

Patients at the centre of design to improve the quality of care; exploring the experience-based co-design approach within the NHS

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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'Stories are just data with a soul' - Brené Brown

Abstract

Patient experience is a key domain within the concept of high quality healthcare and efforts to enhance the experience of care remains a key priority for the National Health Service. Experience based co-design (EBCD) is a quality improvement approach specifically developed for use within the healthcare setting. This thesis aimed to explore how, why and under what circumstances EBCD 'works'. This is in order to understand more about the mechanisms of change over time and contribute towards the evidence base of improvement science. However, the level of staff engagement within the EBCD project declined overtime making it difficult to fully explore the mechanisms of change from multiple stakeholders' perspectives. Therefore, the original aim of thesis was modified in order to explore the experience of participation for people involved within an EBCD quality improvement project in an acute health care setting.

A systematic review was conducted to assess the implementation and the effectiveness of the EBCD approach. The key findings revealed a variation in fidelity, little exploration of the mechanisms associated with the theory of change and little evidence regarding the experience of patients from black and minority ethnic groups.

Through the lens of improvement science three qualitative studies were conducted using interpretative phenomenological analysis to explore the experiences of multiple stakeholders during the EBCD process. The analysis suggests several novel findings that compliment and add to the extant literature: that a richer picture of patient experience is obtained when patients are formally involved in gathering data during the discovery phase; that the use of designers may enhance the approach and help to create a more democratic and user-centred design process; storytelling had therapeutic benefit for patients; that EBCD may be a useful way to engage marginalised groups within quality improvement efforts. However, the consequences of EBCD not being delivered as intended can negatively impact on relationships and achieving successful outcomes. EBCD heralds a different way of improving patient experience and underpins deeper changes to attitudes and behaviour from staff and patients that are required to meaningfully change the way care is delivered and received.

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Chapter 1: Introduction, summary of literature, aim of the thesis and contextual information

1.1 Chapter summary

Improving patient experience continues to be a key focus for the National Health Service (NHS) in England and for health organisations worldwide. The purpose of this chapter is to summarise existing literature about quality and quality improvement (QI) within the healthcare setting, focussing upon the efforts made to enhance the patient experience using a specific intervention: experience based co-design (EBCD). This will provide the context and rationale for the research reported within this thesis.

1.2 Defining quality in healthcare

The concept of quality within healthcare has ranged from simplistic ideas, such as, a mark of excellence or zero defects to more complex definitions that encompass multiple components of care (Campbell, Roland, & Buetow, 2000). The Institute of Medicine (IOM) in the United States (US) perhaps best embodied these complexities in a land mark report '*Crossing the Quality Chasm*' conceptualising quality in terms of six dimensions: patient safety, clinical effectiveness, patient-centred care, timeliness, efficiency and equity with the aim of guiding healthcare performance improvement efforts (IOM, 2001; Berwick, 2002). These dimensions have been broadly adopted by healthcare organisations internationally and frequently cited within a policy context, though based on a US perspective (Beattie, Lauder, Atherton, & Murphy, 2014; Gleeson et al., 2016). For instance, within the NHS in England, high quality care is perceived in terms of patient safety, clinical effectiveness and patient experience (Department of Health, 2008) and is enshrined within English law within the Health and Social Care Act (Gov.uk, 2012).

High quality healthcare could therefore, be defined in terms of an organisation or system in which few errors occur, where treatment and care improves the health of people and where users are satisfied with the care they have received (Vincent, 2010). The following sections will discuss the

patient experience domain and the efforts made to understand and enhance the experience of healthcare.

1.3 What is patient experience and why is it important?

The term patient experience has evolved over the last few decades. It has meandered from considering the rights of patients (Coulter, Locock, Ziebland, & Calabrese, 2014) to the idea of patient advocacy, to ways of understanding, measuring and financially rewarding the quality of care provided (Press, 2014). More recently the concept seeks to embrace both organisational and community perspectives (Wolf, 2014) with patient experience being defined as;

'The sum of all interactions, shaped by an organization's culture that influence patient perceptions across the continuum of care' (Wolf, 2014:p8).

The key idea captured here, is that the experience of healthcare occurs at various times and places along the patient journey. This is affected by organisational expectations of staff with regard to their values, beliefs and behaviours in delivering care. Importantly, this definition emphasises the role of patient's perceptions to determine whether the experience was deemed good or not (Wolf, 2017).

There is increasing evidence to suggest that the good experiences of patients, carers, friends and families are a vital element of high quality care delivery (Sequist, Schneider, Anastario, Odigie & Marshall, 2008, Meterko, Wright, Lin, Lowy & Cleary, 2010; Fenton, Jerant, Bertakis & Frank, 2012; Anhang Price, Elliott, Zaslavsky, Hays, & Lehrman, 2014). A systematic review by Doyle and colleagues (2013) examined the empirical evidence on links between patient safety, clinical effectiveness and patient experience drawn from 55 studies. The conclusion suggested that a superior patient experience was associated with safer and/or more effective care. This finding was displayed across a wide range of healthcare settings, disease specific populations and study designs. Whilst no causal link was identified between the domains, the authors suggest that these three domains should be considered together and not as discrete components of quality.

A positive experience of care has also been linked to better health outcomes for individuals (Confederation, NHS, 2010; Wolf, 2014) and

higher levels of staff satisfaction (Charmel & Frampton, 2008; Sizmur & Körner, 2013; Bodenheimer & Sinsky, 2013; The Beryl Institute, 2015). It is suggested that a main driver of job satisfaction for healthcare professionals is the ability to provide quality care (Friedberg, Chen, Van Busum, Aunon & Pham, 2013). There is also growing evidence that suggests a better patient experience may help to reduce inefficiencies and healthcare costs (Hibbard & Green, 2013). The implications of an ageing population, advances in medical therapies and technology and the current economic climate within the United Kingdom (UK) means that reducing costs whilst improving health outcomes are now an imperative for the NHS (Department of Health, 2010a; Department for Health, 2010b; Department of Health, 2016).

1.4 Improving the patient experience of care

The emphasis on improving the patient experience over the last ten years within the NHS has been informed by numerous national healthcare reviews and policy changes (Ham, Baird, Gregory, Jabbal, & Alderwick, 2015). The impetus for large scale changes has been attributed to the IOM's epoch-making report: *'To Err is Human: Building a Safer Health System'* (Kohn et al., 1999; Vincent, 2010; Department of Health, 2013). It was estimated that in 1997, in the US alone, between 44,000 to 98,000 patient deaths were owing to medical error (Kohn, Corrigan & Donaldson, 2000). Whilst the statistical accuracy of these figures has been questioned (McDonald, Weiner & Hui, 2000) the report is widely regarded as a major catalyst for change (Leape, 2000; Vincent, 2010).

A second significant report; *'An organisation with a memory'* highlighted similar issues being faced by the NHS (Donaldson, Appleby & Boyce, 2000). An expert group on learning from adverse events highlighted the extent and personal and financial cost of healthcare failures in the NHS: annually 10,000 patients experienced adverse drug reactions, 400 people died from reported incidents involving medical devices, there were 28,000 written complaints about care and approximately £400 million was paid out to cover clinical negligence claims (Donaldson et al., 2000).

These reports sparked numerous healthcare reviews and policy changes to healthcare provision within the NHS. Lord Darzi's review (Department of Health, 2008) recognised that patient experience was a key indicator of quality and was framed in terms of how people should be treated; with

compassion, dignity and respect. Recommendations included developing measures to capture patient perspectives regarding the quality of their experiences (Department of Health, 2008).

In 2010, the UK's coalition government published their white paper *'Equity and Excellence: Liberating the NHS'*. This aimed to place patients and the public back at the 'heart' of the NHS by advocating a greater opportunity for choice, more control over their care and feedback mechanisms to report on the quality of care received (Department of Health, 2010a). More recently guidance has been issued for Clinical Commissioning Groups (CCGs) in England upon how to involve people in their health and care in order to improve experience and make better use of resources (NHS England, 2013). The growing interest in providing a good experience of care has also been influenced by recent investigations into major healthcare catastrophes within the NHS (Francis, 2013; Department of Health, 2013b).

Patient and public involvement and engagement (PPIE) is firmly embedded within national policy requirements within the NHS in the pursuit of quality improvement (Department of Health, 2008; Mockford, Staniszewska, Griffiths & Herron-Marx, 2012). Yet bringing patients and healthcare professionals to work collaboratively is fraught with challenges (Martin & Finn, 2011) with the mechanisms that help to facilitate and empower patients to participate in QI efforts remain largely unexamined (Renedo, Marston, Spyridonidis & Barlow, 2015).

1.5 Quality Improvement and associated methods in healthcare

There is no single definition of quality improvement within the literature but a central tenet is the consistent and systematic approach to improve patient experience quality using specific tools and techniques. One definition suggests QI as:

'...better patient experience and outcomes achieved through changing provider behaviour and organisation through using a systematic change method and strategies.' (Øvretveit, 2009: p8).

The underlying principles of QI are about understanding and improving the reliability of the process of care while addressing demand, capacity and flow. This requires engaging and involving staff and patients throughout the process (Health Foundation, 2013).

Quality improvement methodology within healthcare has been largely informed from industrial processes and the pioneering work by Edwards Deming. For instance, the '*lean thinking*' approach developed from the Toyota Production System (TPS) to manage high-quality production (Plsek, 2014; Ham, 2014). The TPS was initially developed to reduce waste from;

'...muda (non-value-added work), muri (overburden), and mura (unevenness).'' (Plsek, 2014; p7)

Quality improvement methodology using lean thinking approaches considers defining value from the customer's perspective, identifying the value stream and removing waste, making value flow without interruption, helping customers pull value and pursue perfection (Plsek, 2014). Yet there is little evidence surrounding the effectiveness of these methods within the healthcare setting (The Health Foundation, 2013). Many QI tools and techniques used within the clinical setting e.g. Total Quality Management (TQM), Plan-Do-Study-Act (PDSA) cycles are based on little proof, are often poorly reported and poorly evaluated (Taylor, McNicholas, Nicolay, Darzi, Bell & Reed., 2013; The Health Foundation, 2013). The development of evidence-based medicine (EBM) is a clear example where using the best available evidence to inform decisions for individual patients has improved health outcomes (Frankovich, Longhurst, & Sutherland; 2011; Shojania & Grimshaw, 2005). This is in stark contrast to QI methodologies which have been described as;

'...proceed(ing) on the basis of intuition and anecdotal accounts of successful strategies for changing provider behavior or achieving organizational change.' (Shojania & Grimshaw, 2005; p138).

Over the last few years the research and healthcare community has seen the rise of a new discipline, the science of improvement. This has been described as:

'...an emerging field of study focused on the methods, theories and approaches that facilitate or hinder efforts to improve quality and the scientific study of these approaches.' (The Health Foundation, 2011a: p6).

Inter-changeable terms are used within the QI literature, such as, implementation science, translational research, quality improvement science, science of quality improvement (Health Foundation, 2011a). There

is great scope to help define the concept and practice of improvement science on a worldwide scale (The Health Foundation, 2011a).

1.5.1 The problem with improving patient experience

There are numerous ways in which patient experience data is currently gathered and used to enhance care (Coulter, Fitzpatrick & Cornwell, 2009). Approaches range from large scale patient questionnaires to more descriptive and arguably less generalisable approaches, such as, patient stories, complaints and compliments (The Health Foundation, 2013). Patient experience measures continue to be largely dependent upon national standardised survey approaches rather than more localised real-time feedback methods (Robert, Cornwell, Brearley, Foot & Goodrich 2011). A key example of this is the annual in-patient survey within the NHS, conducted by the Care Quality Commission (CQC). The results are reported back to the organisations with the expectation that actions are taken upon the findings (CQC, 2016). These findings are also used as key indicators to measure performance within the NHS Outcomes Framework. The Friends and Family Test (FFT) introduced in 2013 was designed to allow patients and families an opportunity to feedback about their experience of care. It initially formed part of the quality indicators used within the NHS outcomes framework but has been heavily criticised for its methodological approach (Greaves, Lavery & Millett, 2013), the appropriacy and relevance for patients (Appleby, 2013) and fairness (Bahgat, Banerjee & Wright, 2015). As a result of a review by the Office for National Statistics (ONS) the FFT results are no longer classed within official statistical data sets for the NHS (NHS, England, 2018).

Though useful to monitor broader trends and health agendas, it is argued that the type of data described above does not help to drive or inform change at a local level (Robert, 2013; Coulter et al., 2014). Staff do not recognise the domains of care being measured as important at a local level (Robert et al., 2011) and difficulties occur translating results into quality improvement actions (Gleeson et al., 2016). The subtle nuances of the patient experience are reduced to an average 'score', as in the FFT, which makes it difficult for healthcare professionals to access and understand the real issues to be addressed (Appleby, 2013; Coulter et al., 2014). The infrequency of data collection also inhibits the detection of any changes over shorter periods of time (Robert et al., 2011). Employing only quantitative methods also means that important aspects of the 'experience'

of care are not adequately captured and organisations may miss what matters most to the patient (Berwick, 2009; DeCourcy, West & Barron, 2012; Robert, 2013). Thus, it is argued that to improve experiences of healthcare both quantitative and qualitative inquiry is required: objective data to measure the impact and success of QI approaches and qualitative data to gather data rich contextual information at a local level (Robert, 2013).

The core principles of improvement require using specific methods, tools and techniques in a systematic and in a consistent manner to bring about change (Øvretveit, 2009; Atkinson, Ingham, Cheshire & Went, 2010; Health Foundation, 2013). In a move to address the issues surrounding understanding and improving patient experience at a local level, the NHS Institute for Innovation and Improvement (replaced by NHS Improving Quality in 2013) drew together a specialist team to develop and test a novel QI approach to enhance the experience of care: experience based co-design (EBCD) (Bate & Robert, 2007a; 2007b). This approach uses predominantly qualitative methods to capture and understand the patient experience with the express aim of improving the 'experience' of care. The following section now examines the theory underpinning this approach and how it has been applied in practice.

1.5.2 Experience-based co-design (EBCD)

Experience-based co-design was developed in response to a recognised need to improve the experience of care, other than considering safety or clinical aspects of care. Experience-based co-design could be considered a complex intervention since it demonstrates many elements of complexity as defined by the Medical Research Council (MRC) such as, the involvement of multiple stakeholders, the variability of outcomes and the difficulty of behaviours of those delivering and receiving the intervention (Craig, Dieppe, Macintyre, Michie, Nazareth & Petticrew, 2008; Moore, Audrey, Barker, Bond & Bonnell 2015).

Experience-based co-design denotes a shift from more traditional QI approaches (see Section 1.5). It is concerned with understanding the relational aspects of care provision rather a focus on processes and outcomes. It is postulated that by re-framing the conversation between patients and healthcare staff using the EBCD process, meaningful changes are made to the patient experience and in turn this can positively alter the behaviour and culture of organisations (Bate & Robert, 2007a; Robert,

2013). Drawing upon four theoretical strands the EBCD cyclical design process incorporates six stages. Before describing these stages in more depth the strands of thought that underpin EBCD are explored in more detail in the following section.

1.5.3 Underpinning theory of EBCD

Experience-based co-design is a theoretically informed QI approach and draws upon four strands of thought, participatory action research (PAR), principles of user-centred design, learning theory and a narrative-based approach to change (Robert, 2013). The features are now examined in relation to the EBCD process below:

i) Participatory action research

Action research has evolved since the initial conceptual work by Lewin (1946) as a process to encourage social change (Gray, 2013). There are now various methodologies, such as, insider action, co-operative inquiry and participatory research (Gray, 2013). Three common characteristics prevail: 1) the research participants are part of a democratic partnership with the researcher; 2) research is seen as an agent of change and 3) data are created from direct experiences of research participants (McNiff & Whitehead, 2011). These features are demonstrated within the very heart of EBCD approach: patients and staff identify working together to co-design improvements to the experience of care delivered and received.

ii) User-centred design

User-centred design is a branch of the design sciences which is characterised by face-to-face collaboration between provider and user. It is concerned with designing the 'experience' of care rather than re-designing 'systems' of care (Robert, 2013). This implies that the focus is placed upon the experience rather than the processes. User-centered design assists with thinking in an alternative manner, trying to make sense of individual experiences in order to improve care and provides tools to aid design solutions. This idea is demonstrated within the co-design phase of the EBCD approach, which relies upon staff and patients coming together to identify joint priorities and working to design or re-design the experiences of care.

iii) Learning Theory

Bate and Robert's (2007a) thinking about the role of learning theory within EBCD is drawn from a range of ideas. This includes the current trend of

arts-based and transformative learning processes (Kerr & Lloyd, 2008). Bate and Robert's (2007a) central argument is that the long-established methods of management and skills training should be challenged. Using transformative learning theory helps to develop more 'reflective practitioners' through a process of critical reflection. Within EBCD this is intended to enable staff to 'pause, reflect and gather information' in order to produce new insights into experiences of care. This learning process requires individuals to become more open to the perspectives of others, being less defensive and more accommodating to new ideas (Kerr & Lloyd, 2008). Bate and Robert (2007a: p142) also suggest that in order to improve patient experiences of healthcare, a conducive and safe environment is required in which to 'practice' these new ways of 'thinking, feeling, doing and relating'. The benefits of an arts-based learning approach are viewed in terms of intrinsic benefits, such as, captivating individuals, increasing empathy, expression of a shared meaning and the development of social bonds (McCarthy, Ondaatje, Zakara & Brooks; 2004).

iv) *Narrative-based approach to change*

A narrative-based approach within the EBCD process is a key theoretical strand. There is a wealth of information that can be obtained from stories often missed with other forms of patient experience measurements (Robert, 2013). The IOM report '*Crossing the Quality Chasm*' (2001) is full of patient stories to illustrate and elucidate the effects of poor quality care.

Bate and Robert (2007a) clearly value the power and significance of storytelling as a natural way to accessing the human condition. A narrative approach fosters a connection between the professional and their patient to allow time for a new, sympathetic and respectful understanding (Charon, 2001). It is suggested that by sharing narratives, hierarchical distances are transcended, which is often inevitable in this type of improvement work between patients and staff. The stories also help to provide an '*internal source of energy*' and once shared and acknowledged by staff '*compel*' people to take action. Change therefore, is seen in terms of a '*personal imperative*' rather than a top down imposition (Bate & Robert, 2007a: p 67). It is suggested that it is difficult for healthcare professionals to remain detached from the change process once engaged with the patient's narrative (Bate & Robert, 2007a). A narrative approach fosters a

connection between the professional and their patient to allow time for a new, sympathetic and respectful understanding (Charon, 2001).

1.5.4 The EBCD process

The cyclical process of EBCD consists of six stages involving discovery and co-design phase (See Figure 1.1).

The process begins with setting up the core project group to manage and oversee the process and an advisory group to help steer the project. Stage two involves engaging staff and conducting in-depth interviews to explore their experiences working within the service. Non-participant observation of the clinical area is also carried out to look at the functional and relational aspects of care delivery. The qualitative interview and observational data is then analysed for key themes and then reported back to staff at a separate meeting. This allows staff to identify their service improvement priorities.

The third stage involves engaging patients in order to capture their experiences of care. In-depth interviews are filmed and analysed for key moments (positive and/or negative) that have significantly shaped the experience of care. These moments are conceptualised as 'touch points' and are described as the pivotal events that 'stand out' for those involved in receiving or delivering the service (Bate & Robert, 2007a: p137).

These touch points are considered highly personal and may refer to emotive feelings and/or stir the cognitive memory to evoke deep and lasting memories. Patients return to these touches points when telling and retelling their stories. A short (approximately 35 minutes) composite 'trigger film' is created from these interviews in which the 'touch points' are highlighted. This film is then shown to the patient group in order to make any changes before being shared with staff. Stage four marks a significant point of the process with patients and staff coming together at a joint meeting in order to share their experiences. The film is presented and staff feedback their findings which then move to a group discussion to identify the key joint priorities for the service. Stage five involves staff and patients volunteering to join smaller groups to co-design and implement improvements. The final stage brings all the staff and patients together to review work that has been conducted to date and to discuss the next steps in the improvement cycle.

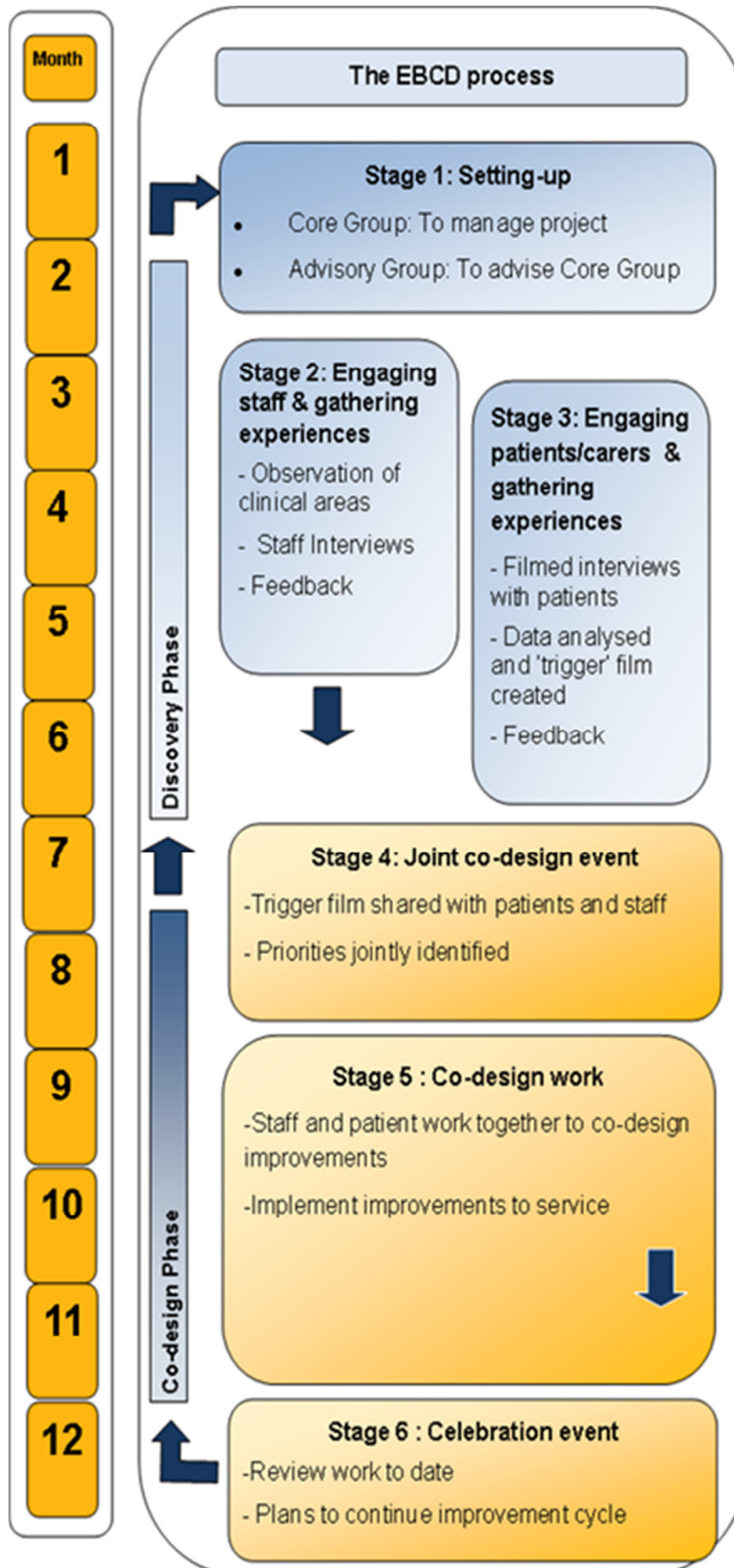


Figure 1.1: The EBCD process and timeline (adapted from Locock et al., 2014)

1.5.5 What do we currently know about EBCD?

The development and testing of EBCD was first described by Bate and Robert (2006; 2007a), as a case study of a service improvement project for patients within a head and neck cancer service, located within an acute hospital in the south of England. It is pertinent at this stage to acknowledge the changing name of the approach over time, from experience based design (EBD) to the now more familiar EBCD. This was owing to the recognition and importance of the word 'co' by the authors, and what this meant to the ethos of the approach: a joint venture between staff and patients and/or carers (G. Robert; personal communication, December 18, 2013).

The current evidence for EBCD and whether it 'works' or not is somewhat limited owing to limited published literature about the approach (Donetto, Tsianakas & Robert, 2014). Chapter 2 will attempt to address this current evidence gap and presents the findings of a systematic review that assessed the implementation and effectiveness of EBCD from published peer-reviewed empirical studies.

A survey produced by Kings College London's National Nursing Research Unit (NNRU) attempted to capture the practice and development of EBCD in the period from 2005 to 2013 (Donetto et al., 2014). The aims were to explore the strengths and weaknesses of the approach, identify any adaptations made to the process, and to consider the contribution of the online EBCD toolkit with regards to implementation (Point of Care, 2018a). The online survey was sent to 107 practitioners known to be conducting or planning EBCD project, with a response rate of 53%. A further follow up telephone interview was also conducted with 18 of the respondents.

The survey identified 59 EBCD projects that had been conducted with a further 27 projects in the planning stage. The studies had taken place across a broad range of healthcare settings including; emergency services, orthopaedics and surgical units, intensive care, diabetes, palliative care, cancer services, genetics, neonatal and paediatric care, haematology, mental health, drug and alcohol services (Donetto et al., 2014). The reported length of time taken to complete projects varied. Forty two of the respondents, stated projects had taken up to a year to complete (50%) with 21% reporting longer than a year, and 29% declaring not-applicable (potentially owing to the fact that projects were currently on-going). The strengths of the approach were seen in terms of the process really

engaging patients and staff, and helping to facilitate 'difficult' conversations. Just over half of the respondents (54%) indicated that the process led to clear improvement priorities and only 51% reported that it had changed practice or the service. Interviews with respondents aimed to explore in further detail the perceived impact upon staff and patients who had participated in the EBCD projects. Findings from staff included: the emotional effect of the patient's voice on film and within co-design activities; motivation increased from positive feedback from patients about the experience of care; feeling listened to and expressing a desire to work with patients more often. The impact for patients was envisaged in terms of patients feeling empowered, pleased with being part of the change process and enjoying a therapeutic aspect of sharing stories and developing relationship.

Of the 41 respondents answering questions about potential areas of weakness within the EBCD process, 45% felt it was too long and 27% thought it was too complicated. The follow up interviews revealed that the process was considered by some to take a lot of organisation and that the time lag between activities may have contributed to projects losing momentum. Interestingly, staff engagement was also reported as a weakness of the approach: organisational culture, unfamiliarity with the process and high clinical workloads were also cited as possible reasons for difficulties faced conducting EBCD projects. Respondents described the ways they had addressed some of these challenges which involved identifying EBCD champions, implementing improvement processes quickly, involving senior staff and communicating with staff at every step of the project.

The reported adaptations displayed a marked variation on the original EBCD process. These included omitting key aspects, such as non-participation observation. The rationale given for this decision was a) the data generated was not considered useful (staff were trying to imagine what it was like to be a patient rather than accessing patient experiences directly) and b) it was thought that sufficient data had already been captured from patient films which negated the need for further observational data. Other changes included different methods to understand staff and patient experiences. Of the 42 respondents only 53% had video-recorded the patient stories. It is unclear if these were later translated into a trigger film. Alternative approaches included: patient diaries and video booths; shortening the co-design process with only one

joint meeting; only seeking to gather patient experiences and using the EBCD approach to co-create resources rather than a method to improve the service. One project made an intentional and notable adaptation to the process. An accelerated version of EBCD (AEBCD) has been developed, tested and rigorously evaluated within an intensive care setting and lung cancer services across two NHS hospital trusts (Locock, Robert, Boaz, Vougioukalou, Shuldham & Fielden, 2014). This project addressed the concerns that the EBCD process was seen as a lengthy and expensive approach. The third stage of the process (gathering patient experience) was expedited with the use of a pre-existing archive of patient stories (held by the Health Experiences Research Group in Oxford) to create the patient trigger film. It was found to be an acceptable and less costly approach by staff and patients. The key findings from the evaluation revealed that AEBCD was a viable alternative, which did not affect staff engagement at a local level, patients felt that the film had reflected key 'touch points' of their care, however, in a slightly more negative tone, than their own experiences. The film helped to frame the discussions between staff and patients which led to 48 co-design activities (Locock et al., 2014).

The EBCD online toolkit was used by 21 out of 47 respondents who suggested improvements to the toolkit which centred on running the activities, how to co-design and further examples of the tools used within the co-design stages.

Evaluations of the EBCD process were mainly confined to internal reports with very few publishing findings in peer reviewed journals: only seven out of the 41 respondents inferred they had published a peer-reviewed paper as a result of their EBCD project. The evaluations were mainly focussed on assessing the sustainability of any changes made to the service; further spread of the approach; staff gaining new skills in gathering patient experience data, and measuring outcomes. Only one project reported costings from economic evaluations.

The report made several recommendations including; responding to the need for more bespoke training and support, reinforcing the importance of observation methods to capture early insights into patient experience, retaining the trigger film as a mechanism to connect patients and staff and a call for strengthening the evidence underpinning the approach compared to other QI approaches since it was recognised there was a lack of formal or systematic evaluations of the process.

The limitations of this survey are clear and recognised by the report authors. The issue of recruitment bias may have affected the results with unsuccessful projects potentially less likely to have taken part, and not all projects may have been captured (Donetto et al., 2014). A second criticism not mentioned by the authors, is the absence of any direct patient input into the survey. Whilst useful to assess the use of the approach from the perspective of staff running service improvement projects, it is unclear what patients thought about the process.

