01	0.50	-0.01	0.04
		High	0.03	0.05	1.00	-0.08	0.14
	High	Low	-0.02	0.05	1.00	-0.13	0.09
		Middling	-0.03	0.05	1.00	-0.14	0.08
Proportion of survey respondents who were female	Low	Middling	0.01	0.01	1.00	-0.02	0.03
		High	0.02	0.04	1.00	-0.07	0.11
	Middling	Low	-0.01	0.01	1.00	-0.03	0.02
		High	0.01	0.04	1.00	-0.08	0.11
	High	Low	-0.02	0.04	1.00	-0.11	0.07
		Middling	-0.01	0.04	1.00	-0.11	0.08
Index of Multiple Deprivation Rank	Low	Middling	-2062.97	1479.54	0.50	-5650.66	1524.73
		High	-14524.60	6109.73	0.06	-29339.92	290.72
	Middling	Low	2062.97	1479.54	0.50	-1524.73	5650.66

		High	-12461.64	6119.15	0.13	-27299.80	2376.53
	High	Low	14524.60	6109.73	0.06	-290.72	29339.92
		Middling	12461.64	6119.15	0.13	-2376.53	27299.80

APPENDIX E

Chapter 7 Topic guide for theatre staff interviews

Imperial College Healthcare NHS
NHS Trust

Topic guide/interview questions

Talk through information sheet first and obtain consent.

Introduction
We will spend a bit of time introducing ourselves, talking about your role and experiences and then I have some more focused questions to ask you, is that Ok?
Are you happy for me to make a few notes?
Tell them a bit about yourself:

Background information
What is your role and job title? Clinical/non-clinical?
Where do you work? (name of ward or department, site)
Locum/bank/permanent

- Walk me through your role in the operating theatre? What is it that you are responsible for?
- Thinking about the theatre environment, and how safe it is for patients and staff, what works really well in theatres here now?
- What needs to change here to make the theatre culture and environment safer? And who needs to be involved (Themselves as individuals? The department? The Trust?)
- From your experience of working in theatres, what kind of things might inhibit these improvements?
- Would you be interested in being involved in future work around the Trust's new culture of safety programme (if so, how?)
- Anything else you would like to add about safety in theatres?