1.6 The importance of understanding further how and why EBCD 'works'

A prime concern within QI efforts is implementing interventions without really understanding the underlying mechanisms of the approach. This has been dubbed by Dixon-Woods (2014) as 'cargo cult quality improvement'. She refers to an historic address by Feynman, an American physicist, to students at Caltech in 1974 (Hanlon, 2013). He tells the story of islanders in the South Pacific, during World War II, having seen airplanes land full of prized materials, they went on to develop a religious 'cargo' cult. This cult built replica wooden 'airports', and waited for airplanes to land and bring the associated riches. The logic from the islanders was unfortunately misplaced and no planes landed. This metaphor neatly illustrates the importance of understanding the mechanisms that help to produce the desired outcomes in order to prevent 'pale and distorted imitations' of an intervention (Dixon-Woods, 2014; p94). The Michigan programme is a good example where the success of the project (significantly reducing infection rate related to central venous catheters for patients in intensive care units), was distilled to the use of a 'checklist' (Bosk, Dixon-woods, Goeschel, Pronovost, 2009). However, it is suggested that much of the programme's positive outcomes were owing to the development of a networked community who shared learning and fostered social norms (Dixon-Woods, Bosk, Aveling, Goeschel & Pronovost, 2011). When this intervention was replicated in England, the 'Matching Michigan' programme also demonstrated significant reductions (60%) in blood stream infections. However, the data also revealed strong secular trends with infection rates of preceding intervention groups matching the previous post intervention group's rates, with similar results seen for pre-ICU infections. Thus, the fall in infection rates may have been also attributable to the simultaneous

improvement efforts and the effects of a national programme raising awareness (Bion, Richardson, Hibbert, Beer & Abrusci, 2012).

Whilst the evidence about EBCD presented in the first two chapters appears to suggest that it 'works', which is to say, that it appears to be a largely acceptable and feasible approach to improving the experience of care, there is less evidence to support 'how and why and under what circumstance it 'works' (Rohde, Brosseau, Gagnon, Schellinck & Carleton, 2016). Understanding the effectiveness of an intervention or the 'active ingredients', is essential for everyday practice (Haynes, 1999). This requires more than describing an intervention in general terms (for example, feedback sessions) but by identifying the 'concrete' activities, the type of participant exposure to these activities, combined with exploring their experiences (Hulscher, Laurant & Grol, 2003). It is suggested that using a qualitative approach may be beneficial when trying to understand participants experiences of the intervention (Hulscher et al. 2003; Moore et al., 2015) and help to uncover any mechanisms needed to bring about change (Aveling, McCulloch, Dixon-Woods, 2013; Moore et al. 2015; Portela, Pronovost, Woodcock, Carter, & Dixon-Woods, 2015; Leung, 2015).

1.7 Improvement science

QI work in healthcare has come under increasing scrutiny over the last ten years and is criticized for its apparent non-scientific manner, poor reporting and a lack of thorough evaluations (Shojania & Grimshaw., 2005; Davidoff, Dixon-Woods, Leviton & Michie., 2015; The Health Foundation, 2011; Marshall, de Silva, Cruickshank, Shand & Wei, 2017). For example, the difficulties of learning from reflections using 'lean' methodology have been noted with little known about the sustainability of the approach over time (DelliFraine, Langabeer & Nembhard, 2010; Glasgow, Scott-Caziewell & Kaboli, 2010; Mazzocato, Savage, Brommels Aronsson & Thor, 2010; Poksinska, 2010). It is also argued that poor dissemination of improvement work is an inefficient use of resources with unintended consequences going unreported (Davidoff et al., 2008; Marshall et al., 2017).

The science of improvement is a growing discipline and attempts to ensure QI efforts are based upon a sound and rigorous evidence base (The Health Foundation, 2011). This has led to the emergence of improvement research, which is focused on the scientific study of methods, theories and

approaches that help and/or hinder quality improvement in healthcare (The Health Foundation, 2011). The benefit of expanding our knowledge around such interventions is to inform practitioners, managers and policy makers on the best approaches to enhance aspects of quality in relation to patient care based on evidence. Improvement science seeks to provide further clarity on what does and does not work to improve healthcare and thereby, strengthening the evidence-base for QI efforts.

For the purposes of clarity within this thesis a working definition has been provided for the following terms, intervention components, active ingredients, mechanism and theory of change (See Table 1.1).

Table 1.1 Key terms for interventions

Term	Working definitions
Intervention components	Hypothesized intervention-specific components to promote desired outcomes (Abry et al., 2014).
Active ingredients	Active ingredients describe interventions mechanisms and distinguish from nonessential components. By identifying active ingredients this may help to refine an intervention and improve its effectiveness and help practitioners to focus on the key priorities to get the most from the intervention (Abry et al., 2014).
Mechanism	This is a component of an intervention that either mediates or moderates between two other components (Chen, 2005).
Theory of change	A set of assumptions about the mechanisms that link an interventions processes and inputs to the outcomes, which may be intended and/or unintended, and the context needed to be for effective (Davidoff, Dixon-Woods, Leviton & Michie, 2015)

EBCD is based upon sound theoretical foundations, but the essential argument is that existing evaluative and QI studies have not sufficiently explored what takes place during key components of the process from a multiple stakeholder perspective. Investigating the EBCD approach has been couched in terms of possible ‘mechanisms’ and ‘active ingredients’ within the ‘black box’ of an intervention. These terms are loaded with epistemological assumptions associated with realist evaluation (Marchal,

van Belle, van Olmen, Hoerée, & Kegels, 2012). However, the research conducted within this thesis has been approached through the lens of improvement science. This focusses on 'systematically and rigorously' exploring what works to enhance the quality in healthcare and to 'ensure positive change' (The Health Foundation, 2011:p4). Though very similar to the aims of realist evaluation, there is a subtle distinction to be drawn here which affects the overall aim and objectives of the thesis and ensuing methodology and research questions. This particular lens also appears to be in keeping with current thinking about theoretical and evaluation approaches for complex interventions which have shifted towards thinking more about relationships and resources (Hawe, 2015).

1.8 Aim of the thesis

Following the literature reviewed in Chapter 1 and 2 a key evidence gap relates to our understanding exactly how, why and under what circumstance EBCD may or may not work. Therefore, the original aim of this thesis was to generate new empirical evidence in relation to exploring the mechanisms of change that link the activities and outcomes of the EBCD QI approach. However, over the duration of this research project the level of engagement with staff participants diminished over time, making it difficult to capture the perspective from all the stakeholders (within the improvement project) in a consistent manner. Thus, the aim of the thesis was adapted to explore the experience of participating within an EBCD project.

A qualitative research approach will be adopted to explore participants experiences with the underpinning theoretical perspective and methodology discussed in more detail in Chapter 3.

1.9 Thesis overview

Chapter 1 has provided a broad overview of the academic literature pertaining to QI efforts in healthcare, patient experience and EBCD as a specific QI method. It has provided a clear rationale for research to explore EBCD in order to understand further how, why and under what circumstance the approach 'works'.

Chapter 2 addresses the first thesis aim and presents a systematic review investigating the implementation and effectiveness of EBCD within the

healthcare setting. This involved devising a search strategy which was applied to six electronic databases. Articles included in the review were drawn from peer-reviewed literature and consisted of EBCD projects and evaluative studies. A narrative synthesis was conducted in order to answer the following questions a) in which healthcare settings has EBCD been applied b) how the EBCD process had been implemented and reported c) reported outcomes and impacts of EBCD projects and how cost effective is the EBCD approach. The findings from this narrative review helped to identify research objectives and inform the methodological approach adopted.

Chapter 3 provides the theoretical and methodological foundations for the research conducted. It describes and discusses interpretative phenomenological analysis as an approach and in relation to qualitative longitudinal research, and the novelty of using the approach to explore experiences within the framework of process evaluation.

Chapter 4 presents the analysis of a qualitative study that explored the experience of patient volunteers, staff and designers conducting observations as a part of the EBCD process. The results from the analysis are presented and discussed considering a broader literature base when compared to extant EBCD empirical literature.

Chapters 5 and 6 present the analysis of a qualitative longitudinal research study exploring the co-discovery and co-design phases of EBCD over time through the lens of multiple stakeholders, patients, patient volunteers, staff and design engineers. The findings are discussed drawing upon wider relevant literature and in relation to the theoretical strands that underpin the approach.

Chapter 7 draws together the results of all three studies which are discussed in relation to the current EBCD literature whilst assessing whether the thesis aims have been met. A quality assessment of the three qualitative studies is also provided and issues concerning the methodology are discussed. Final reflections, suggestions for future research and implications for practice are offered in the closing section of this thesis.

Chapter 2: Assessing the implementation and effectiveness of EBCD within the healthcare setting: a systematic review

2.1 Chapter summary

This chapter presents the findings of a systematic review which aimed to investigate the implementation and effectiveness of EBCD within the healthcare setting. The chapter commences with a description of the method including, the aim and objectives, eligibility criteria, search strategy, data collection, assessment of study quality and analysis and synthesis of the data. The results are presented and subsequently discussed drawing upon relevant literature. The implications of these findings have helped to inform the research aims and questions addressed within this thesis.

2.2 Introduction

Chapter 1 presented an overview of the issues facing healthcare organisations with regard to improving the experience of care and discussed the development of EBCD as a quality improvement approach to specifically enhance patients and staff experiences of care.

This chapter attempts to assess the extant literature about EBCD. Systematic reviews remain the standard for synthesising empirical evidence owing to the methodological rigour and approach adopted to reduce bias (Green, Higgins, Alderson, Clarke & Mulrow, 2011; Tait & Voepel-Lewis, 2015). They can also assist with the development of clinical practice since the volume of information now available is considered 'unmanageable' for most clinicians to routinely appraise and use to inform healthcare decisions (Green et al., 2011; Moher, Shamseer, Clarke, Ghersi & Lierati, 2015). Following a preliminary search (March 2014) of the Cochrane Database for Systematic Reviews (CDSR) and the Database of Abstracts for Reviews of Effect (DARE) no reviews investigating EBCD were identified. In absence of any existing reviews it was considered appropriate to appraise the empirical evidence about EBCD to a) synthesise current knowledge and understanding about the process and outcomes of the approach and b) inform further areas for research.

2.3 Aim and research questions

The aim of this systematic review was to assess the implementation and effectiveness of EBCD within the healthcare setting drawing upon peer-reviewed literature. Thus, the following review questions were addressed:

1. In which healthcare settings has EBCD been applied?
2. How has the EBCD process been implemented and reported?
3. What were the reported outcomes and impacts of EBCD projects?
4. How have costs been measured and reported?

2.4 Methods

The protocol for this systematic review was developed using the Centre for Reviews and Dissemination (CRD) guidelines (CRD, 2008). Protocol amendments made during the process of the review were documented in a protocol addendum and have been discussed as required within the review chapter (See Appendix 1). An advisory group (PG, RL, JoH and AG) offered methodological guidance while developing the protocol and conducting the review (See Appendix 1).

An attempt was made to register the review on PROSPERO (the international prospective register of systematic reviews). At the time of registration data extraction had already commenced and it was therefore deemed ineligible. Subsequently, the criteria for registration have changed and systematic reviews can still be eligible for inclusion until data extraction is complete (Centre for Reviews and Dissemination: PROSPERO dataset and summary guidance).

The structure of chapter 2 was guided by The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman & Group., 2009).

2.4.1 Inclusion criteria

Studies were included if they had applied either the EBD, EBCD or AEBCD approach within any study design, any healthcare setting and within any disease specific population.

The rationale for adopting a broad study design was to capture any empirical papers pertaining to the implementation and/or effectiveness of EBCD. This included papers reporting upon QI projects, which were

differentiated from studies aiming to evaluate and advance the science of QI. This decision was necessary in order to address the research questions posed in the review.

Abstracts were included if data was provided in order to extract information with regard to methods, participants, intervention, outcome measures and results. Studies needed to have reported empirical data, in peer reviewed journals, from 2005 onwards and were available in English language.

2.4.2 Exclusion criteria

Studies were excluded if they did not report any empirical data from EBD, EBCD or AEBCD studies, were not published in a peer reviewed journal or were not accessible in English.

2.4.3 Search strategy and information sources

The search strategy employed several methods which included:

- Relevant electronic databases
- Scanning reference lists of eligible studies
- Contacting experts within the field of EBCD

Searching electronic databases

The search strategy was developed after reviewing key documents from the EBCD literature (Bate & Robert, 2007a; Donetto et al; 2014), discussion with the advisory team (PG, RL, JoH and AG) and a review by a specialist librarian for the Medicine and Health Faculty at the University of Leeds (UoL). A combination of keywords and MeSH terms were used within the search strategy (See Table 2.1).

For the purposes of reporting this review, the global term EBCD has been used to refer to the approach, but the original and earlier derivation of the approach, known as 'experienced based design' (EBD) and more recently, an accelerated version of the EBCD approach (AEBCD) were also used within the search terms (as discussed in Chapter 1.5.5).

The following electronic databases were selected and searched from 2005 to July 2014: Web of Science, Ovid MEDLINE, Ovid EMBASE, Ovid PsychINFO, Ovid CINAHL, and The Cochrane Central Register of Controlled Trials. An example of the search string used to retrieve studies from Ovid Medline is presented in Appendix 2. The time filter was applied from 2005 since it was assumed that as the EBCD approach was developed in 2005 there would be no identifiable studies before this date.

Table 2.1: Search strategy: Keywords and MeSH terms

Search terms	Keywords	MeSh terms
Population	patient* inpatient outpatient Accident and Emergency patient hospital inpatient hospital adj3 patient hospital outpatient hospital adj3 outpatient patient* adj3 community adult child\$ or kid\$ or toddler\$ or bab\$ or school age or schoolage or school-age or pre\$school\$ or schoolchild\$ young adult or adolescen	Patients Inpatients Outpatients exp Transition to Adult Care/ or exp Adult Children/ or exp Adult/ or exp Young Adult exp Child, Preschool/ or exp Pediatrics/ or exp Child/ or exp Infant/ or exp Adolescent
Intervention	Experience-based co-design EBCD Experience based design EBD accelerated experience-based co- design AEBCD	Quality improvement

A decision was made not to conduct a grey literature search. Though incorporating grey literature within health and social science reviews may help to reduce the effects of publication bias, the limitations relate to the reliability of the findings. There is a lack of a rigorous peer-review process to detect issues such as errors or fraud and to ensure clear reporting (Smith, 2006) thus, making it difficult to assess the methodological quality (Rothstein et al, 2005).

Scanning reference lists

Reference lists of eligible studies were also scanned in order to identify any additional studies eligible for inclusion. This was conducted at the final stage of the study selection process.

Contacting experts within the field of EBCD

Contact was made with Catherine Dale (programme Manager of the Patient-Centred Care Project and co-developer of the EBCD toolkit) via email and followed up with a face-to-face meeting at Guy's Hospital in London (22 November 2013).

Glenn Robert (GR) (Professor of Healthcare Quality & Innovation, King's College London, co-developer of the EBCD approach) was approached via email (18/12/2013) and followed up with a face-to-face meeting at King's College London (13/01/2014).

Relevant literature was discussed at these meetings and a key bibliography on EBCD was obtained from GR and checked against retrieved citations from the electronic and reference list scan searches

2.4.4 Study selection

Reference management software (Endnote v6) was used to collate and manage the citations returned from the search strategy. A two stage approach was adopted with regard to study selection.

Stage I consisted of removing duplicate studies with remaining titles and abstracts assessed by the main reviewer (LT) against the inclusion and exclusion criteria. If the citation did not meet the eligibility criteria it was instantly rejected but, if it was unclear the article was included for further assessment. Over inclusion at this stage of a review was considered a pragmatic approach to avoid missing relevant studies (CRD, 2009).

A proportion of citations at stage 1 (551/559, 99%) were then divided between second reviewers (RL, JoH and AG) and independently re-assessed. Agreement between reviewers was formally assessed using a Kappa statistic (CRD, 2009). The Kappa scores at stages 1 and 2 are presented in Table 2.2. There was a substantial (LT and JoH) to strong agreement (LT and RL, LT and AG) between assessors at the first stage (Viera and Garrett, 2005).

Table 2.2: Level of agreement between reviewers at study selection stage

Reviewers	Number of citations reviewed	Kappa statistic (κ)	
		Stage 1:	Stage 2:
LT and RL	181/559	$\kappa = 0.94$	$\kappa = 0.85$
LT and JoH	186/559	$\kappa = 0.66$	-
LT and AG	184/559	$\kappa = 0.85$	-

The second study selection stage involved full paper retrieval of the remaining citations for a detailed assessment. All studies were assessed

by the first reviewer (LT) against the inclusion and exclusion criteria. At this point no refinements were made to the inclusion criteria. All studies (100%) were independently re-assessed by a second reviewer (RL). Any disagreements were discussed and decisions were documented during a face to face meeting. The inter-assessor reliability demonstrated a strong agreement between reviewers ($\kappa=0.85$).

2.4.5 Quality assessment

Assessing the quality of included papers was necessary in order to determine the strength of evidence provided by the review. Owing to the heterogeneity of study designs included within the inclusion criteria, the Quality Assessment Tool for Studies with Diverse Designs (QATSDD) was initially pre-specified as an appropriate method to assess study quality. This validated tool has demonstrated good internal reliability and is seen as a pragmatic approach to providing a robust, transparent and standardized method to assess quality across different research methodologies (Sirriyeh, Lawton, Gardner & Armitage, 2012).

The QATSDD tool consists of up to 16 criteria for mixed method studies and 14 criteria for quantitative and 14 criteria for qualitative studies. Each criterion is assessed and given a score from 0 to 3, against a set of guidance notes used to determine the level and completeness of reporting. Final scores can range between 0 and 48 for mixed method studies and a maximum of 42 for qualitative or quantitative studies. The raw score is then converted into a percentage to allow for a standardised comparison across all study types. Although this tool was anticipated as an appropriate method, when piloted by the main reviewer (LT) the criteria did not map onto the reported content of the EBCD QI projects. This meant that relevant data was not accurately assessed and ultimately made the comparison between the EBCD QI projects and evaluative and research papers problematic. For instance: evidence of sample size considered in terms of analysis, representative sample of target group of a reasonable size and fit between research questions and method of analysis were not considered to be routinely reported aspects of EBCD QI projects. Therefore, a dual approach was taken to assess the quality of included papers within the review. This is considered to be a pragmatic and accepted method of quality assessment for reviews including diverse study designs (CRD, 2009). In discussion with the supervision team (PG, RL, JoH and AG) the Template for Intervention Description and Replication

(TIDieR) checklist was adopted for use in order to assess EBCD QI papers (Hoffmann et al., 2014).

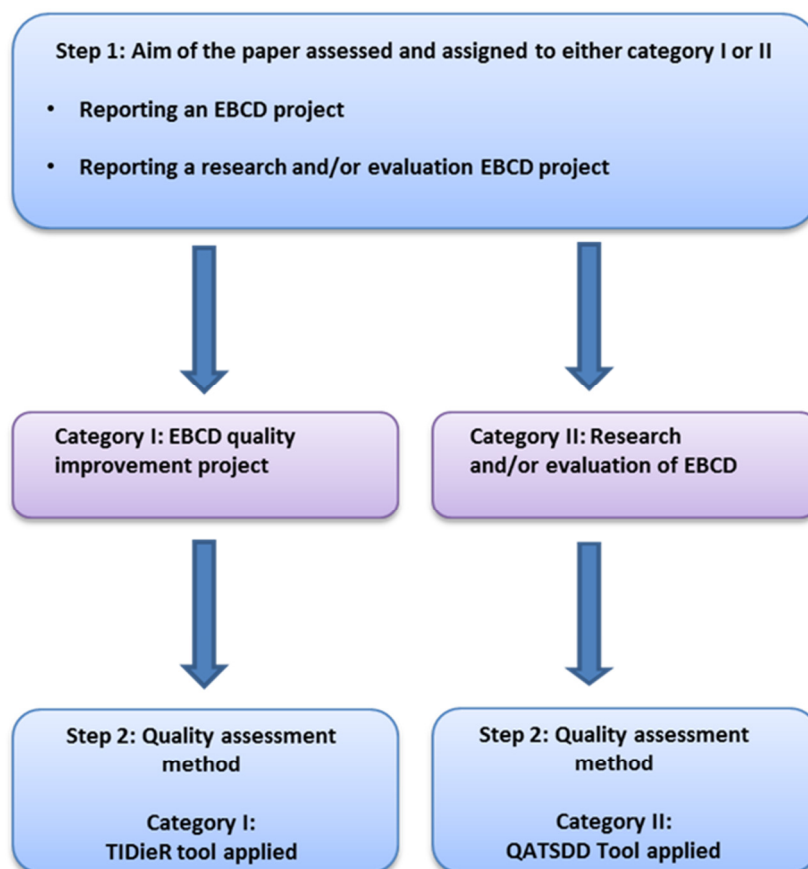


Figure 2.1: Flowchart of the quality assessment process

The TIDieR checklist was primarily developed to improve the reporting of interventions (Hoffmann et al., 2014), but the authors suggest that the guide may assist with describing interventions within a systematic review (Hoffmann et al., 2014) and has been adapted for use and applied as a method to assess the quality and completeness of reporting within a systematic review investigating perioperative literature on QI methods and quality interventions (Jones et al., 2015). The checklist comprises a 12 items with an accompanying explanatory statement. Each item is assessed and rated as either a 'Yes' to signify that a full description was provided or 'No' to signify that the item was not reported or incomplete. Nominal data ('Yes' or 'No') are used to report the proportion of complete and incomplete items from the TIDieR checklist. Using the stated aim and objectives in the main report, each paper was assessed and assigned a category: papers reporting an EBCD QI project (Category I) or papers reporting evaluations or research on the EBCD approach (Category II).

Category I papers were assessed using the TIDieR checklist and Category II papers were assessed using the QATSDD tool (See Figure 2.1).

All papers were assessed and categorised by the main reviewer (LT). The 12 papers were evenly distributed amongst the second reviewers (PG, RL, JoH and AG) and independently re-assessed. A face to face meeting was held with each assessor to check for agreement and reliability of decisions made.

A formal statistical test to measure inter-rater reliability was not considered methodologically appropriate owing to the subjective and iterative approach to quality assessment. Any disagreements about categorisation, scores using the QATSDD tool or decisions using the TIDieR checklist, were discussed at the face to face meeting. A consensus was reached by the reviewers with the final outcome and rationale noted.

2.4.6 Data extraction

A data extraction sheet was developed, using Microsoft Excel, in order to capture and record relevant data. The categories were relevant to the review objectives and general study characteristics. These consisted of a mixture of categories, with numerical data, fixed text option (yes, no, unclear) and free text:

- Study design e.g. RCT, qualitative, quantitative, mixed methods
- Aim and objectives of the study
- Length of study / Any follow up?
- Where has the EBCD project taken place?
- What is the disease specific population/ or population that the EBCD project has targeted?
- Have all the stages within the EBCD been reported? i.e. setting up gathering staff experiences, gathering patient experiences, joint co-design meeting, smaller co-design group work, celebration event
- What were the key reported findings?
- How has the impact of EBCD been reported? E.g. reducing length of hospital stay, improving patient satisfaction scores
- Has the cost/cost effectiveness been measured and reported?

The data extraction form was piloted using three studies to ensure that all the relevant data were captured. Having been familiarised with the data within the papers three additional categories were included which were

pertinent to the implementation and effectiveness of the studies. This included:

Who conducted the study? E.g. Health care researchers/ academics affiliated to a university/ health care professionals / or a mixture?

- Rationale for using EBCD over traditional methods of quality improvement tools and techniques
- How has the study been reported?
- Were the SQUIRE guidelines used? (Yes/No)
- Other / narrative approach

Data extraction was independently checked for accuracy and completeness by a second reviewer (RL) for 75% of papers. A face to face meeting was held to discuss data extracted and check for agreement. Owing to narrative data captured a formal statistical assessment was not appropriate, with any disagreements noted and resolved.

2.4.7 Data synthesis

A narrative synthesis (NS) approach was taken as an appropriate approach to synthesise the evidence. This was owing to the inclusion of a diverse range of study types within the review and the inclusion of qualitative findings (Popay, Roberts, Sowden, Petticrew, & Arai, 2006). The framework for the narrative synthesis was informed by Popay et al.'s (2006) guidance. It was developed in order to provide a more transparent and systemic approach to the narrative synthesis process, which in the past has been criticised methodologically for possibly introducing bias into a review (Popay et al., 2006). The overarching framework consists of four non-sequential elements. This includes:

- developing a theory of how the intervention works and under what circumstances,
- developing a preliminary synthesis of the results of included studies,
- exploring relationships in the data
- assessing the robustness of the synthesis

There are various suggested tools and techniques that can be used during the NS process. Not all elements may be conducted within a review. As a result the theory underpinning EBCD was not developed as this has already been articulated (Bate and Robert, 2006, 2007a). For the purpose of this review the specific process is outlined below in Table 2.3.

Table 2.3 Tools and techniques used within the NS process

Element in NS	Tools and techniques used
Preliminary synthesis	<ul style="list-style-type: none"> • Tabulating textual descriptions of included studies • Grouping by study type • Thematic* and content analysis
Exploring relationships in the data	<ul style="list-style-type: none"> • Qualitative case descriptions • Thematic analysis (Braun and Clarke, 2006)
Assessing the robustness of the synthesis	<ul style="list-style-type: none"> • Quality Assessment using the QATSDD and TIDierR assessment tools

2.5 Results

2.5.1 Search results

Electronic database search results

A total of 753 citations were identified from the electronic search strategy. Duplicated citations were removed, which resulted in a total of 559 articles eligible for first stage study selection process.

After the first stage of study selection process 537 studies were excluded. The principle reason for exclusion was that the citation was unrelated to EBCD (n=454) with one citation not reported within a peer reviewed journal. The remaining 22 articles were subjected to a detailed assessment at stage two of study selection against pre-specified inclusion and exclusion criteria. Subsequently, a further 14 articles were excluded for the following reasons:

- A lack of reported empirical data (n=2)
- Not related to EBCD (n= 5)
- Not from peer-reviewed journals (n=6)
- Not in English (n=1) (published in Chinese)

Scanning reference lists of eligible studies and contact with experts

A further eligible paper was identified as eligible from the reference lists of papers included at the second stage of the selection process. This met the criteria after a full paper review and was included in the final review.

Three further papers were eligible from a bibliography list (G. Robert, personal communication, 18 December, 2013). At this stage after a full

paper review, two were excluded as they did not pertain to the entire EBCD process, only parts of the theory underpinning experience based design.

Included studies with the review

The study selection process retrieved a total of 12 papers to be included within this review (See Figure 2.2).

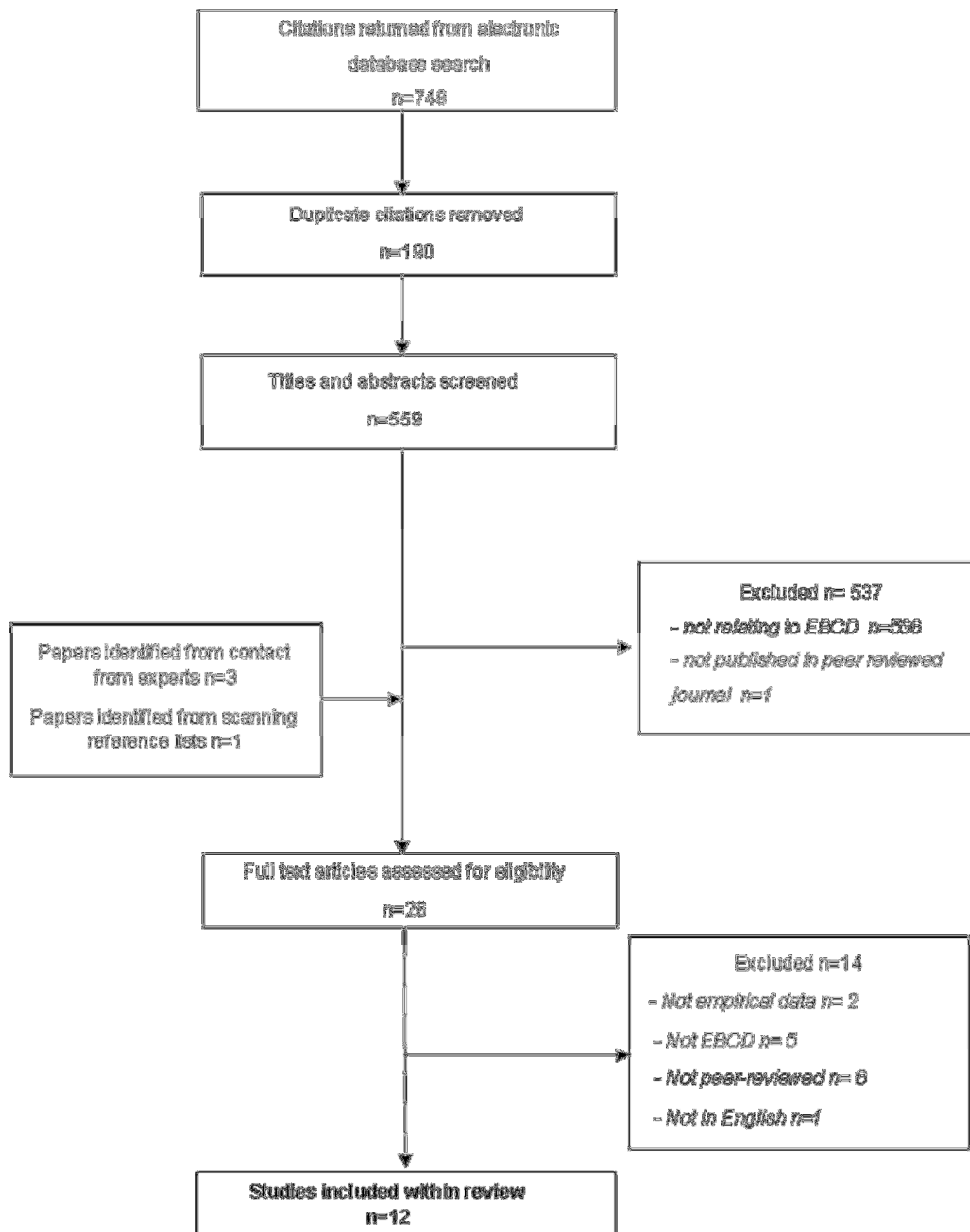


Figure 2.2: PRISMA flow diagram summarising study selection

2.5.2 Study overlap

There were 12 papers included within the review that were reporting different aspects of the same studies, which resulted in the identification of seven unique study settings:

- The EBCD QI papers by Bate & Robert (2007b) and Pickles, Hide & Maher (2008) both reported upon different aspects of a pilot study within a head and neck cancer service. Bate & Robert (2007b) reported in depth about the conceptual ideas behind EBCD and reported a case study to illustrate the implementation of EBCD in practice. Whilst Pickles et al. (2008) reflected upon the experiences of participants of the EBCD process being piloted.
- The EBCD QI paper by Wolstenholme, Cobb, Bowen, Wright, & Dearden (2010) was subsequently evaluated and reported within Bowen, McSeveny, Lockley, Wolstenholme & Cobb et al.'s (2013) paper.
- Tollyfield (2014) paper reported upon on the experiences of facilitating an AEBCD project which was part of a much larger research and evaluative study conducted by Locock et al. (2014).
- The evaluative papers by Iedema et al. (2010) and Piper, Iedema, Gray, Verma, & Holmes. (2012) both reported on the same EBCD project spread across seven Emergency Medicine Departments, in Australia but at different time points.
- Two papers by Tsianakas, Robert, Maben, Richardson & Dale (2012a) and Tsianakas, Maben, Wiseman, Robert, & Richardson (2012b) reported different studies but within the same EBCD improvement project which concerned enhancing the experience of care for breast and lung cancer patients.
- The papers by Boyd, Mckernon, Mullin & Old (2012) and Tunney & Ryan (2014) were unique study settings.

2.5.3 Quality Assessment

The TIDieR checklist assessment revealed a range of completeness and quality in reporting from four out of twelve items to ten out of twelve items with an average score of six out of twelve items (See Table 2.4). No paper reported any form of intervention adherence assessment and related strategies to maintain or improve the fidelity of the EBCD approach. For four of the QI papers there was little explanation for any apparent

modifications to the process. It was also unclear for most papers how the intervention was delivered; how often, who delivered the sessions, where they had taken place and adequate details of the activities within each stage of the process. Overall, a good rationale and theoretical justification for the EBCD approach had been reported.

For research and evaluative papers the QATSDD scores ranged from 33% to 74% with an average score of 48% (See Table 2.5). For lower quality studies (Piper, Iedema, Gray, Verma, & Holmes, 2012; Iedema, Merrick, Piper, Britton & Gray, 2014) there was little justification for sample size, methods of data collection and analysis with few details concerning recruitment. There was one paper that was assessed as high quality having provided sufficient information detail across the majority of criteria (Locock et al., 2014). For all papers there was no reference to user involvement with study design. Most of the papers provided a limited description of participants with no details of age, gender or ethnicity. The research setting was generally described well within included papers.

There was some discrepancy over initial scores for both TIDierR and QATSDD tools used between the main reviewer (LT) and the second reviewers (PG, RL, JOH and AG). When comparing independent assessments at one-to-one meetings, differences over the interpretation of criteria were discussed, this enabled an agreed score to be awarded. The main area for discrepancy between the main and second reviewers for both assessment tools was related to methodology criteria and subjectivity over scoring.

The quality assessment for both EBCD projects and evaluative/research papers demonstrated overall a medium level of reporting quality overall which will be discussed in the findings.

2.6 Key findings

These are presented in relation to the findings of the key characteristics. Findings are presented separately in order to demarcate findings from EBCD QI projects and evaluative/research papers (See Tables 2.4 and 2.5). They include, author and year, healthcare setting, study design and aim, participant details, key results and quality assessment scores. There were virtually no demographic details about participants involved in the project in terms of age, gender or ethnicity. The exception was Tunney & Ryan (2012) which provided the mean age of participants (64.5 years).

Table 2.4 Key characteristics of EBCD QI projects EBCD process stages reported Key: Y = Yes, N = Not reported, U = Unclear

Author and Year	Country	Healthcare setting	Study design & Aim	Participants	Key results	Funding	QA: TIDieR score
Bate & Robert, (2007b)	England, South-East	Head & Neck cancer service, Secondary care	Case study To improve services for head and neck cancer patients and staff	Researchers (n=2) External graphic designer (n=1) External film maker (n=1) Hospital improvement specialists (n=2) National sponsor (n=1) Staff (n= not reported) Patients (n=8)	Touch points identified by: -Patients and Staff: Point of diagnosis in the clinic signified losing identity and power -Staff but not patients: crowded and long waits in clinics -Staff: Multi-Disciplinary Meetings Small scale changes: -Weighing scales moved in clinic from public to private room	NIHR	10/12 items
Boyd et al., (2012)	New Zealand, North & West Auckland	Breast service Secondary care	QI project To improve patient experiences and services for breast care patients	<i>Mapping workshop:</i> Workshop organisers (n=2) Patients & supporters (n=14) Staff (n=5) <i>Co-design workshop:</i> Workshop organisers (n=3) Patients & supporters (n=12) Staff (n=11) Community representatives (n=3)	Small scale changes: - A suite of patient information leaflets - Mammography gown re-designed - Patient journey guide - Communication guide for patients and staff in poster format - A double sided card for patients to track their appointments Education and training - A map of the patient journey for staff - Co-design toolkit and website for healthcare services	District Health Board, NZ	8/12 items
Pickles et al., (2008)	England, South East	Head & Neck cancer service Secondary care	QI Project To redesign services for head and neck cancer patients based on their experiences of health services	Not reported	Small scale changes - Moving the weighing scales in clinic - Lean principles used to improve the safety and productivity of the ward e.g. making equipment more easily accessible for staff and patients Re-designing processes within the service -no more than 2 members of staff during consultations	NIHR	4/12 items

Author and Year	Country	Healthcare setting	Study design & Aim	Participants	Key results	Funding	QA: TIDieR score
Tollyfield., (2014)	England, South East	Cardiothoracic Intensive Care Unit (ICU), Secondary care	To recount the experience of facilitating a EBCD QI project in order to encourage other healthcare settings to undertake similar improvement work	Staff interviewed (n=15) Total number of staff involved (n=50) Patients (n=19)	<p>Key priorities identified from joint event:</p> <ul style="list-style-type: none"> - Enhancing basic care - Reducing noise and sleep deprivation - Improving communication <p>Demanding nature of Stages 1-4 of the EBCD process – no time for clinical work</p> <p>A key role of the facilitator was perceived to be an 'enabler'</p> <p>Training and Support Training received by facilitators and provided with email/ telephone support and use of the EBCD toolkit</p>	NIHR HS & DR	8/12 items
Tsianakas et al. (2012a)	England, South East	Breast and lung cancer service Secondary care	To enhance the experience of breast and lung cancer service patients	Breast patients (n=32) Lung patients (n=13) Qualitative researchers (n=3) Staff -breast service (n=37) Staff - lung service (n=26)	<p>Small scale changes</p> <ul style="list-style-type: none"> - Patients kept with family - More information about symptoms - Patient information leaflets for specific points in care - A second breaking bad news room <p>Re-designing processes within the service</p> <ul style="list-style-type: none"> - Appointment system altered - Clinic re-structured - reduced waiting - Link nurse to improve working across sites and nurse led end of treatment clinics <p>Education and training</p> <ul style="list-style-type: none"> - Administrative staff received customer care training 	Guy's & St Thomas' Charity	7/12 items

Author and Year	Country	Healthcare setting	Study design & Aim	Participants	Key results	Funding	QA: TIDieR score
Tunney & Ryan (2014)	Northern Ireland	Stroke carer support group Community/Primary care setting	To explore how members of a stroke carer support group perceived that services for patients and cares could be improved	Practice development nurse (n=1) Carers (n=10)	<p>Experience Questionnaire:</p> <ul style="list-style-type: none"> - Fear and worry common emotional response at initial contact with providers - Worry, frustration and loneliness during admission through to discharge <p>Listening Lab:</p> <ul style="list-style-type: none"> - Sense of loneliness, lack of information, effects of the stroke upon relationships, emotional effect on carers, lack of on-going support 	FoNS and Burdett Nursing Trust	4/12
Wolstenholme et al., (2010)	England, North	Medical out-patients service Secondary care	A design-led service improvement project for older adults using Medical Outpatients	Practitioners and researchers (n=not reported) Volunteers (n=not reported) Clients and carers (n= not reported)	<p>Small scale changes</p> <ul style="list-style-type: none"> - Appointment letter redesigned - New signage and maps <p>Education and training</p> <ul style="list-style-type: none"> - Interactive learning event to present a story from the staff and patient perspective 	Sheffield NHS Primary Care Trust	4/12

Table 2.5 Key characteristics of EBCD evaluative studies and research

Author and Year	Healthcare setting	Study design	Aim of the study	Participants	Key Findings	Q/A: QATSDD score
Bowen et al., (2013)	Medical outpatients service Secondary care hospital England, North	Evaluative study Qualitative Post project of a service improvement project for older adults using Medical Outpatients	To explore how the project revealed issues of wider relevance to participatory health service design and suggest ways for dealing with issues	Patients n=2 Patient advocate n=1 Staff n=6 Estates manager n=1 Graphic designer n=1	Participants talked about the benefits of storytelling and emotional mapping activities in terms of making their perspective understood by others, and helping to build group empathy and cohesion. Participants did not perceive being actively involved with the co-design stage Dissatisfaction with the effectiveness of the project - prior assumptions about the change process could not be explored because of study design Motivation for taking part differed amongst stakeholder groups	19/42 45.23%
Piper et al., (2012)	Australia, New South Wales Emergency Department (ED) service, Secondary care (multi-site study n=7) (multiple stage study n=2)	Evaluative study Qualitative post-project	To evaluate the impact of EBCD on patients experience of ED care	<i>Programme 1: stage 1 Evaluation (across 3 sites)</i> Project staff (n=10) Staff (n=15) Consumers (n=9) <i>Programme 1: Stage 2 Evaluation (across 3 sites)</i> Project staff (n=10) Staff (n=18) Consumers (n=7)	Both programme 1 and 2 sites found EBCD burdensome with competing busy work schedules Project staff wanted more support with resources and reporting opportunities at executive levels The healthcare setting was challenging with regard to recruiting and maintaining involvement with the target population Simultaneous improvements were perceived in terms of operational	14/42 33.33%

Author and Year	Healthcare setting	Study design	Aim of the study	Participants	Key Findings	Q/A: QATSDD score
Piper et al., (2012) continued.../				Programme 2: stage 1 Evaluation (across 4 sites) Project staff (n=17) Staff (n=22) Consumers (n=9)	<p>efficiency and inter-personal dynamics of care</p> <p>EBCD gave stakeholders a better understanding of each other's experience of the process of care</p> <p>Evaluation at stage 2 programme revealed sustained and possible extension of improvements, and saw changes in practice.</p> <p>EBCD may be an effective way of engaging healthcare professionals and patients to develop solutions to problems</p>	
Iedema et al., (2010)	Australia, New South Wales, Emergency service, Secondary care (multi-site: n =3)	Evaluative study Qualitative Independent post-hoc evaluation of EBCD project to improve patients and care givers' experience of emergency department care.	To establish how effective the co-design outcomes were in the eyes of those involved in the project across the three sites	Project staff (n=15) Staff (n=12) Health Department employees (n=3) Patients (n=10)	<p>Co-design is a process that engaged patients and care givers but perceived to be of greater benefit for health care professionals, with an opportunity to listen to patient experiences</p> <p>Project staff carried the burden of ensuring the process sustained momentum and maintaining patient involvement with a short stay patient group</p> <p>Participants perceived that the service had been improved with changes to the physical environment but solutions meant competing for funding within existing budgets</p>	14/42 33.33%

Author and Year	Healthcare setting	Study design	Aim of the study	Participants	Key Findings	Q/A: QATSDD score
Locock et al., (2014)	England, South East Intensive care and Lung Cancer services, Secondary care	Research study and Ethnographic evaluation Evaluation data collection methods: - Observations (n=155hours) - Group interviews (n=2) with patients (n=8) - Evaluation questionnaires at the end of patient, staff and joint events (n=170) - Reflective diaries - Document analysis - Cost data - Comparative EBCD data from other studies	Research study To use a national video and audio archive of patient experiences to develop, test and evaluate a rapid patient-centred service improvement approach Ethnographic evaluation To observe the implementation process and evaluate the acceptability and impact of the adopted approach	Clinical staff (n=96) Patients and family members (n=63)	An accelerated version of EBCD, using a national archive of patient narratives was an acceptable adaptation for staff and patients. The approach may have made the filming process less challenging and threatening, The trigger film served its purpose of fostering discussions between stakeholder groups to bring about changes to the service. There were 48 co-design activities across 4 care pathways reported as a result of the EBCD QI project The financial cost of the approach was reported as being up to 40% less than the traditional EBCD process The costs of resources was related The large workload but was offset in terms of building staff capacity and capability There was evidence of spread and adoption of the approach in other clinical pathways in the trusts involved.	31/42 73.80%
Tsianakas et al. (2012b)	England, South East Breast cancer service, Secondary care	Research study Multiple methods: -Narrative interviews -Patient experience survey	To compare two different types of datasets of patient experiences collected within a breast cancer service	Patient narratives (n=23) Patient survey (n=164)	A comparative analysis of data revealed patient experience survey data lacked depth when trying to understand what to do to improve a service when using	27/48 56.25%

2.6.1 Question 1: In which healthcare settings has EBCD been applied?

2.6.1.1 EBCD QI projects

There were seven EBCD quality improvement projects, mostly conducted in the UK: five in England (Bate & Robert, 2007b; Pickles et al., 2008; Tollyfield., 2014; Tsianakas et al., 2012a; Wolstenholme et al., 2010), one in Northern Ireland (Tunney & Ryan , 2014) and one in New Zealand (Boyd et al., 2012).

There was a degree of clinical heterogeneity with projects conducted within, ICU (Tollyfield., 2014), services dealing with head and neck, lung and breast cancer (Bate & Robert, 2007b; Pickles et al., 2008; Tsianakas et al., 2012a; Boyd et al., 2012), stroke services (Tunney & Ryan , 2014) and medical outpatients (Wolstenholme et al., 2010). All but one was located within a secondary healthcare setting with one project located in the community (Tunney et al., 2014). All projects were conducted within the adult care setting.

2.6.1.2 Evaluative and research papers

There were four evaluative papers (Bowen et al., 2013; ledema et al., 2010; Piper et al., 2012). Two papers evaluated a multi-sited EBCD service improvement project within emergency departments (EDs) in Australia (ledema et al., 2010; Piper et al., 2012). Bowen et al., (2013) reported upon an evaluation of an EBCD project by Wolstenholme et al., 2010. An ethnographic process evaluation reported upon the development, testing of an accelerated version of the EBCD approach (AEBCD) (Locock et al., 2014). This was set within ICU and lung cancer service within two NHS hospitals trusts in England. There was one mixed methods research study that compared different approaches to collecting patient experience data in a breast cancer specialist service. This included patient narratives within the EBCD process and using survey data (Tsianakas et al., 2012b).

2.6.2 Question 2: How was the EBCD process implemented?

The way in which the EBCD approach was applied concerned two aspects of implementation: who implemented the process and what was implemented? These have been presented separately below:

2.6.2.1 Who implemented the process

The EBCD projects and evaluations were led by a mixture of academic health researchers, internal hospital QI specialists and /or healthcare professionals (See Table 2.6). No project had been led exclusively by healthcare professionals.

Table 2.6 Characteristics of core teams within EBCD projects

Constitution of teams	
<u>EBCD QI Projects</u>	
Bate & Robert (2007b); Pickles et al., (2008); Wolstenholme et al., (2014)	Academic health researchers Internal hospital QI specialists
Boyd et al., 2012	Specialist improvement team
Tollyfield, et al., (2014)	Healthcare professionals with academic support
Tsianakas et al, (2012a)	Academic healthcare researchers
Tunney & Ryan, (2014)	Nurse academics
<u>Evaluative and research papers</u>	
Iedema et al., (2010); Piper et al., (2012); Tsianakas et al., (2012b)	Academic researchers based within a university setting
Bowen et al., (2013); Locock et al., (2014)	A combination of researchers and healthcare professionals and QI specialists within hospital trusts

2.6.2.2 What was implemented?

EBCD QI projects

A varied approach to implementing the EBCD process was evident with no single study either conducting or reporting every stage (See Table 2.7). There were very few details about stage 1 with regards to project set up, how access to the service was negotiated and how governance was managed during the project. One paper (Bate & Robert, 2007b) described the function of an advisory group (a team of service users, senior clinical and management staff) as providing advice, encouragement and warnings for the core team, and they went on to assist with the design of the intervention (Bate & Robert, 2007b).

Table 2.7 EBCD QI papers: Reported stages of the EBCD process

Study	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6
Bate and Robert, 2007b	✓	✓	✓	✓		
Boyd et al., 2012				✓	✓	
Pickles et al., 2008;		✓	✓			
Tollyfield, et al., 2014		✓	✓	✓	✓	✓
Tsianakas et al, 2012a		✓	✓	✓	✓	
Tunney & Ryan , 2014			✓			
Wolstenholme et al., 2014	✓			✓		

Key: ✓=reported

Stage 2 is concerned with gathering staff experiences through interviews and non-participatory observations of clinical areas. The EBCD projects that reported gathering staff experiences all used the same approach, one-to-one interviews led by qualitative researchers (Bate & Robert, 2007b; Pickles et al, 2008; Tollyfield, 2014; Tsianakas et al., 2012a). Other than the number of staff involved, there were no details reported about how staff were recruited, how interview data were analysed to identify key touch points or how this informed the interview guide for patients. No papers reported the findings from staff interviews other than to state that they were broadly in keeping with issues identified by patients (Pickles et al, 2008). Only two projects reported conducting observations within the clinical setting and were conducted by experienced qualitative researchers (Bate & Robert, 2007b; Tsianakas et al., 2012a). There was no rationale provided for the number of hours conducted or specific details how the observations were documented, analysed and how they informed the co-design process. Gathering patient experiences involved numerous approaches. These included,

- One-to-one filmed interviews with patients conducted and analysed by qualitative researchers which were used to produce a trigger film,

with the aid of an experienced film maker. (Bate & Robert, 2007b Pickles et al., 2008; Tsianakas et al., 2012a),

- Patient journey mapping exercise (Bate & Robert, 2007b; Boyd et al. 2012)
- Patient experience questionnaires (Boyd et al. 2012, Tunney & Ryan, 2014)
- The use of a pre-existing archive of filmed patient narratives (from a similar disease specific population) to create a trigger film (Tollyfield. 2014)
- The use of lay volunteers from a third sector organisation, which were provided with interview training, and went out into the community to audio record interviews with the target population (Wolstenholme et al., 2010).
- Listening Labs (audio-taped discussion about content from the questionnaires) (Tunney & Ryan, 2014).

The cited rationale for adaptations to the process at this stage were a) pragmatic concerns by researchers, for instance, getting the target population (house-bound older adults with complex and long term health conditions) to physically attend meetings (Wolstenholme et al., 2010) and b) being part of a larger research project (Locock et al., 2014) which bypassed the prescribed patient interview.

Stages 4, 5 and 6 were not uniformly reported and mainly focused on the outcomes of identified patient touch points and changes made to the service (Bate & Robert, 2007b; Pickles et al., 2008; Boyd et al., 2012; Tsianakas et al., 2012a; Tollyfield., 2014). Complimentary quality improvement tools and methodologies were also used when re-designing the patient experience, such as, applying 'Lean' principles to improve ward efficiency (Bate & Robert, 2007b; Pickles et al., 2008. However, there was insufficient detail reported to discern further what occurred during the co-design phase with regard to how many meetings were run, how trigger films informed the discussions, how joint priorities were agreed, and how and why participants chose the smaller co-design working groups.

Evaluative/research papers

The evaluative papers reported variation in implementation of the approaches (See Table 2.8). Bowen et al., (2014) provided a very brief

overview of implementation and omitted details about clinical observations or if a trigger film was developed. Iedema et al., (2010) and Piper et al. (2012) reported that stages 2 and 3 were not uniformly conducted across all the participating sites. For example, the observation activity between sites ranged from 0 to 20 hours. The number and frequency of co-design workshops (stages 4 and 5) demonstrated a marked variation from 1 to 12 per site and was related to the number of touch points identified: more themes led to a greater number of workshops. All sites within the evaluation conducted patient and staff interviews, but it was unclear whether trigger films had been created (Bowen et al., 2013; Iedema et al., 2010; Piper et al., 2012). It was unclear who had analysed the data and how the touch points had been elicited (Bowen et al., 2013; Iedema et al., 2010; Piper et al., 2012).

Table 2.8 Evaluative papers: Reported stages of the EBCD process

Study	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6
Bowen et al., (2013)	✓	✓	✓			✓
Piper et al., 2012	✓	✓	✓	✓	✓	
Iedema et al., (2010)		✓	✓			
Locock et al., (2014)	✓	✓	✓	✓	✓	✓

Key: ✓ = reported

Locock et al (2014) reported in detail the whole EBCD process and described in detail the adaptations, with a clear rationale for doing so. This involved the creation of a trigger film using the Health Experiences Research Group (HERG) archive before following the co-design stages of the process (stages 4 and 5). This was in order to develop a more feasible EBCD process that addressed the issues concerning costs, time and efficiency of the approach, whilst honouring the methodological and theoretical commitments of the EBCD.

Stage six was reported but with little detail regarding what happened, who attended and whether there were any plans made for continuing the cycle

of improvement as the EBCD approach advocates (Bowen et al., 2014; Locock et al., 2014).

2.6.3 Question 3: What were the reported outcomes and impact of EBCD?

1. EBCD QI projects

Outcomes and impact were described in terms of patient identified touch points (See Section 1.5.4) changes made to the services as a result of the co-design work, and the sustainability and spread of EBCD.

Patient touch points:

Cross cutting themes were evident across the projects, within disease specific groups and across all groups. This consisted of:

- The desire for compassionate care (Bate & Robert, 2007b; Boyd et al., 2012; Tsianakas et al., 2012a; Tollyfield., 2014; Tunney & Ryan, 2014; Wolstenholme et al., 2010)
- Improving communication and information between patients and the service (Bate & Robert, 2007b; Boyd et al., 2012; Tsianakas et al., 2012a; Tollyfield., 2014; Tunney & Ryan, 2014; Wolstenholme et al., 2010)
- Concerns over care transitions (Boyd et al. 2012; Tsianakas et al., 2012)
- The need for support, both physical and psychological, during the patient journey (Boyd et al., 2012; Tunney & Ryan, 2014; Tsianakas et al., 2012a)
- More support when receiving a diagnosis (Bate and Robert, 2007; Boyd et al., 2012; Pickles et al., 2008) Tunney & Ryan, 2014; Tsianakas et al., 2012a)

Changes to the service

Reported outcomes and the impact of EBCD to the services (See Table 2.4) were ascribed to three themes:

1. Small scale changes – improvements that involved little change of no change to usual practice (n=13)
2. Re-designing processes within the service - new procedures requiring a change to working practice (n=4)
3. Education and training for staff (n=5)

Changes were reported as lists of actions taken with little description how changes were put into practice. The majority of changes were considered to be small scale changes with the caveat that these addressed the issues that mattered most to patients (Pickles et al., 2008).

No details were reported about how these changes had been introduced into the services, whether there were any unintended consequences, and how improvements were measured.

Sustainability and spread

Boyd et al. (2012) reported the spread of the approach to the Melanoma Service within the organisation (Waitemata DHB, NZ). No papers reported whether changes to the service had been sustained.

2. Evaluative/research papers

The reported outcomes and impacts reported related to the specific study aims (See Tables 2.5), study designs and data collection methods (See Table 2.9).

Three evaluations adopted a post hoc qualitative approach to explore the experiences of participants taking part in the project (Bowen et al., 2014) and to evaluate the impact of EBCD upon patient experience of care (Iedema et al., 2010; Piper et al., 2012). The evaluation by Locock et al. (2014) aimed to observe the implementation process and evaluate the acceptability and impact of the AEBCD approach. A longitudinal comparative case study design with ethnographic observation was employed as a method to study complex change (Pettigrew, Ferlie and McKee, 1992; Fitzgerald & Dopson, 2009).

Various data collection methods were used which included, semi-structured and unstructured interviews, ethnographic observations, group interviews with patient participants, evaluation questionnaires, feedback forms, reflective diaries and document analysis (See Table 2.9). Data was collected at predominantly one time point (Bowen et al., 2013, Iedema et al., 2010; Piper et al 2012) with a sample of participants involved in the EBCD projects (See Table 2.9).

The comprehensive evaluation conducted by Locock et al (2014) used a variety of data collection methods but was not consistently applied to all participants. For instance, patient participants were interviewed within a group setting at the end of the process, whereas staff had been interviewed

at the start and end of the process. Evaluation questionnaires for staff and patients were administered at the end of patient, staff and joint events.

Table 2.9 Evaluating EBCD: data collection methods and time points

Study	Data collection method	Point in time for project
Bowen et al., (2013)	semi-structured interviews via telephone and face-to-face <i>Topic guide</i> Open ended questions about each stage of the process – responding to statements that declared the design teams perspectives and beliefs	End of project
Iedema et al., (2010)	semi-structured interviews via telephone and face-to-face <i>Topic guide</i> - not reported	End of project
Piper et al., (2012)	semi-structured interviews via telephone and face to face <i>Topic guide</i> What were the specific improvements delivered? What did it feel like to take part? What are the key success factors? What can the pilot tell us about sustainability and spread? What can lessons can be drawn for the future?	End of project
Locock et al., (2014)	- Observations (recorded as field notes and transcribed)	During project
	- Group interviews with patient participants <i>Topic guide</i> Involvement and perception of each stage of the process	End of project (Stage 6)
	- Evaluation interviews with key members of health care staff <i>Topic guide</i> Perception of the process, Involvement in the project, Project contributions to service delivery, Project sustainability and legacy	Beginning and end of project
	Asked about personal insights into implementation process	Not reported
	- Evaluation questionnaires – staff and patients	End of events
	- Feedback form- – Staff and patients <i>Topic guide</i> To capture experiences of participation and perceptions impact	End of event (stage 6)
	- Reflective diaries from project facilitators	During project
	- Document analysis	During project
	- Cost data	During and post project
	- Comparative EBCD data (pre-existing)	Not reported when this was collated

The main findings from the evaluative papers are presented below under two thematic headings: EBCD as a deliberative process and the challenges and achievements of EBCD.

EBCD as a deliberative process

The EBCD process employed specific tools and techniques in a sequential manner to bring about improvements to a service. Activities within the co-discovery phase, such as sharing stories and emotional mapping were seen as a way of empathetically connecting staff and patients in order to understanding different perspectives of the delivering and receipt of care within the service (Bowen et al., 2012; Iedema et al., 2010; Piper et al., 2012; Locock et al., 2014). These activities appeared to give patients and staff a deliberative opportunity to engage with each other to identify the key touch points on the patient journey (Bowen et al., 2012; Iedema et al., 2010; Piper et al., 2012). However, tensions were apparent in terms of staff being frustrated by repeatedly explaining processes (Iedema et al., 2010) and patients feeling disrespected by staff and researchers (Bowen et al., 2013).

The use of a trigger film created from national narratives appeared to be an acceptable alternative to the longer EBCD process (Locock et al., 2014). It was suggested that the film may be less threatening or challenging to staff, as it was derived from patients not directly involved in the QI project. The end of event questionnaire revealed that patient participants appeared to find the adapted film generally represented their experience, though at times was perceived to be more negative than their actual experience of care. Free text responses demonstrated that patient participants found the film was difficult to watch. Conversely, some patients found the film powerful and cathartic when they initially watched it although these feelings diminished with further viewings (Locock et al., 2014).

The remaining evaluative papers did not refer to the use of trigger films by the EBCD projects. No additional information was reported about the effect of the film upon patients, carers, staff or researchers. Observations made at the celebration event by an evaluator commented on the potential loss of a therapeutic element to storytelling that may have been lost with the accelerated version of the approach (Locock et al., 2014).

The co-design work was seen as a way for stakeholders to identify the issues that mattered to patients and carers (Bowen et al., 2012; Iedema et al., 2010; Piper et al., 2012; Locock et al., 2014). However, patients also

perceived the main benefits of co-design were in terms of improving work processes and facilities for staff (Iedema et al., 2010; Piper et al., 2012) or that 'co-designing' was something that was done by others, that is, the designers did the designing (Bowen et al., 2013). Conversely, Locock et al., (2014) found patients perceived themselves as being actively engaged and part of the process: they were surprised that they were listened to and their concerns were taken seriously.

The challenges and achievements of EBCD

The challenges of EBCD as perceived by staff participants were in terms of the process being burdensome, owing to time commitments, and competing workloads (Bowen et al., 2013; Iedema et al., 2010; Piper et al., 2012). There was considerable pressure to complete stage 2 (gathering staff experiences) within the shortened AEBCD approach which was managed with support from senior staff, and working additional hours at the start of the intervention (Locock et al., 2014).

The fidelity to the EBCD process also proved a challenge in terms of issues concerning the project setting and target population. The transient nature of patients through Emergency Departments meant that different patient groups were used at the discovery and co-design phases, with the latter mainly recruited via a statutory hospital consumer engagement structure (Piper et al., 2012). The time commitment from frontline staff and insufficient resources were also seen as key reasons for adaptations to the process (Iedema et al., 2010; Piper et al., 2012).

Differing implementation styles were seen as being attributed to the personal qualities of the facilitators (Locock et al., 2014). Being recognised as skilled and experienced in EBCD and a trusted individual were considered essential traits for successful implementation. This was despite different approaches adopted, such as leading the co-design work, or facilitating design groups. Analysing qualitative data also proved problematic for clinical staff. This required the adoption of a more pragmatic approach to data interpretation, collating notes made during staff interviews to produce anonymised feedback (Locock et al., 2014).

A sense of ownership and good facilitation were seen as important factors that affected the success of the project (Bowen et al., 2012; Iedema et al., 2010; Piper et al., 2012). Bowen et al (2012) described differences between the locus of control for patients and staff. Patients were invited to the project whereas staff were 'told' to take part, while senior managers

saw their role as tertiary to the project. This in turn was seen to affect the legitimacy of the group and perceived sense of agency to affect changes.

The success of the EBCD projects was couched in terms of making improvements that mattered to service users, improvements in delivering operational efficiencies and improving inter-personal dynamics between staff and patients (Bowen et al., 2013; Iedema et al., 2010; Piper et al., 2012). Piper et al., (2012) provided scant empirical evidence to support the earlier claims reported by Iedema et al. (2010) following the first EBCD programme.

Sustainability and spread of the EBCD process was followed up in a second evaluation from the QI programmes within ED departments (Piper et al., 2012). The evaluation reported that EBCD teaches new skills and enabled staff to be more appreciative of the patient experience. The idea of spreading the concept of EBCD was demonstrated by other departments taking up the approach through informal channels of communication between staff, but there is no supporting evidence with Piper et al.'s (2012) evaluation to substantiate this finding.

The spread of the AEBCD approach was reported across the organisation, with some services planning to use the approach again. At a trust level there were plans to train staff with a view to employing the methodology more widely. Despite the burden of AEBCD, the facilitators identified positive benefits which included new insight into collaborative working methods for staff and patients, and plans for using the approach in the future.

Research papers

Tsianakas et al. (2012b) compared the qualitative themes derived from patient narratives using EBCD and responses from a patient survey in the same clinical area. The study revealed that both methods elicited similar issues about the patient experience however, the survey was seen as acting as a screening tool but the patient narratives provided a far richer picture to help to inform next steps in service improvement. It was suggested that patient narratives are a meaningful way to capture, understand and improve patient experiences.

2.6.4 Question 4: How have costs been measured and reported?

The direct costs of the EBCD approach were not reported by any study other than an economic evaluation of the accelerated EBCD approach by

Locock and colleagues (2014). The implementation costs of a previous EBCD project estimated at £50,761, were compared with the total cost of the AEBCD approach, reported as £28,565 (44% cheaper than the traditional approach). Further reductions could be made by re-using existing trigger films, potentially lowering the overall cost by 60% (Locock et al., 2014). It was suggested that since the outcomes from both approaches bought about similar results, AEBD appeared to represent good value for money (Locock et al., 2014).

Costs were considered by one study in terms of the perception of participants challenging the amount of resources and time the approach had taken for apparent modest changes that had occurred (Bowen et al., 2013). One study considered the cost implications of the project and reported that many of the changes to the service were described as cost neutral (Tsianakas et al., 2012a) but there was no empirical evidence to assess this claim. One study cited the lack of evaluation as a limitation of the study (Boyd et al, 2012).

2.7 Discussion

The aim of this review was to assess the implementation and effectiveness of the EBCD approach using existing published empirical evidence.

The key findings revealed: a lack of fidelity to the process and/or creative adaptations to the process, a similarity of patient touch points elicited across different health care settings, the majority of improvements were identified as small scale changes and activities within the EBCD process appeared to foster a deliberative process to improve the experience care. The process was considered acceptable by staff and patients, with an accelerated version found to be more cost effective and taking less time to implement.

With regard to fidelity, no EBCD project demonstrated complete fidelity to the six stage process with little evidence reported about what occurred during the co-discovery and co-design phases of the full EBCD approach. Only one evaluation took a more in-depth ethnographic approach but this was in the specific context of assessing the acceptability of an accelerated version (Locock et al., 2014). A key reason for this finding could be attributed to quality of reporting. It was difficult to assess whether the lack of detail about each stage was owing to poor reporting or had been simply omitted. This is not an unusual feature within QI efforts with interventions often poorly described (Michie et al, 2013: Hoffman, Glasziou, Boutron,

Milne & Perera, 2014) and poorly conceptualised in terms of what they intend to change (behavioural, social or technical processes) and how this will be achieved. The SQUIRE guidelines describe a set of criteria developed specifically to improve the quality of reporting of improvement interventions in healthcare (Davidoff et al., 2008). Evidence suggests that since its introduction there has been little difference in the completeness of reporting (Howell, Schwartz, O'Leary & McDonnell, 2015) with the guidelines seen as being complicated and unhelpful (Davies, Batalden, Davidoff, Stevens & Ogrinc, 2015). Thus, the quality of reporting within this review was not a unique finding within the body of QI literature. The SQUIRE 2.0 guidelines are revised version and are anticipated to deal with the complex nature of methods used within QI and to encourage improvement scientists and practitioners to publish future discoveries (Ogrinc, Davies, Goodman, Batalden & Davidoff, 2016).

There was a paucity of papers eligible for inclusion in the review despite the number of identified projects (over 60) within EBCD literature (Donetto et al., 2014). This may infer publication bias, as published work is more likely to report positive findings, which may in turn lead to an over estimation of effect(s) (Dwan, Gamble, Williamson & Kirkham et al, 2008). This issue is important in terms of advancing the field of the science of improvement. Only by sharing the successes and failures of improvement efforts can healthcare professionals, patients and the public be reliably informed what works, how it works and under what circumstances (Ogrinc et al., 2016). Whilst a limitation of this review accepted that not all studies may have been captured, the lack of studies reporting any 'failures' of the approach or elements of the approach, make it difficult to fully comprehend the 'black box' of an intervention (Schouten et al., 2008).

In order to draw conclusions about what works, evaluating the process usually attempts to capture the way an intervention was delivered (whether it was as intended or not) (Moore et al., 2015). It is argued that without assessing fidelity it is impossible to determine whether reported impacts were owing to poor implementation or a fault within the intervention itself (Carroll et al., 2007). Intervention fidelity can be defined as *'the extent to which the components of a program, differentiated from "business as usual," are carried out as intended upon program enactment'* (Abry, Hulleman & Rimm-Kaufman, 2015: p321).

Despite no formal process evaluations, the review did reveal tailoring of stages according to contextual factors. The variation of methods to gather patient experiences appeared to have little effect on reported outcomes, with all projects identifying joint service priorities which resulted in local changes. This finding is not unusual, with positive outcomes being achieved even though an intervention was not delivered as planned (Moore et al., 2013). Complex interventions, like EBCD, are often subject to adaptations owing to context (Hawe, Shiell and Riley, 2004). What this review may offer is capturing this evidence with a view to begin to understand further what happened in practice. It may be difficult to determine if the adaptations ensured a best fit or whether they undermined the intervention. Bate and Robert (2007a) argue that certain elements within the EBCD process are essential, such as early observational work in clinical areas and the use of trigger films. Yet, these elements appear to be routinely omitted (Donetto et al., 2014). Without a clear rationale for omitting these activities it is difficult to determine what has led to the reported successful outcomes (Davidoff et al., 2015). This is all despite EBCD approach being a theoretically derived and clearly articulated approach (Bate & Robert, 2006, 2007a).

An evaluation report of the EBCD projects described by Tsianakas et al. (2012a; 2012b) not included within this review (as it was not published in a peer reviewed journal and thus did not satisfy the inclusion criteria) summarised key success factors for implementing service improvements (Farr, 2011). These included:

- Staff and Patients working together – The EBCD process provided a more equal space for discussions between staff and patients outside usual clinic appointments.
- Staff dedication was seen as an important factor to ensure the success of the approach. Success within smaller co-design work was attributed to greater staff engagement. Where there was a lower staff engagement level the groups ‘folded’ (Farr, 2011:p3).
- The trigger film had a powerful effect upon staff which was seen as a catalyst for action
- An ‘enabling environment’ (Farr, 2011; p4) - When the EBCD project linked in with other organisational activities and aligned with roles and responsibilities with health care professionals, changes were more likely to be successful.

- Extra facilitation required to support co-design work with clinical staff needing to take ownership of co-design groups.

The success factors described within the report suggest how the EBCD process brings about change but it remains unclear how staff and patients actually experienced the process.

A key limitation of the evaluations was the post-hoc study designs which were unable to explore changes over time (Bowen et al., 2012; Iedema et al., 2010; Piper et al., 2012). A longitudinal approach is well suited to capturing changes and/or consistencies over time owing to data collection at multiple time points (Nielson & Randall, 2013; Moore et al., 2015). The most comprehensive and highest quality study identified within this review conducted an ethnographic evaluation, collecting data over the duration of the project (See Figure 2.5). However, the evaluation was primarily concerned with exploring the acceptability and impact of the AEBCD approach for patients and staff. Focus group interviews with patients were conducted at the very end of the process, and interpretation of the acceptability of the adapted process drew upon data from observations, diaries (mainly staff participants) and evaluation questionnaires. Although the methods were entirely appropriate to explore the experience of participants, it is argued that the evaluation was concerned with understanding the acceptability and feasibility of a rapid version of EBCD, and not the EBCD process per se. The use of questionnaires at the end of events could have also been threatened with response bias owing to test conditions (it may have been difficult to report negatively at the event and participants may have had a vested interest to report more positive findings) and/or internal factors such as characteristics of the respondents (response styles may be affected by socio-demographic differences) (Meisenberg & Williams 2008).

EBCD is partly about improving the experience of care for patients. Despite the heterogeneity of clinical settings it was interesting to note the commonality of patient touch points. The recurrent theme of enhancing communication between patients and the service was evident within all the EBCD projects. This may be owing to the way in which patient touch points were identified and selected as service priorities but with little detail exactly what happened during the joint co-design meeting (Stage 4) is difficult to determine. The quality of communication routinely features within large national patient experience surveys (CQC, 2016). In order for teams to

address specific concerns, it is argued that more careful measurement, documentation and interpretation of patients subjective experiences are required (Coulter et al., 2014). Despite the commonality of themes, what EBCD does appear to offer is a deeper understanding of the exact improvements needed at a local level (Bate & Robert, 2007b; Locock et al., 2014). The outcomes from the included studies demonstrated very specific changes within specific services.

A key evidence gap raised from the review was the total lack of evaluative or research studies exploring the experiences of patients from different ethnic origins. The importance of acknowledging cultural differences when developing services has been previously identified within diabetes research and national policies strongly support the need to provide equitable and inclusive healthcare (Stone, Patel, Daly, Martin-Stacey & Amin, 2008; Department of Health, 2003). There has been little investigation of ethnic or cultural differences or issues when using the EBCD approach, with evidence to suggest that patients from a South Asian origin are more dissatisfied with their experience of care (Lyrtzopoulos, Elliot, Barbiere, Henderson, Staetsky, 2012; Department of Health, 2009). Furthermore, literature suggests that the South Asian population is an under represented group within healthcare research (e.g. in clinical trials) owing to factors such as language barriers and the perceived effect on time and cost of taking part and the potential for more passive exclusion by researchers as a result of cultural stereotyping (Hussain-Gambles, Atkin & Leese, 2004). Exploring the experience of involvement within an EBCD quality improvement project across different ethnic populations is, therefore, a novel research question. It is anticipated that by investigating differences in the experience of the approach from different patient populations this may increase our understanding of how EBCD works in practice.

The findings from this review raise questions about understanding the mechanisms underpinning the activities employed to bring about change. The theory underpinning EBCD suggests that changes happen not only at service level but at a personal level, especially for staff to re-engage with patients and the whole journey (Bate & Robert, 2007b). Whilst observations may support this theory (Locock et al., 2014), there is less reported evidence from stakeholders exploring their experiences in-depth of taking part and how power relations can be managed during the process (Bowen et al., 2013). It is also suggested that there is an opportunity to develop the discovery phase and explore what patient involvement can

bring to this aspect of the process (Locock et al, 2014). All of the EBCD projects and evaluations were supported by academic staff, which may not be a realistic approach, if the EBCD is intended for large scale adoption and use across the NHS. Despite the AEBCD version significantly reducing the cost of the approach, with the possibility of reducing costs further, EBCD could be seen as an expensive way in which to bring about small scale changes. However, it could be argued that the 'small things' were often what mattered most to patients, with expectations about improving relational aspects of care (Bate & Robert, 2007b, Pickles et al., 2008). This relied upon staff making subtle changes to the delivery of care, often requiring little or no change to usual practice. Where complex interventions may fail to produce long lasting effects, changing the organisational culture (staff thinking differently about patient experience) combined with small fixes, may be more sustainable and desirable in the long run, than large sweeping changes to the delivery care. However, without fully understanding the essential elements of the approach, it is argued the theory underpinning EBCD is under-investigated. Understanding the science behind an intervention is a key factor when exploring how an intervention intends to bring about change (Dixon-Woods, 2014).

Therefore, in order to further understand how and why EBCD works, further evaluation is required. Capturing the experience of individuals involved with this type of improvement intervention may assist with unpacking how this approach may or may not work in practice, and what the barriers and facilitators are with regard to a successful EBCD project.

2.8 Limitations

It is acknowledged that not all studies may have been captured from the search strategy. Generally, the limited number of articles retrieved did not reflect the current number of projects identified in survey by Donetto et al., (2014). This may have been owing to the search strategy and not including grey literature. However, efforts were made to check references from included studies and there was personal communication with Glenn Robert to identify any additional studies.

It is argued that narrative reviews are prone to bias, but using the guidance by Popay et al. (2006) steps were taken to avoid weighting studies in favour of others, with careful representation of data and the quality of

individual studies was assessed using appropriate validated tools (Popay et al. 2006).

2.9 Implications of the review and development of thesis objectives

This systematic review has identified evidence gaps in understanding how the EBCD process works, this requiring further explanation. The reported implementation process is at best sporadic, in terms of how it was delivered and what was delivered. Some of the contextual factors that affected the implementation have been identified but less evidence reported on the possible contextual factors that may affect the theory of how EBCD works. The current approach attempting to capturing participant's responses to and interaction with EBCD have not been able to explore any changes over time.

Reflexivity point: Thoughts about patient experience and EBCD at the start of the thesis

It is at this point of the thesis I offer my reflexive thoughts about my personal position with regard to my views on patient experience and EBCD with the rationale and theory for providing reflexive comments (See Section 3.12.1).

Progress in developing and testing methods to improve patient experience has been slow over the last decade when compared to the patient safety movement. Yet it is vital aspect of care and can shape the way patients, carers and families interact with health care professionals and services.

The need to enhance patient experience within NHS England is reflected by national policies and mandates. It is a key principle within the NHS Constitution that patients are at the heart of everything that is done.

However, patient experience is difficult to capture using solely quantitative measures. Picking up upon the relational aspects of care requires a complimentary qualitative enquiry to help identify and change what matters most to patients, families and staff.

Experience based co-design as an improvement approach appears to be a rigorous way to capture more about patient and staff experiences of delivering and receiving care and making meaningful changes in a joint partnership. I believe it is an ideal approach to foster a collaborative approach to improving care. The underpinning theory supports the tools

and techniques used within the EBCD process to thoughtfully bring about changes. With this in mind, the process does require some expert knowledge and skills about improvement. Activities such as, conducting interviews, analysing data and creating a trigger film could be seen as challenging aspects for clinical staff within a service, without adequate training or support. However, with the emergence of specialist QI staff now routinely part of NHS organisations, there may be support to deliver this type of improvement project, to ensure that efforts followed the key principles of QI and conducted to a high standard. I am interested in what happens to people taking part in an EBCD project and to explore how the theory contributes to the process. I will revisit this reflexive point at the end of the thesis to highlight any changes in my thinking (See Section 7.7).

This thesis aimed to explore the experience of participating within an EBCD project. This is in order to generate new knowledge about the process regarding how, why and under what circumstance EBCD works or does not work and to contribute towards the evidence base of the science of improvement. The specific objectives to meet this aim were:

1. To explore further the specific activity of observation within the EBCD process. This is owing to a) being perceived as an essential element of the process yet is the most commonly omitted b) little empirical evidence what the experience was like for participants conducting observations and how this activity contributed to the discovery phase and c) increasing patient involvement during the discovery phase, in keeping with the theory and ethos of the approach.
2. To understand further the mechanisms that link the process to outcomes by exploring participant's lived experience of the EBCD approach over time from multiple perspectives. This is order to appreciate how the effects of EBCD occurred and how this may be reproduced in future projects.
3. To explore the experience of patients from different ethnicities, to compare similarities and/or differences between patients taking part in EBCD.

The following chapter will now expound upon the theoretical and methodological foundations of the studies contained within this thesis.

Chapter 3: Theoretical and methodological foundations of the research

3.1 Chapter summary

This chapter presents the theoretical and methodological foundations that underpin the research conducted within this thesis. In terms of contribution towards the science of improvement research, using IPA as to explore how people making sense of the EBCD process could be seen as a novel methodology, with no existing EBCD evaluative or research studies having previously applied the approach. The following three chapters detail the studies that have been conducted to address the research question posed at the end of the previous chapter.

3.2 Background

Chapter 1 discussed the importance of improving patient experience and the slow development of methods to capture, measure and enhance experiences of care (Doyle, Lennox, & Bell, 2013; Locock et al., 2014). EBCD was designed, developed and tested within and for the NHS to address these issues (Bate & Robert, 2007a). It is suggested that EBCD may be an acceptable and feasible way to improve patient experience (Donetto et al, 2014; Locock et al., 2014). However, the findings from the systematic review in chapter 2 suggest that the mechanisms of change underpinning the approach have been sub-optimally reported and under-researched (Donetto et al., 2014; Robert, 2013). Using a qualitative approach to inquiry may help to make sense of what happened by focussing on meaning ascribed by individuals (Hulscher et al., 2003). Thus, this chapter presents the theoretical and methodological foundations of three qualitative studies reported within this thesis, with the practical application of the methodology detailed within subsequent empirical chapters owing to the different approaches taken during the analytical process.

3.3 Selecting a research design

Designing a research study requires clarifying a research question(s), deciding the type of study and identifying how data will be generated and

analysed (Green & Thorogood, 2009). The research design should demonstrate a methodological fit between the study type, methods adopted to collect data and ensuring that this will assist with answering the question posed. Creswell's framework (Creswell, 2009) is a useful guide when thinking about the fundamental elements when designing a study and considers three key components;

1. The philosophical world view, that is, a set of beliefs about how knowledge is created and deciding what type of knowledge is legitimate (Gray, 2013);
2. The strategy of enquiry related to this world view
3. The particular methods used to convert the approach into practice

The starting point for this thesis was informed by the literature reviewed in Chapter 2. The findings revealed gaps in evidence about understanding the mechanisms of change within the EBCD approach. Thus, it was anticipated that by exploring the lived experience of participants taking part in an EBCD project, this may help to unpack the 'black box' of the intervention in order to understand how and why the intervention 'works'. For example, exploring participants' experience of the joint co-design meeting to determine what factors may influence participation. To this end, a qualitative approach was adopted, in keeping with an inductive style and concentrating on individual meaning. Figure 3.1 illustrates how Creswell's framework (2009) was applied to the development of the research proposal. It highlights the relationship between the philosophical assumptions or 'world view' of the main researcher (LT), how the selected strategy for inquiry related to this epistemological view point and the methods applied in practice. These components are discussed in more detail in the following sections. This is in order to make explicit the connections between the different components associated with the research design.

3.4 Ontological and epistemological perspectives - the philosophical world of the researcher

Epistemology refers to theory of knowledge, how researchers come to know the world and thus, decide what type of knowledge is considered valid and trustworthy (Guba & Lincoln, 1994; Green & Thorogood, 2009). The explicit epistemological stance of the researcher is often hidden (Slife

& Williams, 1995) but in fact is a vital element of research design (Creswell, 2009). Madill and colleagues suggest that researchers have a duty to make their position transparent, carry out research that is sympathetic to their philosophical position and present the findings in a manner that enables an appropriate evaluation (Madill, Jordan, & Shirley, 2000). Therefore, stating the epistemological position allows the reader to understand the assumptions underlying the research strategy (Creswell, 2017).

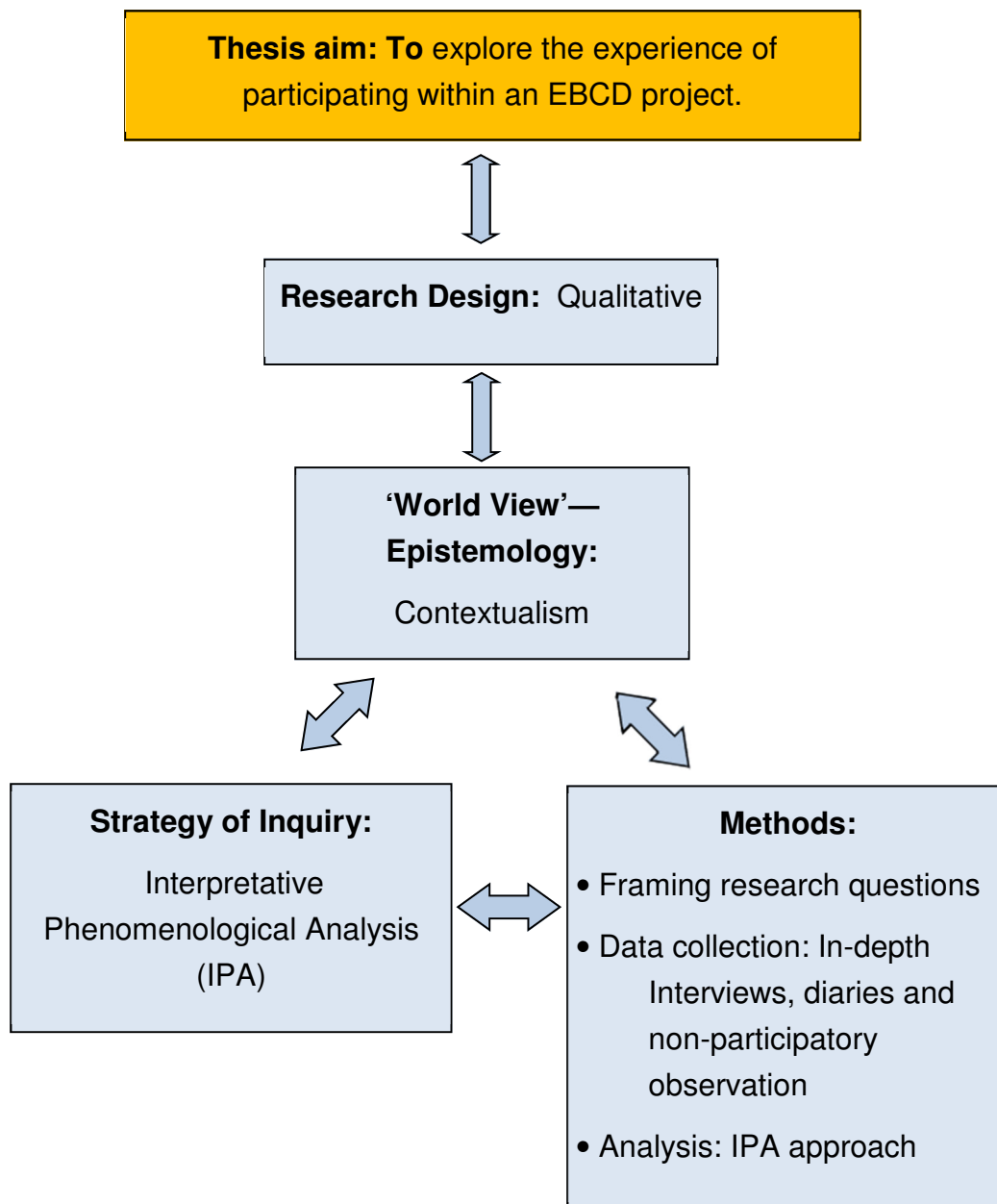


Figure 3.1 Application of Creswell's' framework (2009) to illustrate the inter-relationship between the elements of research design

The design of this research project was determined by the initial aim and objectives of this thesis (See Section 1.8). This required making sense of the experience from multiple stakeholders' perspectives and acknowledging that different versions of realities may co-exist. For instance, the experience through the lens of a patient perspective may be very different from that of a member of healthcare staff or designer within the project. It may be equally different for individuals within a stakeholder group. This implies looking for and interpreting a complex landscape of views. It required getting close to the participants being studied in order to understand interactions between individuals and the specific contexts in which people live and work.

This thesis, therefore, relied heavily upon the views of participants, whilst adopting a broad and open approach to questioning, to allow participants the scope to construct their own meaning of the phenomenon, in this case, involvement within a specific EBCD project. By adopting a contextualist position the researcher does not assume a single reality and views knowledge as 'emerging from context' (Braun & Clarke, 2013: p31). Therefore, knowledge generated is dependent upon the situation and remains provisional (Jaeger & Rosnow, 1988, Madill et al., 2000). Knowledge is relative because it exists within a particular 'socio-historical and cultural' context which are not perceived as 'stable' concepts. Thus, knowledge creation is viewed as an 'active, practical and constructive affair' with the researcher actively participating in the 'discovery, construction and transformation of psychological knowledge' (Jaeger, & Rosnow, 1988:p73). The manner in which the researcher interprets these subjective views in the social world depends upon their own beliefs, values and expectations (Bunge, 1993). This epistemology assumes a knowable world that can be accessed by the researcher through subjective and 'socially-located knowledge' (Braun & Clarke, 2013). However, since this knowledge is socially constructed, it is recognised that it is only possible to access this reality in part (Smith, 2011; Braun & Clarke, 2013).

Having made the claim that it is possible to obtain a 'truth' through a process of 'valid knowledge production' (Braun & Clarke, 2013; p29), a contextualism position was adopted as an interpretative framework in which to explore the rich complexity of individuals' experiences of EBCD. It is recognised that contextualism sits between the epistemological positions of constructionism and positivism (Braun & Clarke, 2013). It does not subscribe to the existence of a single reality (such as the positivist position)

but recognises that a genuine reality exists in order to produce knowledge that might make a difference (Braun & Clarke, 2013).

The significance of context here is related to the findings of a study which may be different depending on the way data is gathered and analysed. However, contextualism is concerned with understanding a truth, and that this truth will be valid in some contexts (which pure constructionism rejects) (Braun & Clarke, 2013). Hence, the duty of the researcher is to portray a participant's perspectives through their description of the phenomenon under investigation (Madill et al., 2000). At the same time it does subscribe to trying to make sense of a 'truth', and so has a realist aspect. Whilst Tebes (2005) suggests that there is no single approach to accessing the truth, in some contexts knowledge will be true, a concept refuted within the world view of constructivism.

3.5 Strategy of inquiry

It is widely acknowledged that qualitative research has contributed greatly to health research (Dixon-Woods, Shaw, Agarwal, & Smith, 2004; Green & Thorogood, 2009) and specifically towards improving quality and safety of healthcare (Taxis & Barber, 2003); Bradley et al., 2004; Pound et al., 2005). Interpretative Phenomenological Analysis (IPA) is a specific qualitative research methodology which involves examining the 'lived experience' of participants and how participants 'make sense' of that experience (Eatough & Smith, 2006; Smith, 2009). The critical realist position underpins the qualitative approach of IPA and hence, is in keeping with the subscribed world view as discussed in the section above (Braun & Clarke, 2013).

The rationale for using IPA over other qualitative methodologies, such as grounded theory, is that IPA offers a different perspective. The latter, for example, sets out to generate a theoretical account of a phenomenon with larger samples of participants to substantiate the theory (Smith, 1996). IPA is concerned with understanding how individuals make sense of their world by identifying, describing and interpreting their 'objects of concern' and their 'experiential claims' (Smith et al, 2009: p46). As a result, IPA methodology has been adopted with regard to the research conducted in this thesis on the basis that it fits with the overall aim and objectives (See section 2.9). For instance, by exploring individual accounts of the lived experience of an EBCD project this may illuminate how the process of EBCD bought about

change. It is anticipated that by using this strategy of inquiry it may shed more light upon the mechanisms of change within EBCD than previously revealed within existing evaluations. Thus, it is also suggested that this is a novel way in which to explore the lived experience of participants within the realm of this specific QI intervention.

The theoretical foundations of IPA and how they relate to the research conducted within this thesis are described in more detail in the next section, followed by the application of IPA in healthcare research.

3.6 Interpretative Phenomenological Analysis

IPA was developed as a psychological experiential research methodology by Jonathan A. Smith (1996) during the mid-1990's (Smith & Osborne; 2015). It has become an increasingly favoured approach within the applied areas of health and psychology, with an accessible guide to help conduct IPA research (Braun & Clarke, 2013).

IPA is primarily concerned with a committed examination of how people make sense of significant life experiences. It has been described as a contextualist approach because of the focus upon persons-in-context (Larkin, Watts, & Clifton, 2006). IPA draws upon the concepts from three key areas of philosophy: phenomenology, hermeneutics and idiography (Smith, 2009). These elements are outlined below and discuss how they relate to the study design.

3.6.1 Phenomenology

Phenomenology is the study of experience and refers to a broad type of philosophical enquiry and a range of associated research methods (Eatough & Smith, 2008). IPA is phenomenological because it is concerned with the detailed exploration of an individual's experience. Smith draws upon the work of four influential phenomenological philosophers: namely Husserl, whose body of work firmly establishes the significance of focussing on experience, and Heidegger, Merleau-Ponty and Sartre who contribute to the notion of individuals being 'embedded' within a world of 'objects and relationships, language and culture, projects and concerns' (Smith et al, 2009:p21). Therefore, IPA attempts to understand an individual's relationships with the world and how they make sense of what they are experiencing. Husserl is also credited with the idea of 'bracketing' (or epoché) as a device to set aside things that are 'taken-

for-granted' whilst focussing on interpreting the 'perception' of that world (Langridge, 2008; Smith et al., 2009: p13). In relation to this research project, it was anticipated that by undertaking a detailed exploration of participants' experiences of the ECBD process, the mechanisms that link the activities with outcomes may be better understood. This is in terms of what barriers and facilitators affected the success or failure of the prescribed stages of the process and the process as a whole.

3.6.2 Hermeneutics

Hermeneutics is the theory of interpretation. IPA combines this theory in relation to the specific approach to analysis. This involves a detailed level of analysis in order to offer meaningful insights into participants' claims. However, IPA acknowledges that there is no direct route to experience since the researcher is in fact 'accessing' the experience through the participant's account. This is in keeping with the assumptions of a critical realist position, as discussed above. Thus, IPA research has been described as 'experience near' rather than 'experience far' (Smith, 2011:p10). The notion of a 'double hermeneutic' is implied in IPA, as the researcher is attempting to make sense of the participant making sense of a particular experience (Smith et al., 2009).

Smith (2009) acknowledges the 'hermeneutic circle' as a useful way to describe the iterative approach adopted in data analysis. This concept relates to the researcher moving back and forth between parts of the text, to the account as a whole, and in turn the entire account in relation to the other accounts. This is a key principle of IPA: that analysis is an iterative process and by using a dynamic approach it enables the researcher to think differently about the data (Smith et al, 2009).

By taking a transparent and reflexive approach to the process of analysis of participant's accounts, it was anticipated that it would allow the reader to understand what has influenced the researcher's interpretation of events. Whilst the main researcher (LT) attempted an independent stance whilst evaluating the EBCD process, the role of facilitation however, meant the researcher was more involved in the process than initially perceived or intended (See Section 4.3). Being reflexive is considered an essential element of good IPA research which is discussed in Section 3.5 (Smith et al., 2009).

3.6.3 Idiography

The third element is IPA's commitment to idiography, the concern with the particular. This concept refers to a level of detail and depth adopted during analysis, and a commitment to making sense of an experience from the perspective of a specific individual, within a specific context (Smith et al., 2009). It is suggested that rather than taking a nomothetic approach to inquiry, that is, making generalised predictions about a population by investigating inter-individual variation (Molenaar & Campbell, 2009), idiography can explore intra-individual variations since the assumption is that participants are heterogeneous and perceptions can change over time. This implies that a longitudinal IPA approach is well suited to study changes and/or consistencies over time. Importantly, taking an idiographic approach within the analytical process allows movement from single cases to more generalised claims but still enables the researcher to trace back to particular claims made by participants. Claims at a broader population level can be made through the notion of theoretical generalisability. This allows the reader to assess the analysis in relation to existing literature and evidence, as well as their own professional and/or personal experiences, which, in turn, enables a wider generalisation to their patient populations (Smith et al, 2009). In addition, it is argued that generalisations from qualitative research can be made through 'theoretical inference' by exploring deviant or divergent cases in order to refute theories (Silverman, 2011).

The value of an idiographic sensibility in the context of the studies reported was in relation to providing an in-depth and nuanced analysis of participants' lived experience of a real world EBCD project. This is in order to make a contribution to the empirical evidence about EBCD and how it brings about change and under what circumstances.

3.7 Quality assessment and IPA

Assessing the quality of qualitative research has generated much debate as to the best approach (Dixon-Woods et al., 2004). A key argument lies within what constitutes 'good' qualitative research and whether a universal set of assessment criteria should be applied to studies from diverse epistemological and theoretical starting points (Dixon-Woods et al., 2004; Green & Thorogood, 2009). Yet, there remains a need for an appraisal

method to ensure policy and clinical decisions are based on sound evidence (Green & Thorogood, 2009).

There are numerous checklists for qualitative research (CASP, 2001; Green & Thorogood, 2009; Sirriyeh et al., 2012) but there is little commonality between the different sets of criteria that have emerged (Dixon-Woods et al., 2004). As discussed in chapter 2, a secondary method was used to assess the quality of evaluation studies illustrating the issue of criteria created for 'universal' features and not the 'specific' (Dixon-Woods et al., 2004).

With this in mind, Smith et al. (2009) advocate using a set of guidelines developed by Yardley (2008) as assessment criteria for IPA research. This considers four domains;

- Sensitivity to context
- Commitment and rigour
- Transparency and coherence
- Impact and importance

Smith (2011) subsequently developed some specific criteria. This involves an assessment to whether the study ascribes to the theories underpinning IPA, demonstrates sufficient transparency with regard to the method, produced a coherent, plausible and interesting analysis and shows sufficient evidence from participants for each theme, partially dependent on the sample size. The criteria used by Smith (2011a) to assess the density of evidence for themes within the data are presented in Table 3.1. By applying these criteria a judgement can be made to then categorise the research as good, acceptable or unacceptable (Smith, 2011). It is suggested that the guidelines could be used by IPA researchers as an aid to achieve high quality studies and a framework to evaluate IPA research.

The concluding remarks from Smith (2011) thus describe the key features of a 'good' IPA paper as:

- Having a clear focus
- Having strong data
- The paper should be rigorous
- Sufficient space given to the elaboration of each theme
- The analysis should be interpretative not just descriptive

- The analysis should be pointing to both convergence and divergence
- The paper needs to be carefully written

These criteria will be applied to assess the quality of the studies presented within this thesis (See Section 7.5).

Table 3.1 Suggestion of sampling to demonstrate the density of evidence for themes

Number (N) of participants	Sampling
N = 1 to 3	Extracts from every participant for each theme
N = 4 to 8	Extracts from at least three participants for each theme
N = 8 and above	Extracts from at least three participants for each theme and a measure of prevalence of themes, <i>or</i> extracts from half the sample for each theme.

3.8 The application of IPA in healthcare research

The reported use of IPA in health research has increased over the last 10 years and has primarily been used to explore the lived experiences of illness (Smith, 2011; Shaw, 2011) (See Table 3.2). However, it is suggested that IPA could be used in the realm of applied health research and medical science (Smith, 2011) as it may be a useful method to explore elements of complexity, process or novelty (Smith, 2011; Brocki & Wearden, 2006). As discussed in chapters 1 and 2, EBCD may be perceived as a complex intervention (Craig et al., 2008), employing a novel approach to improvement (Bate and Robert, 2007a), and in which the process has been under-explored (Robert, 2013).

IPA has been used more recently within evaluative frameworks for quality improvement studies (Livingood, Sabbagh, Spitzfaden, Hicks & Wells, 2013; Inmans, Van Rossem, Knottnerus, & Spigt, 2015). A mixed methods

Table 3.2 Categories of studies within Smith' (2011) review of IPA published studies from 1996-2008 (adapted from Smith, 2011).

Key terms used to categorise studies	Number of papers
Patient's illness experience	69
Psychological distress	45
Carers' experience	30
Client's experience of therapy	18
Reproduction	18
Genetics	15
Health professionals' experience	14
Dementia	14
Occupational psychology	14
Sex/sexuality	13
Gender	11
Eating disorders	10
Therapists' experience	9
Learning disabilities	7
Sport/exercise	7
Religion/spirituality	5
IT	5
Education	4
Addiction	4
Alcohol	4
Alternative therapy	3
Music	3

process evaluation explored participant's experiences of the development of a lifestyle intervention for people with Type 2 diabetes in primary care (Linmans et al., 2015). The analysis of data included taking a phenomenological approach, drawing upon IPA techniques that recognised

the role of the researcher in interpretation. Another mixed methods evaluation used IPA as part of a suite of qualitative approaches taken to explore data collected via observation of meetings, interviews, and archival data (Livingood et al., 2013). The aim of the project was to assess the impact of a QI intervention to improve immunisation rates for young children, as part of a wider public health initiative in the US. Thus, IPA could be seen as an appropriate method by which to explore the experience of participants taking part in an EBCD QI project. It has been used previously as a method to interpret the experiences of service users in a mental health service following admission during treatment for early psychosis within an EBCD project (Fenton, Larkin, Boden, Thompson & Hickman, 2014; Larkin, Boden & Newton, 2015).

However, the use of these studies in terms of applying previous methods to investigate EBCD as a QI approach is limited. Fenton et al. (2014) provided a high quality and detailed IPA account of service user's experiences of mental health care but was not specifically useful in terms of providing a method of evaluating the EBCD process. The previously cited studies using IPA as an evaluative framework also suffered from several limitations in terms of informing the methods for the studies within this thesis. There was a lack of reporting of the analytical process adopted (Livingood et al., 2013), an extremely limited narrative account of the IPA findings (Linmans et al., 2015) or no account at all (Livingood et al., 2013). Using Smith's (2011) criteria to assess the quality of an IPA paper, both could be considered as unacceptable (See Section 3.7). This is problematic for two reasons a) it is unclear how IPA contributed to making sense of participants' experiences within the context of quality improvement efforts and b) there is little information for other researchers to follow in terms of the method and writing up results which are useful when informing study designs (Smith, et al., 2009). Thus, it is anticipated that through a detailed description of the method of using IPA here within the context of a quality improvement intervention, this may contribute towards the body of knowledge for the science of improvement.

3.8.1 Longitudinal qualitative research and IPA

Longitudinal qualitative research (LQR) is considered a methodology in its own right and embraces a range of concepts, approaches and designs (Thomson & McLeod, 2015). Though the concept of pairing longitudinal and qualitative elements within research is not new (Henderson, Holland &

Thomson, 2006), LQR is being increasingly applied to studies exploring events that occur over time (Thomson & McLeod, 2015) and can be useful for assessing interventions (Calman, Brunton, & Molassiotis, 2013). This has advantages over cross-sectional studies or post hoc evaluations, since the methodology considers temporal effects (Thomson & McLeod, 2015). It is suggested this specific methodology may also help to elucidate the causes and consequences of change by capturing 'critical moments' (Calman et al., 2013: p1) and help to identify the direction of change (Snelgrove, Edwards, & Lioffi, 2013). It is also suggested that thematic analysis is often used within LQR but tends to produce descriptive accounts at single time points rather than exploring the notion of change (Calman et al., 2014). Thus, the use of IPA within a LQR design could offer further insight by providing in-depth synthesis of data from multiple time points. This methodology is particularly relevant to studies 2 and 3, which aim to explore the experiences of participants over the duration of an EBCD improvement project. It is anticipated that by adopting a longitudinal approach that this may capture any moments that are related to change, intended or not.

Simpler IPA study designs usually involve collecting data at one time point, from a small and similar population (Chapman, Parameshwar, Jenkins, Large, & Tsui, 2007). However, it is suggested that more flexible and 'adventurous' designs can be adopted (Smith et al., 2009; p52). Some published IPA studies have explored multiple perspectives (Clare, 2002) (Larkin & Griffiths, 2004) or combined interviews from participants at different time points (Clare, 2002; Snelgrove et al, 2013; Pini et al, 2016). For instance, Snelgrove and colleagues (2013) explored patients' experiences of chronic low back pain (CLBP) over a two year period. The IPA study revealed that there was a continuity of themes for these patients: the constant management of pain and the 'almost intolerable' physical sensations related to CLBP (Snelgrove et al., 2013). This study provided an insight into the continuity of experiences, rarely explored within health literature (Saldaña, 2003). The implications for practice were concerned with the need for early psychological support but more importantly, the authors suggest that the study findings helped to re-conceptualise CLBP and its management.

Exploring phenomenon from multiple perspectives and at multiple time points can help to achieve a more rounded understanding of the event (Clare, 2002). This refers to the concept of data source triangulation

(Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014; Denzin, 1988), in which data from multiple sources aim to improve the validity of findings, not in relation to the concept of producing a more accurate account but rather to improve our understanding of the experience (Denzin, 1988). In terms of relevance for studies 2 and 3 this was an invaluable element in order to explore any changes or consistencies over time from multiple perspectives. However, there are several issues concerning LQR and IPA which are discussed in the section below.

3.8.2 Challenges of LQR and IPA

There are various ethical, pragmatic and methodological challenges that need to be considered when undertaking LQR (Calman et al., 2013). These include issues with regard to recruitment of participants, the developing rapport between researchers and participants, closure of relationships, time points when data are collected and the process of synthesising large data sets (See Table 3.3).

Whilst conducting the research reported within this thesis, these concerns were considered and actions were taken to mitigate against certain concerns. For example, recruiting healthy patient volunteers required a continued sensitivity with regard to on-going or new health concerns and potential distress caused by involvement within the EBCD process (EBCD is based on exploring the experience of the health event, which may conjure up negative, as well as, positive aspects of the experience). These concerns were addressed within the project protocol, which received ethical approval from the UoL. Writing field notes was a useful way to record thoughts and feelings at the time of certain interactions with participants. This allowed subsequent examination of events, which may affect the interpretation of experiential claims during the process of analysis.

Snelgrove et al. (2013) reported similar concerns when using a LQR approach with IPA. For, instance, during one interview with a CLBP participant he had recorded that they did not appear to be in any pain and in fact appeared 'fit and well'. On re-reading his field notes he believed he had made a judgemental call, possibly being influenced by societal notions that people with back pain are unbelievable. The importance of reflexivity during the analysis within IPA thus, helps the researcher to acknowledge preconceived ideas that could affect the interpretation of a participant's account. This level of detail demonstrates the rigour of the approach and improving the credibility and trustworthiness of the qualitative findings.

Table 3.3 Challenges of LQR and studies within the thesis

Challenges of LQR	Specific Issues	Actions taken
Ethical	<ul style="list-style-type: none"> Recruitment of patient participants shortly after significant diagnosis and treatment (Within 3- 6 months) Blurring of boundaries as relationships with staff and patients developed Potential for patients/service users becoming unwell or dying during the study Closure of relationships 	<p>Mindful of on-going health needs and sensitivity during interviews. Procedures put in place - detailed within project protocol.</p> <p>Field notes recorded interactions with participants. This included researcher feelings about these interactions –facilitating critical reflection during the interpretation during the analytical process.</p> <p>Sensitive to needs with long term health conditions. Making it as easy and accessible as possible for participants to take part.</p> <p>Participants kept informed of findings and invited to join other PPI groups. End of EBCD event planned.</p>
Practical	<ul style="list-style-type: none"> Time points when data was collected 	<p>Attempted to collate interview data within a designated time period at both time points.</p>
Methodological	<ul style="list-style-type: none"> LQR data sets are large and complex and can be analysed in multiple ways from different perspectives 	<p>Used literature, advice from supervision team and expert advice from experienced qualitative researchers to develop an analytical framework for the IPA studies.</p>

One key issue is the methodological implications of IPA when applied in a longitudinal manner. There appears to be very little literature within LQR that assists with the issues of *when* and *how to* combine data (Henderson et al., 2007) with few details within IPA literature how interview data is synthesised from multiple time points and how supplementary data is used to develop analysis (Smith et al., 2009). Thus, using literature that was available (Clare, 2002; Larkin and Griffiths, 2004; Smith et al., 2009; Smith, 2011, Snelgrove et al., 2013; Pini, 2014) combined with discussions with

the supervision team (PG, RL, JoH and AG) and experienced qualitative researchers (AM, LS) analytical frameworks were developed by LT for studies 1, 2 and 3. The application of these analytical frameworks is detailed within the following chapters for each individual study.

3.9 Research Methods

This section provides details with regard to the specific methods of IPA. This was an important stage of translating the focus of this thesis and the research questions posed, into an IPA framework.

3.9.1 Research questions

The IPA studies require specific research questions that are focussed upon exploring participants' understanding of their experiences. Research questions are angled towards the process and the 'concrete causes and consequences' of the phenomenon under investigation (Smith et al., 2009; p47). Thus, when exploring a participant's experiences, questions are usually situated within very specific contexts and do not attempt to be too far reaching in scale. Therefore, the following research questions have combined the language and use of IPA methods, with the overall aim and objectives of the thesis to produce more specific research questions as follows:

- 1) How do patients, staff and designers experience non-participant observations, as part of an EBCD project?
- 2) How do patients, staff and health researchers involved in an EBCD project within a cardiology service, make sense of their experience of EBCD?
- 3) How do patients from a South Asian origin compared to White British patients make sense of their experience, as part of an EBCD project within a cardiology service?

3.9.2 Samples and sample size within IPA

IPA studies are concerned with representing a particular 'perspective' rather than a 'population' (Smith et al., 2009; p49). They are often characterised by small sample sizes with the express aim of uncovering something about an experience from each of the individuals taking part, which are in turn compared and contrasted with each other (Smith, 2011). Small sample sizes are a common feature of qualitative research and are

often cited as a limiting factor due to the potential lack of generalisability to a larger population (Silverman, 2011). However, Smith et al (2009) argue that IPA allows for more in-depth analysis, otherwise lost in larger samples and where the researcher is 'encouraged' to go beyond immediate themes (Pringle et al, 2011). Smith and colleagues (2009) also argue that by selecting a reasonably homogeneous sample, similarities and differences can be explored in detail, with findings then broadened through the concept of theoretical generalizability (See section 3.4.3).

A purposive sampling strategy was employed to recruit participants from a local service improvement EBCD project for all three studies within this thesis. This strategy was consistent with the aims of the studies and the underlying methodological and theoretical assumptions. Owing to the lack of previously published work using IPA to explore experiences of EBCD the sampling strategy could not be informed from previous studies, which is considered relevant when designing this type of study (Smith et al., 2009). IPA studies usually seek to recruit a homogenous sample so that the research question(s) is considered pertinent to those participating (Smith et al., 2009). For the purpose of this study the notion of 'homogeneity' was defined in terms of the target population being bound by a commonality of a discrete and significant 'event' (the local EBCD project) rather than the experience of a disease or long term condition. The exact recruitment strategy for each study is detailed in the following empirical chapters.

The ideal number of participants within IPA studies and the implications for writing up the analysis has been addressed by Smith et al. (2009). It is recognised there is no right answer in terms of the size of a sample within qualitative research and is dependent on the aims of the study and what is expected of the data in terms of answering the question (Green and Thorogood, 2009). Smith and colleagues suggest that PhD research projects, usually reporting three unique studies, employ a sliding scale in terms of the number of cases and potentially using more complex designs (See Table 3.4).

This thesis has used complex IPA study designs (See Table 3.5). This was in terms of a) exploring the experience of EBCD from different stakeholder's perspectives (studies 1, 2 and 3) and b) exploring the experiences over time (studies 2 and 3).

Table 3.4 Sample size and professional levels of study

Academic level of study	Undergraduate and Masters	PhD research projects	Professional doctorates
Number of studies and participants	Single study (n=3)	Study 1 (n=1) Study 2 (n=3) Study 3 (n=8)	-
Number of interviews	-	-	n = 4 - 10
Complexity of design	Simple - Homogenous group of participants - Data collection at one time point	Complex - Multiple perspectives - Unit of analysis e.g. dyads - Data collection at multiple time points	Complex - Multiple perspectives - Unit of analysis e.g. dyads - Data collection at multiple time points

Key: n =number of individual participants

When using Smith et al's guide above for an 'acceptable' sample size for academic studies (loosely applied owing to the epistemological positioning of a qualitative research paradigm), it would appear the studies reported within this thesis meet the requirements for sample size and level of complexity within the context of a PhD research project (See Table 3.4 and Table 3.5).

Table 3.5 IPA study designs within thesis

Studies within thesis	IPA study design	Number of participants	Stakeholders P=Patients PR=Patient Volunteers S=staff D=designers	Number of time points	Number of interviews
1	Complex	n=6	PR, S, D	n=1	n=6
2	Complex	n=13	P, PR, S, D	n=2	n=22
3	Complex	n=8	P, PR	n=3	n=14

Key: n =number of individual participants

3.10 IPA and data collection methods

Data collection methods used within IPA are related to the underlying epistemology and methodology of the approach. Thus, methods employed to gather data aim to capture detailed thoughts and feelings about the

phenomenon under investigation. The primary source of data was in-depth interviews. Additional data sources were used to contextualise the interview data, as suggested by Smith et al (2009). This can be helpful when understanding the specific context and activities related to the phenomenon under investigation (Smith et al., 2009). Participant diaries, non-participant observations of co-design meetings and field notes were used for contextualisation and analysis development. The specific methods used for each study is presented in Table 3.6.

3.10.1 Primary data collection method

In-depth interviews

The most utilised approach within IPA research has been semi-structured one-to-one interviews (Redid, Larking and Flowers, 2005) and is considered an appropriate fit when attempting to develop a rapport (Green & Thorogood, 2009) and provide participants with space to think and talk (Smith et al., 2009). Thus, semi-structured in depth interviews were the principal data collection method used within the three studies reported in the following chapters.

Table 3.6 Data collection methods for studies

Study	Interviews	Researcher	Researcher	Participant
		Field notes	Observations	Diaries
1	✓	✓	-	-
2	✓	✓	✓	✓
3	✓	✓	✓	✓

3.10.2 Additional data methods

Participant diaries

In addition to interviews, semi-structured diaries were given to participants to record any thoughts or comments about interactions or activities during the EBCD project. The diary was not considered a compulsory activity and participants were only invited to use them if they desired to do so.

Non-participatory observations

Non-participatory observations were also conducted by the main researcher (LT) during co-design meetings. This supplementary data was used to help contextualise the interview material and is considered a useful

way in which to assist the development of the analysis process (Smith et al., 2009). These observation notes assisted with the interpretation of participants' accounts in an attempt to assist with the contextualisation of any interviews and development of the analysis. Participant observation can be a useful way of further understanding specific local contexts and activities (Smith et al, 2009). An observation sheet was developed using principles of writing up ethnographic field notes and was guided by answering the following questions (Emerson et al., 1995; p146);

- What are people doing? What are they trying to accomplish?
- How exactly do they do this?
- How do people characterise and understand what is going on?
- What assumptions do they mean?
- What do I see going on here? What did I learn from these notes? Why did I include them?

Field notes

Field notes were taken throughout the duration of the research studies. They contained notes, thoughts and impressions with regard to interactions with participants and anticipated concerns before planned interactions. These were used to help reflect upon first impressions and during the process of analysis.

3.11 IPA and the analytical process

As previously discussed, IPA is concerned with the detailed analysis of participants' accounts. Though IPA does not prescribe any single approach, it is concerned with the analytical focus, making sense of participants' experiences (Smith et al., 2009). The commitment to an idiographic approach means that each case is closely examined, which leads to seeking patterns across the corpus of data. It is suggested that good IPA research presents not only the similarities and difference within the sample, but also highlights the way identified themes 'play out' for each participant (Smith, 2011a: p10). During the close reading of individual accounts specific extracts may help to elucidate specific themes, and may offer a better insight into the phenomenon being investigated. These have been referred to as 'gems' which may be explicitly understood by both the participant and researcher (a shining gem) or something meaningful to the

researcher but partially understood by the researcher and requires analytic thought (a suggestive gem) or something that is not apparent to either and is produced during a more extensive analytical process (a secretive gem) (Smith, 2011b).

This process of 'moving from the particular to the shared' employs certain strategies during the analytical process, and maintains an iterative and inductive cycle, in keeping with the underlying epistemological perspective (Smith et al., 2009:p79; Smith, 2007).

This process includes:

- Detailed and close reading and re-reading of the verbatim transcript
- Identifying emergent themes, looking for similarities and differences within and across cases
- Development of a conversation between the researcher and the experiential account, to create a more interpretative account
- Development of a structure to illustrate the relationship between themes
- Organising data to allow the sequence of analysis to be traced
- Supervision and/or collaboration with others to test the plausibility of the interpretation
- Developing a full written narrative
- Reflecting upon the analytical process

For novice IPA researchers, Smith and colleagues (2009) provide a guide or 'steps to analysis' to assist with conducting the analysis. Since the main researcher (LT) was unfamiliar with the specific approach this provided a useful guide to begin analysis. This basic guide is expanded upon in the first empirical study (Chapter 4, See Section 4.4.3). Subsequent studies (2 and 3) used a different analytical approach and are detailed within Chapters 5 and 6 respectively.

3.12 Subjectivity and reflexivity in qualitative research

Subjectivity is valued within the qualitative research paradigm.

Researchers bring their world views, their beliefs and values, and their perspectives and passions, all of which are considered strengths within the process of producing research (Braun & Clarke, 2013). These aspects

reflect who we are as researchers, and subjectivity can be applied through a process of reflexivity (Braun & Clarke, 2013).

The researcher draws upon every day resources to understand the world by exploring their insider and outside positions within the research process (Finlay, 2002 Shaw, 2010; Braun & Clarke, 2006). Reflexivity requires a critical approach to looking and 'thinking back' to oneself (Shaw, 2010: p235). Considering how the researcher has shaped generating and analysing data will depend on their role within the process, as well as, their socio-political and demographic orientation. This requires researchers to expand a similar critical reflection to their practice as well as the topic under investigation (Green and Thorogood, 2009). The role of reflexivity is not an attempt to reduce bias but a way to provide a transparent account of how data was generated (Green and Thorogood, 2009).

The concept of bracketing within IPA is considered a useful device to help the researcher set aside their assumptions of the everyday world (Smith et al., 2009) as this may 'hinder or enhance' sense making of someone's lived experience (Shaw, 2010: p235). Snelgrove and colleagues (2013) discuss this point when reflecting upon their ability to maintain an inductive approach owing to their existing academic knowledge about the topic. Snelgrove et al. (2013) claimed that bracketing helped to suspend a tendency for a priori theorising. However, it is suggested that taking a more reflexive stance may be better suited to phenomenological approaches since the notion of adopting a 'view from nowhere' is virtually unachievable (Langridge, 2008: p1129). The thesis will now examine the issue of reflexivity and consider the implications for the research conducted in the following studies.

3.12.1 Reflexive points within the thesis

Personal reflexivity is described as 'bringing the researcher into the research' whereby the researcher is evident within the research process (Braun and Clarke, 2013: p37). This is important when considering how the researcher may influence the production of knowledge. Personal reflexivity plays an important function within IPA. This is in relation to the idea of a 'double' hermeneutic within the analytical process (Smith and Osborn, 2003). Firstly, the researcher is making sense of the participant making sense of the phenomenon under investigation. This requires the researcher to recognise their own experiential knowledge while making sense of the phenomenon seen through the experiential lens of the

participant. Secondly, in relation to the interpretative nature of IPA, the researcher is positioned between an empathetic and questioning stance (Smith et al., 2009). The researcher is endeavouring to 'understand' in terms of 'trying to see what it is like for someone' and in the sense of 'analysing, illuminating and making sense of something' (Smith et al., 2009; p36).

Functional reflexivity is concerned with critically thinking about the way in which the research process may have influenced the research. For instance, issues with implementation of the EBCD project meant that I conducted the majority of interviews with patient participants. This may have influenced the data generated and the way data was analysed owing to a perceived deeper rapport with patient participants than with staff members. A research journal was kept to record personal thoughts and interactions with others during the process. The journal was useful when looking back and thinking about how I felt at the time when conducting interviews, after observation sessions and less formal interactions with participants. The credibility of qualitative research is seen in terms of transparency and trustworthiness of the account presented (Lincoln & Guba, 1985) and IPA studies should demonstrate an interpretative account (See section 3.5). Combining a reflexive commentary within the results may be a better way of evidencing how the researcher's involvement shaped the research process (Shaw, 2010). Therefore, reflexive comments are presented in blue 'call-out' boxes with an example provided in Box 3.1.

Reflexivity point:

Issues with the implementation of the EBCD project meant that I conducted the majority of interviews with patient participants. This may have influenced the data generated and the way data was analysed owing to a perceived deeper rapport with patient participants than with staff members.

Box 3.1 Functional reflexivity comment

3.12.2 Contextualising data

The IPA studies within this thesis have drawn upon additional data to help contextualise data gathered during the interviews in order to assist with the development of the analysis (See section 3.8). The notion of hermeneutic

reflection within IPA seeks to bring about an awareness between ‘ourselves as researchers and our participants’ data’ as well as research interactions changing our assumed understandings to develop new understandings of the event under exploration (Shaw, 2010: p241).

Therefore, two further ‘call out’ comment boxes are featured within the analysis sections of the studies presented. These include green comment boxes for observational data that was gathered and orange comment boxes that provide diary extracts from participants (See Boxes 3.2 and 3.3). It is anticipated that this additional data supports the underlying themes described within the analysis. In the absence of specific guidance about how to incorporate contextualising data within IPA studies this approach appears to be in keeping with the broader principles of good qualitative research (See Section 3.5). The development of this approach was informed from extant literature addressing the issues of incorporating reflexive comments within IPA studies (Langdridge, 2008; Smith et al., 2009; Shaw, 2010) and in discussion with the supervising team (PG, RL, JoH and AG) and advice from expert qualitative researchers (AM and LS). Smith and colleagues (2009) suggest that there is no right or wrong way to analyse data within IPA and suggest taking inventive steps. This approach to combining contextualising data may be considered a more novel approach and is anticipated to provide a richer and more detailed level of analysis.

Additional data – Non participatory observations

- Reflecting upon non-participatory observational notes taken during co-design meetings.

Box 3.2 Additional data – Non participatory observations

Additional data – participant diaries

- Contextualising data taken from participant diaries entries

Box 3.3 Additional data – participant diaries

Chapter 4: Analysis part 1

4.1 Chapter summary

Whilst the theory underpinning EBCD is clear, the mechanisms through which the QI intervention brings about changes are more uncertain. The observation component within the process has not been explored in any depth within the current literature. Therefore, this chapter presents a qualitative study that explored the experiences of individuals who conducted observations as part of an EBCD service improvement project. This study takes a multiple perspective approach and includes; patient volunteers, nursing staff and design engineers.

This chapter presents the analysis of data using IPA as a strategy of enquiry. It commences with a summary about general issues with QI efforts and then focusses on the role of observation within the EBCD process. This is followed by the aim and objectives of the study and details of the method adopted for this IPA study. The main part of the chapter presents an interpretative account of participant's experiences of conducting observations and concludes with a discussion drawing upon relevant literature with implications for practice and research.

4.2 Background

As discussed in the opening chapter, EBCD can be defined as a complex improvement intervention with multiple interacting components (Craig et al, 2008). Quality improvement methods have shown wide variation in terms of success (Kaplan, Provost, Froehle & Margolis, 2011) with doubt over the effectiveness of interventions in the healthcare setting (Auberbach, Rasic, Sehgal, Ide & Stone, 2007). This uncertainty is owing in part to a lack of understanding about how and why an intervention works, and may lead to 'cargo cult science' (See Section 1.6) where despite all the components in place, an intervention may fail without knowing why (Hulscher et al., 2003; The Health Foundation, 2013).

Whilst the underlying theory and process of EBCD are clearly articulated (See Section 1.5.3) (Bate & Robert, 2007a; Robert et al, 2015) the mechanisms that link the components, processes and outputs have not been investigated in any depth (Donetto et al., 2014; Rohde et al., 2016).

The literature reviewed in chapter 2 revealed specific gaps in our knowledge about the second stage of the process: gathering staff experiences. This stage uses a mixture of participant observation, one-to-one interviews with a cross-section of staff and contextual enquiry to identify service improvement priorities. The review also revealed little empirical evidence about the experience of conducting clinical observations within the EBCD approach. A report into the use of the approach by Donetto et al (2014) also recognises that the observation element is an under-utilised and under reported activity when compared to the other elements, for instance, the acceptability and use of trigger films (Locock et al., 2014). Therefore, the role of observation within the EBCD approach is the focus for this study.

4.2.1 The observation component within the EBCD process

The EBCD process has been previously described in detail within this thesis (See Section 1.5.3). A summary of the key points regarding the observation component will now be provided. For the purpose of this chapter the terms 'non-participant observation' and 'observation' are used interchangeably, but they describe the same activity.

A principle commitment of EBCD is to understand the lives and experiences of others in order to enhance the experience of care. Various ethnographic based methods are employed within stage 2 of the process which includes non-participant observation (See Section 1.5.4). It is suggested that by watching people in their 'natural work habitat' a rich source of information is gathered about how care is delivered and received (Bate & Robert, 2007a). Observational methods have been previously applied to explore 'interactions' between clinicians and patients as this aspect lies at the heart of healthcare delivery (Drew, Chatwin & Collins, 2001; Stevenson, 2013) while the best outcomes of care are recognised to involve a mutual understanding of the 'lifeworld' of the patient (Barry, 2001).

Observation within EBCD is considered a vital component of the discovery phase (Donetto et al., 2014). It is hypothesised that by conducting observations in the clinical setting this will capture important aspects of care or 'touch points' (See Section 1.5.4) that may not be revealed through staff interviews or contextual enquiry; gain early insights into the patient experience; help to shape interview schedules for patients; and build a

sense of trust and rapport with staff within the service (Bate and Robert, 2007a).

An EBCD study described the observation activity as 'organisational loitering' which involved observers quietly watching and making notes (Bate and Robert, 2007a: p 88). The EBCD toolkit, as described in chapter 1, advocates the use of healthcare staff within the service and/or other colleagues and/or outside observers. The toolkit suggests observers should 'be friendly and ask questions', whilst simultaneously providing practical tips such as; being unobtrusive as possible and avoiding direct eye contact (The King's Fund, 2013: Point of Care Foundation, 2018a). Thus, the specifics of conducting observations remain hazy at best.

There is some empirical evidence to suggest the value of observation with regard to identifying 'touch points'. Bate and Robert (2007a; 2007b) described the embarrassment and confusion faced by patients at the reception of an oncology clinic where they were asked to move back behind the 'red line' painted on the floor. This line was supposed to provide a comfortable distance between patients waiting to register and facilitate an element of privacy. The reality observed was that conversations between patients and the receptionist were audible to all and the red line caused patients to feel 'silly' having failed to notice its significance. When the observational findings were fed back to the medical director, they reported that they were unaware of any 'red line'.

However, the extant literature and findings from the systematic review in Chapter 2 revealed that despite observations being considered a critical component within the EBCD process (Bate and Robert, 2007a) in practice it is often omitted without explanation (Donetto et al., 2014). Where observation is carried out, there is scant reporting of exactly how it was conducted, how this informed other components within the discovery process (patient interview schedules) and what the experience of observation was like for those involved (Donetto et al., 2014). It is suggested that in order to understand what affects the success or failure of QI interventions it is necessary to explore the concrete components of an intervention (Hulscher et al., 2003). By gathering a detailed insight into the experience of those taking part it is anticipated this may further improve the understanding behind the complexity of the EBCD approach and potentially uncover unexpected mechanisms (Moore et al., 2015). Therefore, in keeping with the aim of the thesis and the main objectives (See Sections

1.8 and 2.9 respectively) this study attempts to explore the experiences of individuals conducting observations within a local EBCD project.

4.3 Research question and objectives

The primary research question was;

1) How do patients, staff and designers experience non-participant observations, as part of an EBCD project?

Owing to the open and broad nature of the research question the following objectives helped to assess the outcomes and scope of the study. This is considered a useful strategy within qualitative research paradigm (Salmon, 2002). The key objectives were;

- 1) To identify and describe the key features of conducting participant observations as experienced by participants.
- 2) To identify the mechanisms behind the theory of change within the observation component of the EBCD approach

4.4 Context - Home is where the heart is: an EBCD project to improve the experience of discharge care from a local placed cardiology service

The following section provides a summary of the EBCD service improvement project in which all three empirical studies were embedded within.

4.4.1 Background

A senior lead clinician from a cardiology service within an acute NHS hospital Trust (in the North of England) approached the Yorkshire Quality and Safety Research (YQSR) group having expressed concerns over discharge care for patients after suffering a heart attack. These included issues such as: drug omissions or additions detected at follow-up appointments; errors and/or omissions with patient discharge summaries; patients not attending routine follow-up appointments. There was also anecdotal evidence from staff concerned that they were being frequently interrupted on the ward having to respond to telephone calls from discharged patients querying aspects of their care. The ward's local patient survey also revealed consistently lower patient satisfaction scores for discharge care from the South Asian population, but they were unsure

about the reasons for this result. Thus, an attempt to improve discharge care was embarked upon using EBCD as an innovative way to enhance the experience of patient care. This was an unfamiliar approach to staff and the supporting QI team. However this approach aligned to grander organisational objectives, such as, the Patient and Public Involvement (PPI) strategy, the 'patient flow' work stream and preventing unnecessary readmissions.

The setting for this EBCD project was a 28 bedded cardiology ward with which also contained a seven-bedded coronary care unit (CCU). This ward also received medical outliers (patients with medical conditions but not necessarily related to the heart and may occupy beds when there is no room to accommodate patients within general medical wards). This ward was extremely busy and at the start of the project the ward (May 2015) was still responding to winter bed pressures with an additional six beds open.

Having approached the YQSR group for support it was at this stage that I began to work with the clinical team and in-house QI team. This involved advising and assisting with stage 1 of the process, 'setting up'. I was also given a contact to support the design element of the project (via RL). This design team was based at a local university and were part of the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Yorkshire and Humber. After obtaining agreement from the operational and clinical leads for the department an EBCD project was set to take place from May to July 2015.

The core team included clinical staff, a hospital QI specialist and health service design engineers. The use of designers is not considered usual practice within the EBCD toolkit but they were invited to take part owing to their expertise in co-design and previous work with developing products with service users and healthcare professionals and were part of the Yorkshire and Humber CLAHRC.

The global aim of the QI project within the service was to improve the discharge experience for patients leaving the ward. As this was a service improvement project formal ethical approval was not required. However, based on the principals of good clinical practice (GCP), where appropriate written consent was obtained for certain activities during the EBCD project. The activities, outputs, outcomes are described in more detail within Table 5.1.

Reflexivity point

With regard to my own knowledge and experience of EBCD, I was familiar with the literature and approach at an academic level. I also attended a bespoke EBCD training day in June 2015, hosted by the Point of Care Foundation. I also attended a two day introductory workshop in Clinical Microsystems at Sheffield Teaching Hospitals, which provided the fundamentals behind QI efforts in the NHS. I have over twenty years of professional experience as a registered nurse (RN) working in the adult acute care setting and more recently within patient safety research, and felt comfortable working with patients, their families and multi-disciplinary teams within the cardiac setting.

4.4.2 Details of the observation component within the EBCD project

Observations were carried out by six individuals from three different stakeholder groups: healthcare staff, patient volunteers and design engineers (See Table 4.1). This was considered to be a novel approach, as more commonly, experienced qualitative researchers and healthcare staff conduct observations (Bate & Robert, 2007a, 2007b; Tsianakas et al, 2013).

The EBCD project team chose to work with patient volunteers to provide an 'outsider' perspective because it was deemed in-keeping with the theory underpinning the approach (see Chapter 1). Therefore, two patient volunteers were recruited via the hospital volunteer group. They were selected on the basis that they had prior knowledge of the ward, from either a personal and/or a volunteer perspective. The patient volunteers had also undergone rigorous governance checks to enable them to work safely within the hospital setting.

The two clinical research nurses that took part in the observation step were based within the cardiology service but were not working directly on the ward. This addressed the capacity issues faced by the ward manager who was unable to release ward staff at this stage of the process.

The two design engineers, specialising in user-centred design research in healthcare, were part of the core EBCD project team. They had been invited to take part by the core team since they had expertise and experience in co-design within the healthcare setting. This project

appeared to be a natural fit for the design engineers, with one designer having worked on an EBCD project previously.

All the observers were given the same instructions at separate face to face meetings with LT. This included a set of guidelines (See Appendix 3) and a proforma to record observations in the clinical area (See Appendix 4). These tools were developed by LT using the EBCD online toolkit and supporting information (Point of Care Foundation, 2018a). The decision to conduct non-participatory observations was shaped by the intention to follow as closely as possible the original purpose of observation component as described within the pilot study by Bate and Robert (2007a). This included sitting and observing without interacting in the clinical area and shadowing key healthcare professionals. The aim of the observation component was to ‘capture the minutiae of the various interactions and all the mundane *bubble and chat* of everyday conversation between staff and patients’ (Bate and Robert, 2002:p121). Written notes were recorded by the researchers during the observation period. It was felt therefore, that the EBCD process was implemented as intended with regard to the initial pilot and advice on conducting observations within the EBCD online toolkit.

A summary of the key details concerning the observation activity are presented in Table 4.1. This includes; gender, the number of unique sessions and hours of observation conducted. The patient volunteers, as a group, conducted the most observations (n=7), with the staff and designers conducting two sessions each.

Table 4.1: Details of observation activity across stakeholder groups

Stakeholder group	Gender	No. of hours of Observation	No. of occasions
Patient volunteer	Female	3	3
Patient volunteer	Female	4	4
Staff – nursing	Female	2	2
Staff – nursing	Female	2	2
Designer	Male	2	2
Designer	Male	2	2

4.4.3 The key findings from observational data

The patient volunteers, staff members and designers recorded their observations in a variety of ways (See Table 4.2 for participant information). This included using the prepared observation proforma (See Appendix 4) and personal notebooks. Examples of their observation records are presented in Figure 4.1

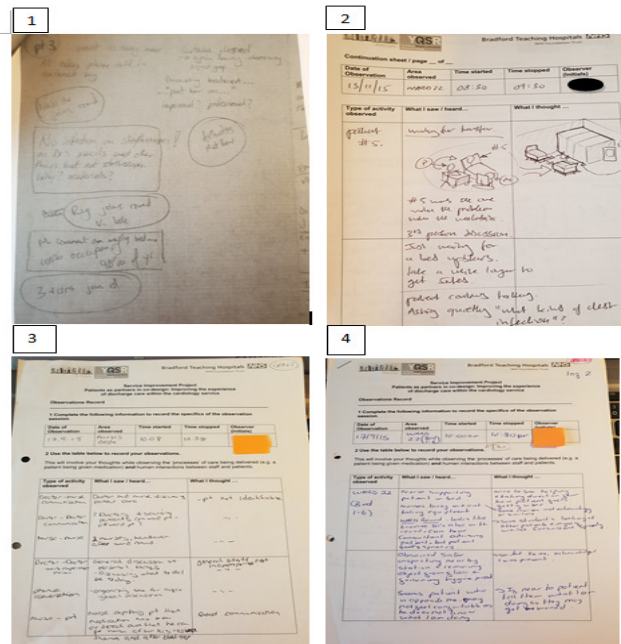


Figure 4.1: Examples of observation records 1) Sam (a designer), 2) Ed (a designer), 3) Martha (staff), 4) Sara (patient volunteer)

The findings from the observation notes were collated and were used in conjunction with the findings from staff interviews, which were feedback to staff before the joint co-design meeting (Stage 4 of the EBCD process). The key findings that were shared at this feedback point are detailed in Table 4.2. However, for the purposes of contextualising data from the study, the orange column indicates who recorded these observations, which was not presented at the feedback session to ward staff.

Table 4.2: Observations feedback to staff

Observations on Ward XX	Observations recorded by
Patient bays	
<ul style="list-style-type: none"> A patient was concerned that they had been given conflicting information by doctors 	Patient volunteers
<ul style="list-style-type: none"> A patient was waiting results from a stress test before being discharged, then was told that they would receive the results in the post. The patient commented that they were confused why they were told they had to wait and then were told they could go home without the results. They thought it was strange that they did not have to sign anything to be discharged. 	Patient volunteers
<ul style="list-style-type: none"> A patient had recently died in the bay but patients commented that no-one had come in to check on them after the event. 	Patient volunteers
<ul style="list-style-type: none"> The housekeeping staff were 'jolly' and were engaging with patients while working 	Designers

<ul style="list-style-type: none"> • A patient was annoyed having to wait for medication 	Designers
Ward rounds	
<ul style="list-style-type: none"> • During ward rounds, the curtains were drawn, low voices providing privacy and dignity. However, sometime curtains were closed with a 'door-sized gap' 	Staff and designers
<ul style="list-style-type: none"> • The communication between the nurses and doctors was good. 	Staff and Designers
<ul style="list-style-type: none"> • The consultant greeted and shook the hands of patients that they met. 	Designers
<ul style="list-style-type: none"> • There was the use of jargon and medical terminology while talking about the patient. 	Designers
<ul style="list-style-type: none"> • The ward rounds were long with team members visibly flagging 	Designers
<ul style="list-style-type: none"> • The 'huddle' of staff appeared to be closed cutting the patient out of discussions 	Designers
<ul style="list-style-type: none"> • The consultant would ask questions about the patient at times and not to the patient 	Designers
<ul style="list-style-type: none"> • Education opportunities on the ward round - teaching medical students but impacts on the length of the ward round 	Designers
<ul style="list-style-type: none"> • The speed of some patient consultation varied with little time for discussion or questions. Some questions that were asked by patients were not registered by staff, unclear whether they heard or not, as patients were asking quietly. 	Designers and patient volunteers

4.5 Method

4.5.1 Design

A qualitative study was designed and collected data at one time point within in the EBCD process (See Figure 4.2) was IPA; the rationale for this approach is discussed in detail within chapter 3 (See Section 3.3).

4.5.2 Participants

An opportunistic purposive sampling strategy was used to recruit participants to the study. Participants were selected on the basis that they had specific experience of the phenomenon under investigation that is; conducting participant observations within an EBCD improvement project. The eligibility criteria included that participants were aged 18 or over, and who were able to read and speak in English. Therefore, the six observers were all invited to take part in the study representing three different stakeholder perspectives: healthcare staff, patient volunteers and designers. All agreed to take part.

In keeping with the theoretical underpinnings of IPA, idiographic pen portraits were developed over the length of involvement in the research study. Pen portraits are a useful way of bringing context and relevant details about participants into qualitative analysis (King and Horrocks, 2010). Pseudonyms have been assigned to participants and to avoid

potential identification certain individual experiences have been omitted (identifying characteristics may be removed in formal publications to preserve the anonymity of participants). Participant pen portraits are presented in Table 4.3 below.

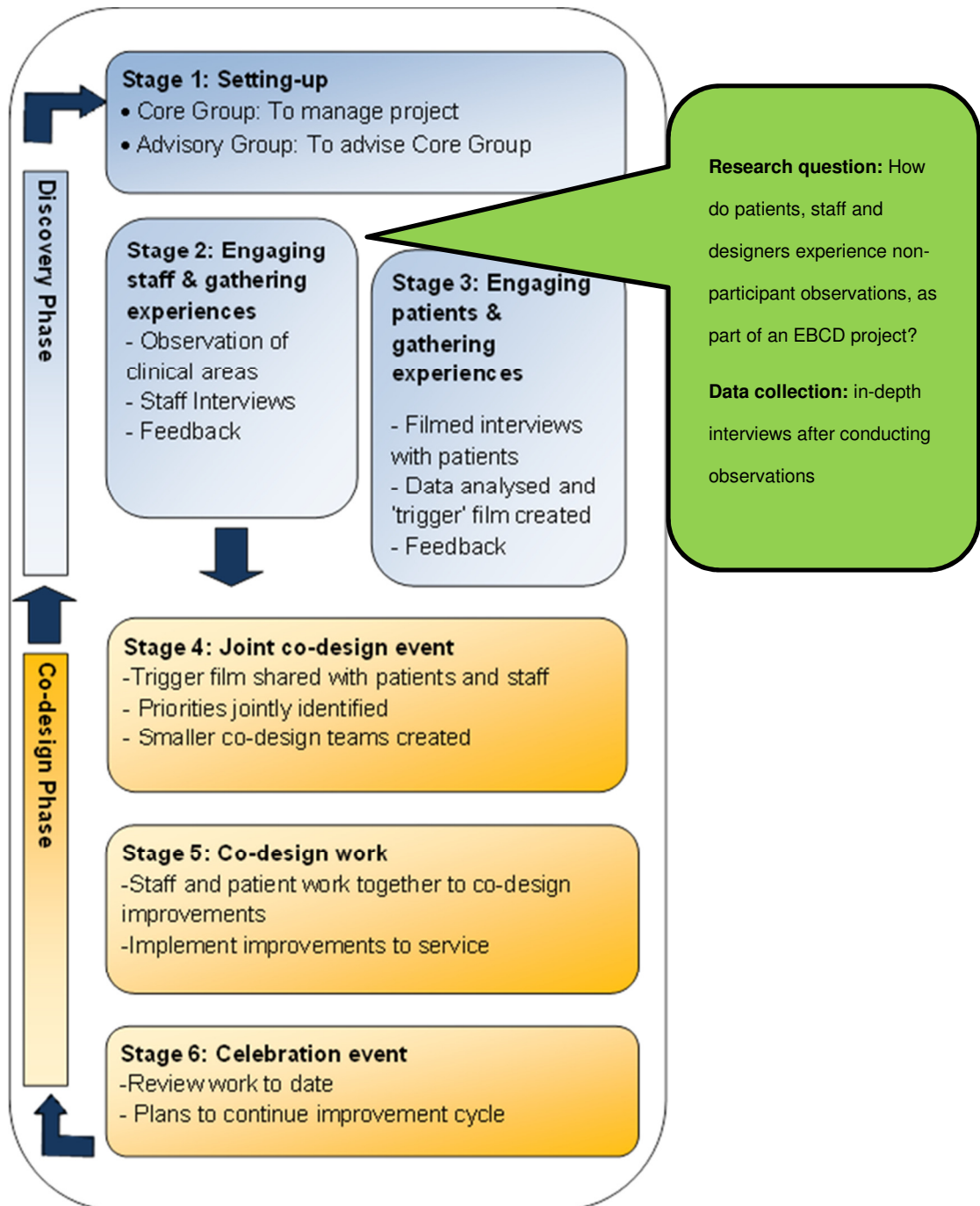


Figure 4.2 Data collection point

Table 4.3 Study 1 - Participant Pen Portraits

Participant	Stakeholder group	Pen portrait
Jean	Patient volunteer	Jean was in her early seventies, of a White British ethnic origin, and had been working within the hospital volunteer service for approximately one year. She was married with grown up children and had extensive professional experience within the education sector. She had worked with vulnerable young people most of her life. She often expressed her fascination with the working life of the hospital, and enjoyed her work within the volunteer service. This had involved collecting patient safety data directly from patients and their families from wards across the Trust and was part of a patient safety intervention.
Sara	Patient volunteer	Sara was in her mid-forties, and was of South Asian ethnic origin. She was married with a teenage child and had lived all her life in the local area. She was an active member of her community and had a legal professional background. She had been a hospital volunteer for over two years and had been involved in collecting patient safety data from patients and families across the Trust. Sara was also involved in patient and public involvement activities within local research groups and had an interest within a local CCG. She often spoke about the need to provide the carer perspective in terms of the service development and research priorities.
Martha	Staff – nursing	Martha was a qualified nurse in her forties and was originally from a European country but had been working and living in the UK for a number of years.
Francesca	Staff – nursing	Francesca was a qualified nurse, in her late thirties. She was originally from Asia, but had been living and working in the country with her husband for a number of years. She had worked on the ward for a number of years and was

familiar with the staff and routines.

Sam	Design Engineer	Sam was in his mid-forties and was of White British ethnic origin. He has worked extensively with the design sciences and health care setting. He was based in a University in the region, but did not live locally to the Hospital where the project had taken place. He was married with, a young family.
Ed	Design Engineer	Ed was in his mid-forties and was of White British ethnic origin. He was married with, a young family. He had worked within the design sciences and health care setting. He was based in a local University in the region and did not live near the hospital. Ed has previously worked on an EBCD project in a professional capacity and was familiar with the methods and ethos of the approach.

4.5.3 Procedure

The study was reviewed and received ethical approval by the University of Leeds, Faculty of Medicine and Health Research Ethics committee (date:15/09/15; Ethics Reference number:15-0153). This research study was judged to be a service evaluation project by the National Research and Ethics Service, therefore, local R&D permissions were sought to ensure governance and checks were in place prior to the study commencing.

All members of the existing EBCD core team were considered eligible to take part in the study. As the participants were known to the main researcher (LT) and consisted of such a small group, all eligible participants were approached by a member of the core project team (CO) either in person or via email, and provided with a participant information sheet and interview schedule. This was to ensure no one felt pressured into taking part. They were all given a minimum of 72 hours to consider the information before being contacted by LT via email or telephone to confirm whether they would like to participate in the study.

After confirmation of participation, a mutually convenient day and time for the interview was arranged. Informed written consent was obtained from all the participants having been provided with an opportunity to ask any questions prior to consent. All interviews were conducted within a private room within an academic research facility and located away from the clinical setting.

The observation sessions were conducted between September 2015 and November 2015. The semi-structured face-to-face interviews were conducted between 03/12/2015 and the 08/02/16 and lasted between 45 to 60 minutes in length. The patient volunteers were reimbursed for their time and travel expenses for this interview at a cost of £20.00 per person. The patient volunteers had also been reimbursed previously for all contact sessions (£20.00 per session) within the observation component of the EBCD process. This reimbursement strategy was guided by the NIHR's policy on payment of fees and expenses for members of the public actively involved with INVOLVE (INVOLVE, 2018).

Staff members and design researchers were not reimbursed owing to the fact that this study was seen as an evaluation of a service improvement project and therefore considered part of normal working duties. However, in keeping with best practice and considering other forms of recognition, healthcare staff and the designers were thanked for their contribution, as well as informed on the progress of the research and were invited to future celebratory events (INVOLVE, 2018).

4.5.4 Data collection

The interview schedule was constructed in order to allow the participants to tell their own story about their observation experience and allow freedom to describe any moments that were important to the participants (Smith et al, 2009).

Following an introduction by the researcher to explain the purpose of the research project and the aim of the interview, the schedule consisted of the following questions:

Experience of conducting non-participation observation:

- Can you tell me how you felt about carrying out the non-participation observation *before* going on the ward?
- Did you have expectations before carrying out the non-participation observation, if any?
- Could you tell me what sort of things you observed on the ward?
- Can you tell me how you felt about carrying out the non-participation observation after going on the ward?
- Did your previous expectations differ *after* carrying out the non-participation observation on the ward, if at all?

Experience of discussions after the non-participation observation:

- Can you tell me about how you felt about having discussions with the patient representative/member of staff/health researchers?
- What were the main differences between your observations and those of other observers that you worked with?

Possible prompts and probes that were used included:

- Can you tell me a bit more about that?
- What do you mean by '.....'?
- Can you give me an example?

This approach is in keeping with the principles of IPA methodology and also allows the researcher to delve deeper onto topics raised that are related to the aims of the study (Smith, 2011). The interviews were audio-recorded and transcribed verbatim by a trained transcriber, based within the University of Leeds, School of Psychology.

4.5.5 Analytic procedure

Data from the interviews were analysed using IPA (Smith et al, 2009) by LT. The general approach to analysis is described in chapter 3. However, the specific sequence of analysis is outlined below:

1. Reading and re-reading

A transcript was chosen randomly and was read and re-read to allow a familiarisation with the data, developing a sense of the account as a whole and ensuring that the focus on analysis was the participant. The audio-recording of the interview was revisited on several occasions in order to check the accuracy of the transcription (having been completed by a third party) and to check verbal and non-verbal parts of speech (why was there a pause in speech? Were they hesitant or was it just a natural pause? What sort of laugh was it? Embarrassed, nervous?) This is considered a useful approach when trying to achieve a more complete analysis (Smith et al., 2009). The margins of the transcript were annotated with immediate thoughts and emotions elicited during this step. This process of 'bracketing' helped to reduce concerns (for a novice IPA researcher) over forgetting things that were potentially important (or not) and may be valuable during the later stages of analysis.

2. Initial coding

This consisted of three processes to produce a detailed set of notes and thoughts on the data. Firstly, describing the content of what was being said by the participant using key phrases from the data. This included 'things' that appeared important to the participant whilst attempting to stay true to

their meaning. Secondly, making comments on the linguistic nature of the data, noting the language used to describe the experience, such as metaphors, analogies, repetition of words, and non-verbal vocalisations. Thirdly, the process of thinking about what had been described and how it had been described started the process of a deeper interrogation of the data at a conceptual level.

3. Developing themes

The third stage was concerned with developing the emergent themes. Discrete chunks of data that had been initially coded were re-read, along with the three levels of coding in order to produce a short summary statement that encapsulated the core interpretative process (See Appendix 5 for an extract of a transcript).

4. Connections across emergent themes

The fourth step involved looking for connection across the emergent themes within case. A process of abstraction brought together a cluster of similar themes in order to create one super-ordinate theme. An electronic table was then created with the emergent themes with key words and phrases, to be able to re-trace the source of theme.

5. Moving to the next participant

This involved repeating the previous four steps for each participant. The use of bracketing again was an important element at this stage of the analytical process. This enabled the suspension of thoughts and connections between the participants whilst analysing each account separately. This is in keeping with idiographic principles of IPA but by capturing and recording thoughts this provided an opportunity for later reflections.

6. Looking for patterns across cases

The final step involved looking for patterns across cases. The super-ordinate themes from each individual account were exported into a Microsoft Excel spread sheet. This was printed out on an A3 sheet of paper in order to gain a sense of the corpus of data. The data was interrogated by asking questions such as: What are the commonalties and differences across participants? Do any super-ordinate themes help to explain other themes? Are there any striking themes?

This data set was reviewed throughout this process by members of my supervisory team (PG, RL, JoH and AG). The purpose was to ensure rigour and validity of the process, and to check emergent themes

development, and that the themes and super-ordinate themes had been grouped in a manner that reflected participants' accounts.

4.6 Results

The results section focusses on two superordinate themes and subthemes that were derived from the analytical process; the challenged self and the reflective self and are summarised in Table 4.4.

Table 4.4 Summary table of key themes

Superordinate themes	Sub-ordinate themes
The challenged self	Emotional consequences Coping mechanisms Dilemmas
The reflective self	Alternative narratives Cathartic role of observation Seeing changes in others Valuing the experience of observation

All the participants described the ways in which they were personally challenged when conducting observations on the ward. These challenges elicited strong emotional reactions at times, and demonstrated similarities and differences across and between the groups. The way participants responded to these challenges was interpreted through conscious and subconscious behaviours described within the accounts. Making sense of the observations was seen in the way that the participants reflected upon the activity. The idea of an alternative narrative was a reaction from direct observations challenging long held perceptions about interactions between staff and patients. Seeing changes in others in terms of behaviour and the cathartic role that a more participatory observation method elicited were also identified by participants. These reflections all served in appreciating the value of the experience from a personal and professional viewpoint. Both of the superordinate themes are now presented in turn with supporting extracts from interview transcripts.

4.6.1 The challenged self

The first superordinate theme was concerned with the effect of the experience on participant's sense of self. There are four subthemes that describe the way in which participants perceived the challenges they faced and how they reacted whilst conducting observations in a clinical setting. This includes the emotional consequences of conducting observations, coping mechanisms and dilemmas.

4.6.1.1 Emotional consequences

All participants experienced degrees of anxiety when conducting the observation activity. However, the cause and level of anxiety differed within and between the stakeholder groups. For Sara, a patient volunteer, her initial worry was owing to how she would be received on the ward by staff and patients:

'I have expectations but . . . anxiety really for whether the staff were going to welcome us because when we, when anybody goes in with a notepad um, I was expecting some hostility. Er, patients, well I was thinking are they going to play ball; are they going to [be] ill or they don't want to talk to, to me. So that hostility and that anxiety was at my forefront of my mind.' (Sara, patient volunteer).

Sara uses the word 'hostility' that implies she was expecting a combative environment. The significance of the phrase 'when anybody goes in with a notepad' appears to symbolise for Sara that observation was seen as a threatening activity by staff. The notepad signifies a level of officialdom and judgement. In the following extract Sara describes the physical and emotional effects she experienced as a result of being challenged by a senior member of nursing staff, whilst observing:

'I was a bit shaky because I was thinking what does she want to look at?! [laughs] 'Can I look at what you're writing down?' and I says, 'Were you not aware of what's happening and why, like why we're noting things down?' and she said, 'Yes, I am but I'd like to see what you're writing.' So it did make me quite nervous because what I was writing down personal to the um, research um, but I didn't sh-I just said, 'Look, you've got the information so there's no point reading my notes.' (Sara, patient volunteer)

Sara described herself shaking which infers she experienced a high level of anxiety over this interaction, and when recalling this encounter her laugh

expressed surprise about being approached in this way. The sense of Sara's legitimacy being challenged is clear but she felt confident enough to hold her ground. This was captured in her account when she states '*Were you not aware of what's happening and why, like why we're noting things down?*' This interaction appears to place Sara in a more guarded position with a sense of secrecy; she did not feel comfortable sharing her notes at this point with ward staff, and downplays the importance of what she has recorded; 'there's no point reading my notes'. However, her sense of feeling empowered because of the preparation for the observation activity helped to readdress this imbalance and direct challenge from a staff member:

'...because of the good instructions...and the leaflets, and made the ward aware of what was going on it made it a lot easier.' (Sara, patient volunteer)

The notion of hierarchy and power demonstrated in this example is further highlighted in a contrasting encounter that Sara described after being directly challenged by a patient:

'So there was that ... chap who did read everything but played dumb. So, 'Right, what are you here for?' and then when we said we left a leaflet, 'Yes, I read that leaflet already.' So, you know it was good to see that he was testing us...' (Sara, patient volunteer).

This response dramatically differed from her encounter with the member of staff. We know this because Sara's description welcomes the patient 'testing' her, despite her earlier anxiety that patients would not 'play ball'. The use of the word 'dumb' when describing the patient also infers a sense that Sara perceives herself to be in a position of knowledge and authority: he played 'dumb' and she went along with his game. These two encounters illustrate the differences in the interactions between senior members of clinical staff and patients, with the former causing more anxiety but owing to her self-confidence and feelings of legitimacy she was able to handle both encounters.

Ed, a designer, also experienced healthcare staff challenging his position on the ward. However, he appeared to find this less anxiety provoking than Sara:

'...one nurse actually er, looked, and peered quite sternly at the notes; and I was, and she was like, like looked at me, and I was like,

'oh, it's [name / project details] or something like that. I don't know whether she knew you or the project but she was like, 'Oh, okay,' (Ed, designer)

His description neatly illustrates the tone of the dialogue between himself and the member of staff. It appears far more matter of fact; an exchange of information. This may be owing to his feelings of legitimacy that he established at the start of the observation session. For Ed, it was important to introduce himself and be acknowledged by the staff he was observing. He described using social cues as way of alleviating anxiety:

'...once you're in there and you've shook everybody's hand, 'That's fine, okay.' And you're there and you kind of get started. And then you kind of lose yourself in it, which is great. So, I suppose the anxiety kind of melts away when you kind of just start doing the work.' (Ed, designer)

It is interesting to note that these incidents also tell us something about the suspicion that participant observation engendered for staff and patients, to the point that they directly challenged the observers.

Jean and Sam expressed different anxieties about their role in observations. They shared a concern about being perceived as being burdensome to the ward staff. Sam typifies these feelings when he described his worry about *'about being in the way'* and recognised the *'acute...context of the ward'*. For Jean, she felt confident being on the ward as long as she *'didn't get, get under anybody's feet'*. Sam appeared to be very sensitive to the clinical environment he was observing; he understood the potential pressures of the ward, he knew that patients may be *'very, very'* unwell, implying his very real concern of *'being in the way'* in an almost apologetic fashion.

Sam also expressed anxiety was over the type of observation being conducted, which for the purposes of this particular EBCD project was supposed to be a non-participatory approach. This challenged his normal inquisitive nature and his own professional working practices, and he was unsure whether he would be able to keep quiet:

'...Um, and the second slightly anxious concern before I started was: would I be able to bite my tongue? And not engage with people. If I saw something that I was curious about my inclination is to ask someone, talk to someone, why, how, when.' (Sam, designer)

The phrase 'bit my tongue' infers that it was going to be a real challenge for Sam, and that by not asking about things that he was observing this would make it more difficult to understand the decision for that interaction.

However, Sam expressed his pleasure at being able to refrain from asking:

'I was able to restrain [myself] when I stepped in to the kind of observer role, which I was quite chuffed about' cause huh! ...It's not really my nature!' (Sam, designer)

However, a divergent finding within Sam's account describes a moment during his observation where he was unable to resist interacting with a particular patient and the conversation with the patient proved to have a significant positive emotional impact:

'There was ...a patient on the ward but she'd been a, a housekeeper on one of the other wards. And I went and spoke to her and she was fantastic. Um, I think she'd worked on that ward previously and all the nurses just loved her....And they used to call her. . . there's something about her singing all the time. She used to just sing all the time um, when she was working... it was lovely speaking to her. Um, it almost feels like you need people like that on every ward. ...The effect on the staff was just amazing um, and I can only imagine what effect she would have had on patients on the ward when she was working. Um, but, you know it was uplifting. It was, it was really kind of um, and let's be honest, sat on a bed on a ward can be bleeding dull day-after-day-after day. Um, even if you're not there for two, I've, I've been there. It's, you know two days on a ward is very, very, very dull. And that doesn't help with your recovery, at all, no matter what, what's the problem with you.' (Sam, designer)

This extract illustrates that through a more participatory observation style, Sam captured a more intimate understanding of interactions between patients and staff. Although the patient was already known to staff in a different capacity, the feel good factor that emanated from this individual was enough to draw Sam back to talk to her. He was able to observe the interactions between nursing staff and the patient and saw at first hand the care and compassion staff gave to this individual. The repetition of the word 'very' serves to emphasise the extremely boring nature of being a patient in hospital. However, the singing patient for Sam changed the atmosphere on the ward, especially for the staff. This conversation for Sam proved to be 'uplifting' and contrasts with the more sober aspects of

care delivery he witnessed. There is a sense here that Sam was able to tap further into understanding the experience of care.

Conducting non-participatory observations was also anxiety provoking for the staff participants. Francesca, when asked by former colleagues: '... I didn't see you for ages, where you been?' felt she had to explain in hushed tones her position:

'...Shush, I'm doing this!' because no-nobody knew I'm doing this and when they knew that I'm, I'm observing, they, 'OMG! What are you doing! What . . .!' you know, like friendly' (Francesca, staff).

It is interesting to note the conflict that Francesca experienced in terms of not wanting to deviate from the planned intention of observation, but owing to her relationship with ward staff found that she had to explain what she was doing. Conflict therefore, arose in terms of remaining faithful to the process of observation whilst still needing to discreetly talk to colleagues in order to feel comfortable with the role. In fact, for Francesca her anxiety over conducting observation went much deeper: the prospect of observing former colleagues was almost impossible to bear:

'...my colleagues and observing them...I know how, hard work they are and how they work and how busy they are. And if I'm finding, no, they did, they did that wrong, they did that wrong; they shouldn't do that. I, I, you know... I don't want to tell that because I have gone through all these things from there. And er, so I know what they feel and what they do, their work and everything I know. So if I'm, no, I'm just feeling, no, I don't want to find anything er, you know. ...They're really, really nice. Really good, you know staffs upstairs, so I can't judge. I can't say anything for, just for that observation because I know them all.' (Francesca, staff)

There is a sense of betrayal for Francesca; that through the act of observation she may compromise former colleagues. The repetitive use of 'I' clearly implies the responsibility that she feels falls upon her shoulders. Her response also suggests the strong ties that Francesca still had to the ward and her strong sense of empathy towards the nursing staff and describes clearly the effect on her ability and desire to observe. The phrase Francesca uses 'I don't want to find anything' implies that she may have limited herself, in terms of what she willing to see, acknowledge or record. Francesca interestingly also framed her anxieties in the context of watching staff and not in relation to observing patients. For Martha, her

anxieties were related to feelings of guilt about conducting observations and discomfort of watched by others. Her perception was that colleagues would be questioning why she was not helping with their busy workloads:

'It's just that I know that they are busy and I am standing here and doing observation, and I could be joining in and mucking in rather than just standing here and putting ticks on a paper...It's pretty much that: well, you're not doing anything. Why don't you join in? (Martha, staff member)

This extract infers a sense that what she was doing may have not been perceived as valuable by her colleagues, or in fact the value she placed on the activity, as she describes herself as 'just standing here and putting ticks on a paper'. Martha also described her relief of not having to be under the gaze of patients for the first observation session, and the relief at not being recognised by staff she was observing on the ward;

'...the first time around I was on a corridor so I didn't have that patient staring in the eyes like everybody else did Um, so, so I was, I was lucky in that point... So I didn't get that being uncomfortable stare like, 'What are you doing?' type thing.' (Martha, staff)

'...most of the people that I saw was doctors and people who came from other units to visit on the ward. So there was lots of strange faces for me. So it was, it was fine.' (Martha, staff)

Observing patients in a non-participatory style clearly made Martha uncomfortable, and she preferred watching staff that she was not familiar with. The phrase 'staring in the eyes' evokes a real sense of scrutiny that Martha felt she was under. Both these extracts demonstrate the awkwardness that she felt whilst observing on the ward.

The way in which the participants managed the challenges they faced on the ward are presented in the following theme, coping mechanisms.

4.6.1.2 Coping mechanisms

This sub-theme describes the various ways participants managed the challenged self, and links with the previous sub theme, in terms of making sense of how they reacted. Participants differed in terms of how they managed the perceived challenges and threats that observation posed from self-protective strategies to perceptions about self-confidence and self-efficacy.

The staff participants, Francesca and Martha, both exhibited self-protective behaviours to counter the unwanted feelings elicited by the process of observing. For Martha, describing herself as an 'outsider' to the ward and staff helped her to place herself in a more comfortable position with regard to observing and the unfamiliarity of staff was welcomed:

'...the first time around... all the doctors were, everybody, all the nurses were busy ... I was able to kind of just sit in this my little bubble and, and just observe.' (Martha, staff)

The analogy Martha employs of being in a 'bubble' gives the very real sense of being closed off to the rest of the world, in a protective atmosphere, so that she was untouchable. The sense of the word 'little' also implies that she wanted to be small and unobtrusive as possible. This self-protective mechanism may have helped reduce the threat of observation that she felt and the scrutiny she perceived from patients, as described in the previous theme (So I didn't get that being uncomfortable stare like, 'What are you doing?'). This notion of being covert was also extended into how she managed unwanted interactions with patients:

'...you have to, you have to kind of . . . play it a little bit with the patients 'cause they don't like to be [ignored] and then think, 'Well, just make it a little bit funny in a way and um, and make it like I'm on a secret mission, just don't talk to me.' Then they will be probably more likely to kind of accept you and, and don't feel that you're as a, as a threat. The other way they might do like, like totally pinned in and 'No, I'm not telling a word. I'm not saying a word 'cause they're an extra pair of eyes in there.' (Martha, staff).

The imagery used here evokes a sense of espionage, that observation is an intelligence gathering activity but without the 'other side' knowing what you are recording. Using humour as a device to diffuse this awkward situation that Martha experienced helped her to present herself in a less threatening light to patients. The notion of playing a game with patients also links with a similar idea Sara expressed in the previous theme: patients' playing ball' and cooperating in the activity.

For Francesca, the way she managed the challenge of observation was to mentally withdraw from the process. The difficulty she faced was almost insurmountable, as discussed earlier in relation to observing colleagues. She described being too close to the process of care delivery on the ward

and identified too strongly with the staff concerns, to feel that she was able to comment reliably on what she had seen.

'But in here [the ward], I knew everything, from morning; half seven what they're doing, half eight... Because I used to work in there ... So, I can't observe because I, I know because I'm thinking like, okay, I'm observing something then I'm thinking, yeah, I know why they're doing [that].' (Francesca, staff)

The concept of self-protection is also extended to wanting to protect staff from any negative findings from her observations; *'I don't want to do that to ... my colleagues'*, as previously mentioned. However, when Francesca was asked if the context had been different, and that she was not part of the service, observation was seen to be a more acceptable task.

'If I'm going to some other ward and absolutely, if, if I don't know anybody.' (Francesca, staff)

Distancing behaviour was also seen in terms of some participants seeking anonymity in order to quietly observe the day-to-day business on the ward. As discussed above, Martha and Francesca suggested that they were happier observing people they were unfamiliar with or being in unfamiliar environments. However, seeking anonymity to manage the challenge of observation for Jean, Ed and Sam, tipped into voyeurism with participants envisaging themselves as 'peeping' into the lives of other people:

'I would have liked to have been a fly on the wall to see, to see what happened next... just out of curiosity really and of my own seeing things through.' (Jean, patient volunteer)

The use of the idiom of the 'fly on the wall' describes Jean's inquisitive nature, but equally reveals something of the nature of non-participant observing. There is a sense for Jean that observing a snapshot of ward life meant she was unable to see how issues had been resolved and that she personally would have liked to have known the outcomes. The idea of being a voyeur was shared with the designers:

'...Um, and the consultant, once I'd introduced myself and so on, he pretty much ignored me um, which was great cause in a sense it made it easier for me to kind of fade into the background and just stand beside the curtain and watch from um, [chuckles] from behind a curtain!' (Sam, designer)

'Yeah. I think [sighs] whenever I do observations I'm obviously very conscious of the fact that I, I know, I kind of get to peek behind the curtain a little bit.' (Ed, designer).

The above extracts both instil the idea of wanting to be invisible, which it made it 'easier' when observing and the sense that staff forgot about their function. Both accounts suggest the voyeuristic nature that the observation activity elicited. The brief chuckle from Sam and the phrase 'peek behind the curtain a little bit' used by Ed, both suggest the odd position they found themselves in, being part of more intimate aspects of care.

The task of non-participant observation also proved to be a challenge for the designers, as this went against their intrinsic inquisitive natures and their professional practices. Sam commented that he would happily continue asking questions until someone 'told me to shut up or throw a book at me.' However, in order to gain a sense of control over the situation they both chose to disregard the pre-prepared observation sheets in favour of their preferred methods of recording observations:

'...my notebook is thick enough and I feel comfortable with and familiar with and used to recording those sorts of things; um, [pauses] I, I did try to use a sort of text-based recording and note-form rather than any kind of sketches or anything um [pauses] so that if the notes were copied they'd be more meaningful to someone else.' (Sam)

'I think it's mostly part of my practice. So I would think very visually about the space that I'm in; and what people are doing in that space.... I think as a researcher or a designer, the tools...that's part of your identity on the ward. So I'd feel very uncomfortable going on the ward without any props' (Ed)

For Sam and Ed, the comfort of employing their own professional practice and accepted ways of working meant that they felt more equipped with the task on hand. Sam's use of the words 'my notebook' and 'comfortable' and 'familiar' all evoke a strong sense of ownership and that the notebook was seen as more than just a medium to record observations. Ed refers to his note book being a 'prop' which all suggest that the notebook is a tool of the trade. Where Sam moderated his usual methods, Ed continued to use a pictorial method to record his observations. This appeared to be an important part of their professional identity and also demonstrated their inherent ability to challenge and adapt what was considered the accepted

way of working. There is almost a sense of deviancy exhibited by the designers but grounded in a more sophisticated and professional understanding of accessing the experience of care.

A final key feature of coping with the challenges was in terms of how the patient participants perceived their level of self-confidence and self-efficacy. For Sara, she felt a great sense of being empowered to conduct the observations, owing to the preparation that she had received prior to the activity but also in relation to her existing knowledge and experience. She had spent time on the ward as part of the hospital volunteer service and also had extensive knowledge of resources in the community, related to her other activities related to healthcare organisations. Jean, as mentioned before, drew upon her knowledge and experience from her educational background, and felt supremely confident that she could act as a conduit between patients and staff, to facilitate conversations in order to bring life to the patient voice.

Throughout the findings reported, the anxieties and self-motivation demonstrated by Sara, and the self-confidence shown by Jean were determined by the feelings of being empowered to do the activity. They both expressed that they had been adequately prepared and supported to do the task, and also drew upon their own experiential knowledge and previous professional lives to manage challenges that they faced. There was also a sense of clearly wanting to empower the patient, whether that was listening to patients moving accounts of care and sharing that with staff (success stories) or enabling patients to ask vital questions about their care. Observation went beyond just watching and recording:

'.. I was ready to go on because I was empowered with all the information: how, what we'd taken; which line we go down; how we're gonna do it' (Sara, patient volunteer)

Jean's explanation for her self-confidence was wrapped up with her former professional life as teacher, together with her current experience working on the ward on a separate patient safety project:

'I was quite comfortable with it really because of the PRASE work so, you know I'd already been onto wards talking to patients. So, and, and talking to people has been what I've done in my job so I, I wasn't concerned about that. So I, I was quite comfortable.' (Jean, patient volunteer)

4.6.1.3 Dilemmas

A challenge that participants also faced was in relation to whether or not to intervene in patient care whilst observing. It is interesting to note that both patient participants 'involuntarily' spoke to patients as part of the observation process, whereas, staff members and designers adhered to the agreed plan for observation.

Sara describes the more active approach to observation that she adopted, which was driven by her concern to assist a patient who had openly expressed worries about going home:

'...one of them was terrified, even to the extent of, 'I've got so many tablets to take, and whether somebody outside in the pharmacy, or the doctor can help me?' ...And if he didn't get those answers, he'd be really, really anxious. I think it would be quite scary to go home...I did give him the confidence to say look, make a list of what you're anxious about um, and get that list and speak to whoever's discharging you, and have it ticked off.' (Sara, patient volunteer)

Sara's reason to intervene and take control of this situation was possibly influenced by her previous personal traumatic experiences of the service, where she had been left in a vulnerable position in relation to her own mother leaving hospital:

'I've had experience with my family as a carer um, and relatives in ward 22 ...my mother had er, heart problems, and problems where an operation went wrong um, they ruptured a vein when they were doing the angio-plasma...it brought back a lot of memories er, but er, um, what kept me going was that your project title of discharge and how, how patients um, feel the discharge is, was, was quite close to me because obviously when my mother was discharged from that ward we had no idea what to do. We had very little support and it was quite scary.' (Sara, patient volunteer)

Both of Sara's extracts use the word 'scary' to describe the situation about going home unprepared. The similarity and tone of both extract infers that Sara closely identified with the anxiety expressed by the patient she was observing and her own previous experiences as a carer. She described a very real and tangible concern over the welfare and safety of the patient. Sara had no compunction whether to say something or not, and was strongly motivated by the fact that she felt she had to intervene. Yet for

Jean, she perceived her role to be more passive; listening and talking to patients and without a sense of self-efficacy to influence or intervene but clearly interested in the patient outcome:

'...in the absence of being able to do anything, I would have liked to have known that at least someone was going to do something.'
(Jean, patient volunteer).

Ed also recalled a particular incident that caused him to feel uncomfortable in his role of observation. He described watching a patient having difficulty holding a spoon to feed herself, and watched as her calls for assistance went unnoticed. The interesting thing to note was the level of reflection by Ed over this incident. He described how he wrestled with the ethics of not intervening, and the challenge that observation can present, his discomfort exemplified by clearing his throat and a slightly nervous laugh:

'And she [the patient] was asking for help 'cause she was, 'I can't lift my spoon. I can't lift my spoon.' And I didn't know whether to intervene but then again like I'm not . . . trained. That's not my role. So it's one of those things like it's difficult to not . . . do something in that [clears throat], in that environment. Even though you're not supposed to because actually that's a dynamite reflection, so to speak [chuckles] but what I did do, I got one of the nurses attention on the clinical team, on the ward round, who then passed that on to somebody else. And a nurse did come and speak to the lady.' (Ed, Designer)

The secondary challenge for Ed with regard to the above scenario was the surprise at the reaction of the nurse that came to help. She suggested that the patient needed to try and practice feeding herself, but for Ed this led to a critical reflection on what he had observed making him 'question the fact' of what he was thinking. This interaction had challenged his assumptions; that someone needed care and yet, as it turned out this assumption may have been incorrect on Ed's part. This level of critical reflection exhibited was owing to his sense of his professional identity and skills and experience as a researcher.

The notion of dilemmas was also exhibited by Francesca in terms of perceiving the value and usefulness of the observation sessions:

'...one hour is nothing for, you know, like to see or um, you know judging somebody er, or analysing their work or something. Um . . .

um [sighs] so, huh! [Chuckles] we can't say anything...' (Francesca, staff)

This short extract has some issues to note. Firstly, the notion that an hour is too short to capture the complexity of care, coupled with the idea that the variability of the workload makes observing a worthless pursuit. Francesca recounts earlier her previous frustrations as a ward nurse, 'Some days it's crap because you can't do anything and, OMG, I couldn't do anything because it was so busy.' This extract also infers a sense that observing was concerned about making judgements about people, something that Francesca found difficult to carry out as described in the earlier subtheme 'emotional consequences'.

Reflexivity point:

A deeper appreciation of the dilemmas and challenges that participants faced was as a result of my own experiences of conducting observations within Study 2. I had taken on the role of a non-participant observer within co-design meetings. However, at times I was directly addressed by the designers, who needed help to answer questions about the processes of care. By not responding I would have felt churlish and also felt a sense of professional duty to help. Reflecting upon this experience made me realise the ambivalence the participants described in terms of wondering whether to intervene or not. I was also aware that these interactions may affect the outcomes of the co-design work. In absence of a member of clinical staff at some of the later smaller group design work, it made me realise that I was potentially filling the place of the clinical staff. I tried to keep my interactions to the minimum but was it difficult owing to relationships that had developed over time.

4.6.2 The reflective self

There are four sub-themes illustrating the main features of self-reflection within the process of observation within participant's accounts. They explore alternative narratives, the cathartic effect of observation, seeing changes in others, and valuing the experience of observation.

4.6.2.1 Alternative narratives

This subtheme describes how participant's personal narratives about healthcare were rationalised during the observation process. For some of the participants; Jean, Martha and Ed, they expressed their surprise and delight having witnessed moments that they believed were good examples of care. These differed from their preconceptions.

Martha, as a member of staff, despite her anxieties over conducting observations, was able to stand back from her role as a nurse and observe care being delivered. She commented on her surprise on what she observed compared to her own expectations of care delivery, from a professional perspective:

'I just went there with, with a fresh pair of eyes and I didn't . . . kind of think anything... 'cause sometimes it's so easy to get your own ideas to get kind of forming things that you want to see and you start looking the negatives and then you will find them if you want to... I was really positively surprised how well the doctors explained to the patients what's going on and um, and, and the plans; and if there was investigations... so that way I kind of understand why it takes so long to do a ward round...' (Martha, staff member)

Martha describes a new insight in fact, in relation to understanding what goes on during a key aspect of care, the ward round, despite being an experienced nurse that has worked on the ward previously.

For Jean, she conjured up the image of gods and mortals when describing her notion of the more 'traditional' doctor-patient relationship. She referred back to her own previous experiences of hospitals and the de-humanising aspects of the 'old' institutions. However, this personal narrative was challenged. The following extract illustrates the surprise experienced by Jean:

'...because of my own personal experience as, as a patient, as I say, being in hospital for several, several times and the ward round sort of went phwww [chuckles] you know that's bed number 1 dealt with, we'll go to bed number 2! It was a bit, a bit um, in that sort of vein so . . . so . . . I think hospitals have changed a lot um, I think the, the, they're far more human places than, than they used to be...because you remember the time, the consultant was God. The

nurses ran round in fear and the patient wondered what was going on.' (Jean, patient volunteer)

Jean then describes a significant moment she observed;

'The consultant got down to the patient's level. And my experience of consultants is they're always been, they're up here. They look down on you. But he got down on his haunches, looks her in the eye, had a chat just like friends....It was fascinating observing um, the relationships between the different professionals and the patient um [pauses] it . . . I was surprised at how . . . how good the consultant was at interacting with a patient....And it was obvious, obvious that, that the staff on that ward were working as a team with the consultant, with the patient. So it was a very positive experience.' (Jean, patient volunteer)

The imagery Jean created here gives the sense of her idea of hierarchy and sense of power between the patient and doctor. Jean's use of the phrase '...they're up here. They look down on you' extending the analogy of consultants as the Gods above. Jean is struck by this new narrative. She demonstrates her reflective ability and recognises the enormity of this small act; the changing relationship between the patient, doctor and ward team. Ed also describes how he was struck observing a conversation between a patients and healthcare worker on the ward.

'Actually a phlebotomist came to do some bloods, and . . . the clinical team hadn't engaged with the, with some of the patients... and I suppose the overall feeling I got was that it was um, polite but curt. Actually, it was interesting that the phlebotomist by the very nature of what he was doing (taking some blood) had far more time to talk...I was kind of impressed with the sort of the easy nature that he, that he had with, with conversation' (Ed, designer)

These examples describe positive experiences of care that interestingly were seen as unexpected. However, for Sam, the observation activity served to reinforce his personal narrative surrounding healthcare delivery. This appeared to be informed in part by his personal beliefs as suggested in the following extract:

'I've never been a big um, er . . . someone who, who's kind of um, hierarchies aren't, don't mean much to me [chuckles] so I've never been, er, not that I don't respect people at the top but rank and so

on, doesn't, doesn't stop me from speaking my mind or doing what I think is worthwhile doing' (Sam, designer)

The use of the word 'rank' is interesting when Sam talks about the idea of hierarchical social structures. Despite Sam admitting he ignores the traditional notion of status and is uninhibited, he recognises that these structures do exist, as he mentions that he respects 'people at the top'. However, owing to his personal convictions and values, if he feels that the cause is 'worthwhile' in his eyes, then he will be undeterred when wanting to challenge the order of things. Sam identifies more closely with the patient perspective, maybe because Sam sees them as the least empowered group:

'Patients are already in a disempowered, horrible situation because they've got an illness or a disease or whatever it is; and they're in an environment that's not their home. And all of those kind of things mean that the patient is already at a massive disadvantage, and shouldn't be disadvantaged more than necessary. That's patient-centeredness to me.' (Sam, designer)

Sam describes the vulnerability and shift in power for individuals that are admitted to hospital. The sense of being 'disadvantaged' infers that staff have the vantage point but it is up to healthcare professionals to recognise that fact and consider care provision around and with the patient. There is also a strong empathetic note from Sam; he is passionate about protecting patients from any additional negative consequences of being in hospital. This is something he sees as a worthwhile cause to stand up for. Through his observations his idea of social structures on the ward, were reinforced with everyone playing their traditional part:

'...among the doctors that was absolutely, yeah. Yeah, there was a definite hierarchy um [pauses] and . . . I think there was between doctors and nurses there was this . . . um, [pauses] it kind of existing on two levels. There was, to a degree a kind of professional respect but there was a definite hierarchy. All the nurses just simply, not always, but mostly, walked out of the bays and made room for the doctor as soon as they came in.' (Sam, designer)

The extract above suggests that what Sam observed fitted with his own narrative of what happens within the social structure on the ward, with the doctors at the top and the patient at the bottom.

'..a lot of conversation between the doctor, consultant and the group of doctors and students following him, um, talking about the patient rather than to the patient and engaging the patient. The patient, all the interaction pointed to the patient being a passive recipient of whatever was determined by the experts. Um . . . it didn't seem to be as much involvement or engagement.' (Sam, designer)

These extracts from Sam begin to build a picture about the role that a designer and his own personal attributes bring to the 'co-discovery' table. He is aware of the imbalance of power that occurs in care delivery. He witnesses first hand patients appearing to be passive recipients and the hierarchy between staff, through physical gestures (nursing staff leaving the ward space). There is also a sense that this is the natural order of things within this microcosm of a social environment. However, for Sam he perceives his role as a disruptor and challenges this notion of hierarchy:

'I do a lot of work that involves um, consultants and professors. Um, as well as more junior researchers and more junior rank doctors. And the core part of our underpinning philosophy of what I do is participatory workshop is that there is no hierarchy. Everyone brings a certain element of knowledge and all of it is needed and necessary to create an output that's meaningful and relevant and valuable to whatever the context is. So my, the aim of the work I do in those groups is about taking away power levels and hierarchies. And I think that translates a lot to my everyday life in sort of working with people. So even within the context of my own university structure, I will offer my opinion to the head of research and institute and the head of the faculty regardless. It's not um [pauses] I don't know whether that's affected my career progression or not. I don't really care! [laughs]. (Sam, designer)

Sam again suggests that he is there to break down the boundaries that exist with the social structure of the ward and between healthcare professionals and patients. Sam infers that this is as much a part of the professional philosophical and theoretical underpinning of the discipline of design, as it is his own personality. He is very happy to appear to challenge and offer more controversial offerings, even to the extent that he may have harmed his career. His strength of conviction and wanting to provide a chance for everyone to contribute is suggested with his apparent throw away comment and chuckle, 'I don't really care!'. This is a bold

statement but demonstrates Sam's belief in removing social barriers in order to make 'meaningful' changes to care for all. It is also interesting to note that this occurs within the workshop setting, that is a neutral space, where people are stripped of their professional and patient roles. The concept of disrupting traditional hierarchical structures therefore was a primary goal for him personally and professionally, in order to empower the patient within the process of co-design.

4.6.3.2 The cathartic effect of observation

The idea of observation having a cathartic effect differed across the participant's accounts. For Jean, the observational activity provided a mechanism of psychological relief for patients through openly talking about their worries and concerns with her. Although, the observation was intended to be non-participatory, Jean recognised and reacted to an 'obvious' need exhibited by patients she was observing:

'...it was obvious that there were times when patients just need to talk. It's all right asking a quick question of a professional who's passing the bed or doing a round. But, I think often patients have this need to, to, to voice what they're thinking and to tease out their thinking. And to just, and to just talk um, and get across how they're feeling about things; 'cause obviously they're all feeling a different things at different stages but it's, it's important to, to allow patients to talk. Um, I think the use of volunteers facilitates that because obviously, professionals are working and they've got many patients to see to. So it, it's good I think to make use of volunteers to have that one-to-one with, with patients who are sometimes just desperate to talk and ask things and get things of their chest' (Jean, patient volunteer)

The above extract describes an almost palpable feeling that Jean detected from patients who were 'desperate' to talk. Jean recognised that the interactions between patients and staff were often short and cursory owing to the clinical workload. The following extract infers a sense that for Jean it was important for her to talk and listen to patients and saw the value of her role in terms of meeting patient needs:

'I felt welcoming of that opportunity [conducting observations] to be open about their, their fears, their concerns. Um [pauses] so, you know it was quite, I felt it was a positive experience for them to be able to do that er, it was cathartic. I couldn't give them many

answers obviously. But I think sometimes it's cathartic to get things off your chest and just voice things. They don't seem half as bad sometimes if you, if you have the opportunity to share your thoughts with someone.' (Jean, patient volunteer)

These two extracts illustrate the cathartic role that a more participatory observation style elicited. This idea is important when understanding the way in which the observational component in EBCD was perceived by Jean. It is also an interesting thing to note here, that despite Jean's sense of a lack of self efficacy, that is, she could not provide much help, she still felt as if she was able to address an unmet need. Allowing patients to verbalise and share their concerns meant that anxiety was potentially reduced. Jean also describes that she 'welcomed' the opportunity to listen and engage with patients and was able to give a voice to the patient's experience of care, which she could share with staff. The following extract describes how much patients wanted to talk about their experiences:

'I take from the fact that they were quite willing to talk, eager to talk, difficult to . . . to shut them up, if you like sometimes! Was, was proof of the fact that they, they, they found it a positive experience. It's something they needed to do. Something they wanted to do. Otherwise I think they just would not have interacted at all.' (Jean, patient volunteer)

The phrase 'difficult to . . . to shut them up' suggests that once patients were given the opportunity to talk that it almost opened a flood gate, and that without that opportunity, these thoughts would have remained hidden to staff. Jean's interpretation of the observation activity may also be part of her inquisitive personality (as discussed in the earlier theme of coping mechanisms) and desire to act as an enabler for the patient voice:

'I think that the fact of giving patients a, a voice is, is crucial really to, to improving things. Because professionals have one view; they have their view and perceptions and what, what's happening and how the patients feel. But at the end of the day, only the patients know what it's like for them.'

Jean felt that it was vital to capture the patient voice in order to make meaningful improvements. Clearly for Jean there was a feeling that staff appeared so focused on the process of care and without the patient's 'voice' contributing to understanding a more holistic experience, this would be lost. She felt that she had the ability and time to explore the real

concerns and worries that patients were going through and this in turn had additional benefits for patients.

Sara also saw the cathartic effect when engaging with South Asian patients during her observation work:

'A lot of the communities [South Asian] just don't complain. Don't speak up 'cause the care might change if they know what you've said. So when I said your name's not going to be on it. You've got no contact at all. Your name, it will not come back to you. Then they opened up.' (Sara, patient volunteer)

The above extract infers a sense of suspicion from individuals from the South Asian community when it comes to being honest about their care in fear of retribution, and adversely affecting their care. The reassurance that Sara provided with regard to anonymity, coupled with the opportunity to talk appeared to give South Asian patients a safe space to share any issues, as the phrase 'then they opened up' suggests.

For Sara, Sam and Ed, the cathartic effect of the observation activity was also seen at a more personal level. This idea links with the previous theme 'emotional consequences' but, differed in the way they used these reflections to make sense of what they observed.

For Sara, the observation activity provided an opportunity to make sense of her previous experiences with her own mother and family members of the ward (as discussed in the sub-theme of 'dilemmas') and may have been a reason for her participatory style of observation. Sara described one interaction with a patient during her observation session, where he repeatedly expressed his worries to Sara about his imminent discharge home and concerns about not understanding his medication. Sara, unlike Jean, felt she could help:

'...because I had all that experience and because I knew what you can do outside, I was able to share that with him; but I did give him the confidence to say look, make a list of what you're anxious about um, and get that list and speak to whoever's discharging you, and have it ticked off.' (Sara, patient volunteer)

The cathartic effect of being able to share concerns for this patient meant that he was supported with some practical advice. Importantly, Sara owing to her self-confidence and feelings of empowerment felt she was able to intervene in a constructive manner. Sara's thoughts about conducting

observations appeared to relieve some of her own anxieties about the care her Mother received and the importance of observations would make to enhance patient care:

'I felt it was really useful. It was really nice to participate in the observation because I knew the observations from your project would give a really good output of discharge. And hopefully would deal with a lot of problems patients were feeling at discharge.'
(Sara, patient volunteer)

For Ed and Jo, making sense of their observations produced a cathartic response. Below, we see how for Sam, the context of his wife's traumatic childbirth experiences, led him to identify closely with the experiences of the patients on the cardiology ward:

'... it makes me feel as though [pauses] whatever can be done to help these people, in whatever way, again, I'm not thinking irrationally but practically. It, it makes it feel like it's a really worthwhile and worthy thing to be involved with and to be trying to help. Because it is such a . . . it's possibly the worse without dying itself but then that's the patient . . . the recipient of death [chuckles] doesn't care. Um, but to get that close is pretty much the worse experience you can possibly have, ever. Um, and the, the, I can only relate it to kind of the emotional thing. So I've got three children and um, on two incidences my wife had to be rushed into um . . . er . . . theatre. Um, and it's supposed to be a natural kind of process. It's supposed to be posi-emotionally positive. But it was just up and down, up and down. It was a roller coaster and that was the most knacker part, physically, mentally, emotionally draining part of the process. And, that's the closest kind of analogy, personal analogy I've got to the experience of those patients. It's just a shock to every part of their system: their physical system, their emotional, their mental system, everything. It's complete and utter shock. And I think that . . . this is, this is where you need a kind of combination of medical model and kind of caring model that considers that, that trauma to physical, mental and emotional states. And tries to find a way of delivering care that addresses all three. Not just the physical, but addresses all three.' (Sam, Designer)

This extract provides several interesting issues to explore. The metaphor of a 'roller coaster' ride that Sam employs provides a powerful sensory

image of his own experience of a life and death scenario. The excitement, nausea and fright induced by a fairground ride aptly describe his experience of childbirth, which was supposed to 'emotionally positive' but was turned out to be 'physically, mentally, emotionally draining'. Sam uses this analogy as a way of connecting with the patient experience and make sense of what he observed on the ward when reflecting on some patients that 'to all intense and purpose [were] ...dead 24 hours ago'. This strong emotional reaction for Sam provides a cognitive insight into the patient experience but more importantly is used to provide a strong personal rationale to improve care in 'whatever way '. His comment 'I'm not thinking irrationally but practically' almost suggests that his emotional outburst could be seen as too subjective and skew the nature of the improvement work., that is, changes need to be seen as pragmatic solutions.

However, Sam and Ed's accounts demonstrate some divergence with regard to expressing their emotional responses to observations on the ward:

'My experience [conducting observations] was significantly different to Sam, because Sam was talking a lot about how people were being referred to in the third person ...which I think was a function of the fact that um, the ward round team had a, a relatively large cohort of students as well. Um, and I can und-I totally get what Sam was saying in terms of that experience, or what that must have looked like. 'Cause I've been in hospital before personally and had a ward round where there's lots of students and that sort of thing. And, yeah, it can be a bit odd being referred to in the third person or by being referred to by your medical condition – if that makes sense.... I'd suspected meningitis.' (Ed, designer)

The extract refers to a conversation held between the two designers when reflecting on their experiences of observation. It is clear from this extract that firstly, it was acceptable to suggest an alternative interpretation and secondly, that a conversation had taken place about their unique experiences. Ed reflected upon his own experience and in the following extract his stoic recall of a serious health event contrasts sharply with Sam's 'roller coaster' ride:

'I never felt like if I asked a question it wouldn't get answered but actually I didn't really care... the consultant had gone through all of the different bits and pieces like, you know specific to how I was

feeling at that time, you know that sort of thing, and then changed to be talking to the students. And I didn't really care, if I'm honest; because like . . . he, I felt, by that point I was starting to feel a bit better. So I didn't so much mind that actually there was a few questions that the doctor probably wanted to kind of . . . point to all of the students: what do you think of this; what about this; what about this?'

Ed justifies the interaction that he saw, and the issue of patients being referred to in the third person as a 'function' of a ward round. This infers that Ed perceives the ward round as a tool for clinicians, a teaching opportunity for medical students and where the patient is tertiary to proceedings. This may have also been owing to his reflections on his own experience of hospital care, not bothered that he was seen his condition was seen as a teaching aid.

For Martha and Francesca the notion of catharsis differed. As described in the earlier theme describing the emotional consequences of carrying out observations was so tied up with feelings of guilt for not helping colleagues and feelings of betrayal if they reported anything considered undesirable examples of care, they were unable to move into a more insightful aspect of what observation could bring to understanding the delivery and receipt of care.

4.6.3.3 Seeing changes in others

This sub-theme refers to perceiving a change in staff behaviour during the observation activity. Sara describes the deliberate actions of staff that appeared to be for her benefit:

Sara: 'It's interesting because when you're observing everybody changes, and that's a true fact from, from the consultant to registrars, to nurses, to everybody. They're on their best behaviour and you can see it clearly.'

LT: 'So why do you think they're on their best behaviour and how do you think things change?'

Sara: 'Because when I was sat there and I didn't have the board in my hand um, just like any other ordinary person there, you could see them running around doing their things, doing whatever, er, a normal day. But when I was sat there with the board and writing notes, then you could see them come in, checking the bins, checking the floor

er, doing the dignity and respect: pulling the curtains round; when the doctor, when shadowing the doctor or the consultant, how they spoke to people – how um, differently they spoke to people, and some of them, the last observation was um, the consultant was testing the registrar and the junior doctor, saying, 'Well I'm not going to advise. I'd like to see you two advise.' So that put them under pressure as well. But you could see the different patterns and the different behaviour'

This extract has several things of note. The significance of the clipboard seemed to signal something to staff. As discussed previously the social significance of the clipboard appeared to provide a cue that the observation may have been seen as official business. Before, Sara had been quietly observing and making mental notes but with the addition of a clipboard this was seen to produce a huge change in staff's behaviour and actions. These changes were perceived by Sara as examples of exemplary care, with the inference that extra attention was taken to ensure privacy and dignity was maintained, 'pulling the curtains round' and the way clinicians interacted with patients, 'how...differently they spoke to people'. Knowingly being observed appeared to have a direct effect on the way care was delivered.

Martha also commented on her perception of behaviour changing:

'I thought it would be a bit more awkward but everybody knew that why I was there. And I felt that there as a sign, bit of change of the behaviour when I kind of walked in the room and, and got myself comfy in the corner, um, I was clocked in straightaway with, with my board and I kind of felt that maybe there was a bit of a change....just the little things...The doctors were really good. They explained, the consultant, he explained to the patient really carefully what was going on; um, and the patient knew what was, what was happening and then spoke with the patient for a long time in the end and actually listened what the patient was saying um, I've been in the environments before where they just, the doctor, totally ignores the patient. They try to say something but just like not being heard; but this, it was just all, all was heard. The patient's opinion was taken into account and explained why we were doing something. So it was very much . . . patient-centred, positive thing.'

As with Sara, the symbolism of the clipboard appeared to signal something to staff in the way that Martha describes as being 'clocked'. Although Martha was unable to demonstrate obvious changes in the way staff were behaving she detected more nuanced changes. For example, the length of the interaction and the quality of the interaction between the doctor and the patient was perceived inconsistent with the care she routinely witnessed.

4.6.3.4 Valuing the experience

Martha, Francesca, Sam and Ed all shared the notion that this was an opportunity to professionally grow and develop. For Francesca and Martha, neither had been involved in an EBCD project before or conducted observations for the purposes of service improvement work previously. Martha commented that it had been revealing to actually stand back and observe care being delivered and had gained further insight into day to day activities on the ward, for instance, what actually happened on a ward round:

'I've just not been able to see that before. I've not been in, in a position to stand around that long to, to actually listen.'

This sentiment was echoed by Francesca:

'...so we never get an opportunity to do anything because coming in, doing handover, doing other job, going home.'

Both the extracts above suggest that there is a lack of time to reflect upon the care that is being delivered, with a sense of the relentless grind of work and the feeling that the value or work from the nursing perspective is not recognised by others:

'...in ward there's no reward..... Nothing, nothing, nobody's recognise anything because, oh yeah, because you should do [deliver care] that's your patient.'

For Ed and Sam, they relished the opportunity to observe in the clinical environment, which added to their existing experience and professional knowledge. Neither had been previously exposed to such an acute setting and both hugely valued the experience and ability to gain access to such a privileged environment.

Jean and Sara also shared this insight and were humbled by the experience. This was in terms of the way that patients were willing to open up about intimate aspects of their care and recognising the privileged

position they had been afforded. For Jean, there was a very keen belief that patient involvement and the observation activity were central to understanding and improving the experience of care. This played a central theme within her narrative, where she felt she was able to act as an 'enabler' to ensure that the patient voice was captured:

'I felt I could be a facilitator really and an enabler. Enabling patients to voice their feelings, positive and, and negative.' (Jean, patient volunteer)

All participants said that they would conduct observations again, with the staff members feeling that it would be easier within an unfamiliar setting. Sam sums up the importance and value of observation within the context of improvement work in the extract below:

'I think it, absolutely, for me; it's absolutely superior to looking at numbers. Um, I think, especially on a ward context, numbers are so variable, with sort of seasonal influences and all that kind of rubbish. Um, that it's very difficult to . . . put too much emphasis on what the numbers actually are saying to you...so direct observation and I think combined with, as this is done, talking to patients in different ways. And perhaps not just talking in a sort of verbal way but perhaps finding other ways of "talking" to patients and getting their insights. But for me, the direct access to the kind of physical context um, and experience it in that multi-sensory way. So you're listening and smelling and seeing and everything else um, I think you absorb more. And this is, I guess, the challenge then becomes how . . . one can access.'

This final extract from Sam describes how observation in the clinical setting taps into a different level of understanding of patient experience, when compared to using more quantitative data. As a designer he is interested in the 'multi-sensory' experience. Clearly for Sam this idea is critical to make sense the way in which patients construct their experience and how this informs the changes that need to be made to improve the experience. His throw away comment 'all that kind of rubbish' highlights his philosophical and professional position in terms of the use of 'numbers' in improvement efforts. He is far more concerned with the value that capturing the sights, sounds and smells adds to understanding and improving the patient experience.

In summary, this theme has explored how participants reflected upon the observation component within the co-discovery phase. There are links with the previous super-ordinate theme but with an opportunity to express strong emotions a more participatory style of observation appeared to have a cathartic effect. Within this study the combination of different stakeholder reflections enabled a deeper understanding of patient care, in terms of those receiving care and of those delivering care.

4.7 Discussion

This study has explored the experiences of patient volunteers, staff members and researchers undertaking participant observations within an EBCD project, based within an acute cardiology ward. The analysis described the key features participants experienced conducting observations, and how they managed these challenges. The experiences within and between the different stakeholder groups have displayed similarities and differences with regard to these features.

The objectives of this study were to a) identify and describe the key features of conducting participant observations as experienced by the participants and b) to identify and describe the mechanisms of change within the observation component of the EBCD approach. The following discussion focusses on these objectives whilst comparing the different experiences across participants' accounts. It is noted that the discussion draws upon wider theoretical knowledge regarding observational methods owing to the lack of published empirical studies investigating observation within EBCD.

The EBCD approach relies upon observational methods in order to gain an insight into the 'everyday' business (Bate & Robert, 2007a), which in this case, related to life on a busy cardiology ward, within an acute NHS Foundation Trust setting. It is hypothesised that by conducting observations it will lead to usable findings that inform subsequent stages of the EBCD process. This includes, capturing aspects of care or 'touch points' that may not be revealed through staff interviews or other types of contextual enquiry (See Section 1.5.4), gaining early insights into the patient experience, shaping the development of interview schedules for patients and building trust and rapport with staff (Bate & Robert, 2007a). It has been argued that observation should be retained as an essential component of the EBCD process (Donetto et al., 2014).

The findings from this study revealed the challenges experienced by participants whilst conducting observations. The emotional conflict experienced by the participants during the observations ranged from feelings with more negative connotations, for example, awkwardness, betrayal, guilt, dealing with hostility to more positive experiences described with surprise and pleasure.

The feelings of discomfort and voyeurism experienced by the participants are consistent with anthropological literature, when considering the activity of observation. The observer strives to strike a balance between intimacy and distancing themselves from the people that they are trying to observe (Hume and Mulcock, 2004a, 2004b). This appeared to be a challenge for the patient volunteers who both adopted a more participatory level of observation. This may have been owing to their personalities (being naturally inquisitive), wanting to help patients (preventing a repetition of past events personally) and recognising an unmet need (patients wanted to talk). The voyeuristic reaction described by the designers and a patient volunteer may help to explain the social awkwardness they experienced observing in a highly sensitive setting. The environment may be more familiar to staff but their perspective and their function have changed for the purposes of observation (they are now the other side of the proverbial curtain). It is interesting to note that the staff members also found observing equally uncomfortable, albeit for different reasons. Donetto et al. (2015) also comment upon the challenges for staff who navigate between the role of 'expert' and being a partner in a collaborative setting. This implies that EBCD could be seen as a complex social intervention and may not be easily applied without considering stakeholders positions within the process.

This phenomenon may also, in some way, explain the internal sources of conflict experienced by staff participants. The act of observation could be construed as being 'socially disruptive' as staff participants attempted to place themselves simultaneously in the role of the 'outsider' and 'insider' (Hume and Mulcock, 2004b). This proved to be personally challenging for staff participants and was demonstrated in terms of how they coped with the challenges they faced. This resulted in feeling compromised in terms of being unable to reliably report observations because of the concern over the potential negative impact on their relationships with colleagues and the potential damage to the moral of hard working colleagues. There was also doubt cast over the usefulness of the data that capturing just a 'snap shot'

of ward activity over a few hours. Subtle changes in staff behaviour were also detected by staff participants who imply care was being delivered in an optimal fashion rather than usual practice. This finding may be related to the Hawthorne effect whereby people behave in a different manner when they are knowingly observed (Hagel et al., 2015). Numerous hand hygiene compliance studies have attributed overt observation and better rates of hand washing within the clinical setting to the Hawthorne effect (Eckmanns et al., 2006; Kohli et al, 2009; Hagel et al., 2015). However, when simply attributing unintended confounding factors as 'Hawthorne effects' it is difficult to know a) what the reasons are for the apparent changes to behaviour and b) if the effects should be considered in an investigation (Adair et al. 1989; Holden, 2001). Various reasons have been used to explain the effects seen in the original Hawthorne studies in the 1930's that included interpersonal relationships, as well as, 'interpersonal relations, social unity, morale and attitude' (Holden, 2001: p65). Unpicking the complexity behind the effects of observations and producing usable findings may benefit from considering different perspectives. One school of thought with regard to ethnographic observations claims only those who are 'closely immersed' in the study field can 'ensure an authentic account' (Allen, 2004: p15). This could suggest that staff could be well placed in terms of being immersed in the field of study. However, the findings from this study demonstrated differences across the three participant groups in terms of what they saw, commented upon or thought were key touch points within the delivery and receipt of care. It would appear that by triangulating data a more complex picture is created in terms of understanding what happens in the clinical setting and what matters to staff and patients. The purpose of triangulation is not to provide a single true reality but relates to the idea of validity within qualitative paradigm and improving understanding of a phenomenon (Green & Thorogood, 2009).

The EBCD toolkit suggests that observations are conducted by clinical and/or non-clinical members of staff (Point of Care Foundation, 2018). Yet, the evidence from the systematic review in chapter 2 revealed that this is often conducted by experienced qualitative researchers. The findings from this study suggest that for some clinical staff conducting observations in a familiar setting may be too challenging, and thus act as a barrier to gathering data on patient experience. The notion of trying to 'imagine' being a patient, or 'seeing the service through fresh eyes as a visitor to that area' (Point of Care Foundation, 2018) was lost for staff when dealing with

the emotional fallout of observing colleagues or finding it uncomfortable to watch and be watched by others. When compared to the patient volunteers and designers' experiences, it would appear that a more patient-centric approach was taken when observing. Although challenged in different ways, the patient volunteers felt enabled and empowered to reflect the patient experience as they observed in the clinical setting. This may have been owing to their self-confidence and feelings of legitimacy within the process facilitated by adequate preparation and support beforehand. It is therefore, suggested that EBCD as a QI method may have helped to reduce the traditional constraints associated with patient and public participation in healthcare improvement efforts (Martin, 2008). The controls that healthcare professionals and managers may exert over patient and public involvement has been seen to reduce the legitimacy of people involved (Beresford, 1994) and dominate the agenda (Williams, 2004). The role of legitimacy appears to play a key factor that served as a facilitator or a barrier, depending on the stakeholder group. The act of observation by non-staff participants appeared to be viewed more suspiciously by staff and patients. The issue of legitimacy may be explained by drawing upon the theory of social power and influence (Munduate and Gravenhorst, 2003). The idea of 'formal legitimacy' suggests that those being observed may have recognised and accepted the status of the observer (the member of healthcare staff). For the patient volunteer observer the concept of 'negative expert power' may help to explain their account of being challenged; that despite recognising the expertise of healthcare staff, there was an air of distrust (Raven, 1993).

The value of PPI is recognised as an important element of enhancing services to meet patient needs (Coulter, 2006; Brett et al., 2014; Ocloo & Matthews, 2016). However, a more participatory approach to observation provides a way for people 'outside' the organisation to contribute. The idea of a professional hierarchy identified by the design engineers was seen as potential barrier to involvement. It is suggested that doctors are at the tip of the professional hierarchy with their power associated with the 'social legitimacy of their mission' combined with their expert knowledge (Currie 2012: p940). Nurses are seen as 'subordinate' to doctors and are concerned with a more holistic and less specialised approach to delivering patient care (Abbott, 1988; Freidson, 1988). Managers are often viewed playing a more diplomatic role to ensure the system operates smoothly (Giaino, 2009; Currie 2012). This suggests that the patient in absence of

expert knowledge and social legitimacy is in a vastly disempowered state when it comes to the clinical setting. Thus, the idea of bringing patients and staff together who currently co-exist within one social world must be considered. The designers recognised this dynamic, in terms of their personal and professional world views, which were reinforced by what they observed. Working in a truly collaborative partnership is fraught with challenges (Martin and Finn 2011). As discussed earlier, the legitimacy of lay knowledge or questioning how representative one person's experiences are in terms of the general populations commonly cited as reasons why healthcare professionals may be sceptical of patient and public involvement in QI efforts (Renedo et al. 2015).

A framework proposed by Renedo et al (2015) suggests there are four elements to successful patient and public involvement within the culture of organisations in terms of QI efforts;

- a focus upon a non-hierarchical structure and multi-disciplinary approach to collaboration between staff and patients
- an ability for staff to model desirable behaviours in terms of QI efforts and displaying mutual respect
- rapidly turning research findings into practice
- the ability to reflect on the use of specific QI methods and to act upon the learning.

The designers clearly recognised the importance of the first element and the implications for future co-design activities were considered. Having a more distal perspective and not being part of this hierarchical structure appeared to give the designers a sense of external legitimacy and power to be disruptive and challenge accepted routine and practices. It is also interesting to note that the findings from this study also highlighted the value of reflection and the learning that took place owing to the observational insights. This was at a personal level but also had an implication for understanding more generally what the experience of care was like for patients within a specific clinical setting.

The therapeutic aspect of the observation activity was seen in terms of being a cathartic mechanism for patients and for the observers. This provided an opportunity for the designers and patient volunteers to reflect on their past experiences of health, which was not evident for staff. However, one of the issues associated with the conflict experienced was also related to conducting non-participant observation. The patient

volunteers described the visible need for patients wanting to talk about their experiences or about more practical concerns about their care (e.g. understanding their medication). It is clear that the observational component in EBCD is considered a vital aspect but the best method remains uncertain. Participant observation has been classically categorised along a continuum that extends from the participant as a complete observer to a complete participant (Gold, 1958). The EBCD online toolkit provides conflicting information with regard to level and type of observation that should occur. Referring back to the original pilot work, the term organisational loitering was the term used to sum up the type of observation conducted, with no reported discourse between observers and the people being observed (Bate & Robert, 2007a). This specific EBCD project took the later approach towards observation, where the observation team were encouraged to record what they saw, heard, smelt and comment on what they thought about the interactions they had seen. However, a key feature was the difference over the approach to observation between the stakeholder groups. Reporting the implementation stage of an intervention is important in terms of recording adaptations that were made, anticipated or not (Hoffman et al, 2014; Knittle, 2015). In terms of unpicking the mechanisms behind the observation component, the distinction between taking a participatory or non-participatory approach appears to have affected the type of data that was collected and the perception of the care being delivered. The patient participants chose to directly engage and talk to patients, whilst the staff members and designers took a more compliant approach to the task. What is interesting to note, is why the patient volunteers decided to go against the planned activity whilst the healthcare staff and designers adhered to implementation fidelity. This may be explained in part by the patient volunteers' previous experiences on the ward. They had both been involved in a separate QI study which involved administering questionnaires to patients at the bedside.

There is some empirical evidence to suggest that observation does assist with early insights into patient experience. These have been conceptualised as four potential scenarios (Bate & Robert, 2007b):

- Staff and patient identifying the same touch points
- Touch points identified by patients but previously not recognised by staff

- Touch points identified by staff that are not significant to patients
- Touch points visible to staff but not visible to patients.

However, it is suggested that by adopting a more collaborative approach to observation within the co-discovery phase it is possible to reveal touch points identified by others that may be hidden to both staff and patients.

The patient volunteers picked up on the cathartic nature of conducting participatory observations and in doing so identified a need that appeared obvious to the outside observer, the need to talk, and identified patient concerns that had not been articulated to staff. The patient participants could visibly see the relief from just verbalising their concerns. The involvement of the designers provided another lens in which to observe the experience of care. The designers, owing to their professional and personal philosophies and their position as an outsider enabled them to transcend a perceived notion of hierarchy and see the experience from both patient and staff perspectives and captured more subtle notions of a good experience. Both the patient volunteers and the designers were also able to record what they perceived as good experiences of care. This may be an important factor when developing relationships between patients and staff during the process of co-design. This may help to provide positive feedback to staff on the ward, and potentially improve relationships. The more mundane and routine aspects of care are identified as important moments in the patient experience and are formally recognised.

Additional contextual information in Table 4.2 helps to illustrate the nature and type of observations recorded by the participant. The key observations fed back to staff included comments from all the participants and were selected by LT and CO. It is recognised that this summary did not report everything, but the type of interaction recorded by the different participant groups are reflected in the participants accounts within the analysis. For example, the designers made observations about relational aspects and hierarchical nature of care delivery. The emotional impact of watching patients concerned about their care was identified by patient volunteers, with staff focussing upon positive aspects of staff interactions with patients.

It is assumed that by conducting observations with staff within an organisation or outsiders, that this will produce usable findings to help inform subsequent stages of the process. A fundamental argument for retaining the observation phase is to capture early insights into the experience of care for patients. The findings from this study though

revealed the difficulty staff members within the service experienced conducting observation. They identified closely with the staff perspective and worried that their involvement would affect relationships with their colleagues. Their empathy lay more with the experiences of staff rather than the patient perspective, and they described their discomfort being under the gaze of patients. Returning to the theory underpinning EBCD, possessing an empathetic stance is seen as a key factor in trying to understand another person's experience. Empathy has a dual aspect here in terms of a 'technique' as well as a 'frame of mind' (Bate & Robert, 2007a; p43). The technical element refers to 'consciously' taking on the 'role' of the 'stranger'. This involves the observer acknowledging they have not had the same experiences as the people they are observing and may have to asking plenty of 'dumb' questions to find out what it is like. It is evident from the accounts that by talking to patients, a wider understanding was gained of the potential touch points for patients and specific patient safety concerns at a local level. It is argued therefore, that by using a more collaborative and multi-disciplinary approach to observation, that is, actively involving patient volunteers and the designers during the discovery phase that a more complete picture of the patient experience could be gathered. It also suggested that the role of the design engineers in the process of co-discovery contributed to understanding the experience of delivering care, with a more sophisticated interpretation of the patient experience.

4.8 Study limitations

IPA studies are usually conducted on small sample sizes, with the aim of recruiting a homogeneous sample so that similarities and differences can be explored in detail (Smith et al., 2009). Whilst small sample sizes are cited as a potential limitation of IPA studies (Pringle et al., 2009), the issue of generalisability is not an uncommon debate within qualitative research (Braun & Clarke, 2013). There is the argument that generalisation is not meaningful within this research paradigm owing to the epistemological orientations; qualitative research is highly contextual and is interested in the detail of the event being explored. Conversely, it could be argued that qualitative research is potentially generalisable (Sandelowski, 2004). IPA involves a detailed examination of each individual with the sample, and should reveal something about the experience for each participant. Whilst the claims made within this study are bounded by this particular group of participants, Smith et al (2009) argue that through a process of theoretical

generalisation, the reader can 'horizontally' extend results (Stephens, 1982) by assessing the evidence in terms of personal and professional knowledge (Smith et al., 2009).

This study sought to explore the experiences of different stakeholder groups, but it is recognised that the frequency and amount of time spent observing was relatively short. When comparing the number of observation hours that have been reported by EBCD studies, this was in fact a similar amount of time.

Chapter 5: Analysis part 2

5.1 Chapter summary

This chapter presents the analysis of a qualitative longitudinal study using IPA to explore the experiences of participants involved in a local EBCD project over time. This study takes a multiple perspective approach and includes patients and patient volunteers, healthcare staff and design-based healthcare researchers.

The chapter starts by summarising the issues about our understanding of the discovery and co-design phases of EBCD. Following on, the study's aim and research questions are presented and the method adopted for this qualitative longitudinal study. The results are split into two analysis chapters and present an interpretative account of participants' experiences.

5.2 Background

Chapter 1 discussed the rationale and development of EBCD as an approach to enhance the experience of care for patients and staff (Bate and Robert, 2007a; Coulter, 2013). It was also suggested that further empirical evidence of QI interventions was needed in order to reliably inform organisations, healthcare professionals and the research community, in terms of what 'works' and why (Shojania & Grimshaw, 2005; Davidoff et al., 2008; The Health Foundation, 2011; Dixon-Woods, McNicol & Martin, 2012; Marshall et al., 2013; Hoffmann et al., 2014; Rohde et al., 2016). This is to ensure that QI efforts proceed on best available evidence and avoid the trappings of 'cargo cult science' (See Chapter 4) (Shojania & Grimshaw, 2005; Dixon-Woods et al., 2014).

The evidence gaps identified from the systematic review regarding EBCD, in Chapter 2, were conceptualised in terms of the 'black box' of the intervention: what happens in the 'space' between the planned activities and the expected outcomes of the EBCD approach (Stame, 2004 p58; Dixon-Woods et al., 2011). The review revealed few published evaluations of EBCD projects with most taking place post-hoc (Iedema et al., 2010; Piper et al., 2012; Bowen et al., 2014). An evaluation conducted by Locock and colleagues (2014) employing a longitudinal comparative case study

design, focussed primarily as assessing the feasibility and acceptability of an accelerated version of EBCD. The limitations of the evaluation designs were discussed in Chapter 2, and highlighted the need to try and capture different stakeholder perspectives and changes that occurred over time (Nielson and Randall, 2013).

Understanding how and why an intervention ‘works’ is vital in terms of the effectiveness of an intervention in everyday practice (Haynes, 1999) and grappling with the ‘active ingredients’ and how they ‘apply’ their effect (Øvretveit & Gustafson 2002; Walsh, 2007; Craig, Dieppe, Macintyre, Michie & Nazareth, 2013). This knowledge is essential to ensure interventions are applied in the most appropriate manner (Michie & Abraham, 2004) and to avoid costly errors (Craig et al., 2013). The MRC’s process evaluations framework is useful when thinking about the key components within complex interventions and considers three inter-related themes: context, implementation and mechanisms of impact (Craig et al., 2008; Moore et al., 2015) (See Figure 5.1). This approach to evaluation is widely cited within the literature and considered relevant within the field of health service research and so pertinent to investigating the EBCD approach (Craig et al., 2013; Moore et al. 2015). The study reported in this chapter attempts to explore the third theme: mechanisms of change. It is suggested that using a qualitative approach is beneficial when trying to understand participants’ experiences of the intervention (Hulscher et al. 2003; Moore et al., 2015) and may help to uncover the mechanisms needed to bring about change (Aveling et al., 2013; Moore et al. 2015; Portela et al., 2015; Leung, 2015).

There is little evidence to date about the mechanisms of impact (Donetto et al., 2014; Abelson et al. 2015; Rohde et al., 2016). How do the activities within the EBCD approach actually produce change? Evaluating the process may help to elucidate the mechanisms responsible for the outcomes, explain variations that may occur (Hulscher et al. 2003) and identify unforeseen mechanisms (Bonell, Fletcher, Morton, Lorenc & Moore, 2012). It may also assist with demarcating between any inherent flaw of an intervention (the underpinning theory is faulty) or whether results are affected by poor implementation or a mixture of both (Dixon-Woods et al., 2011).

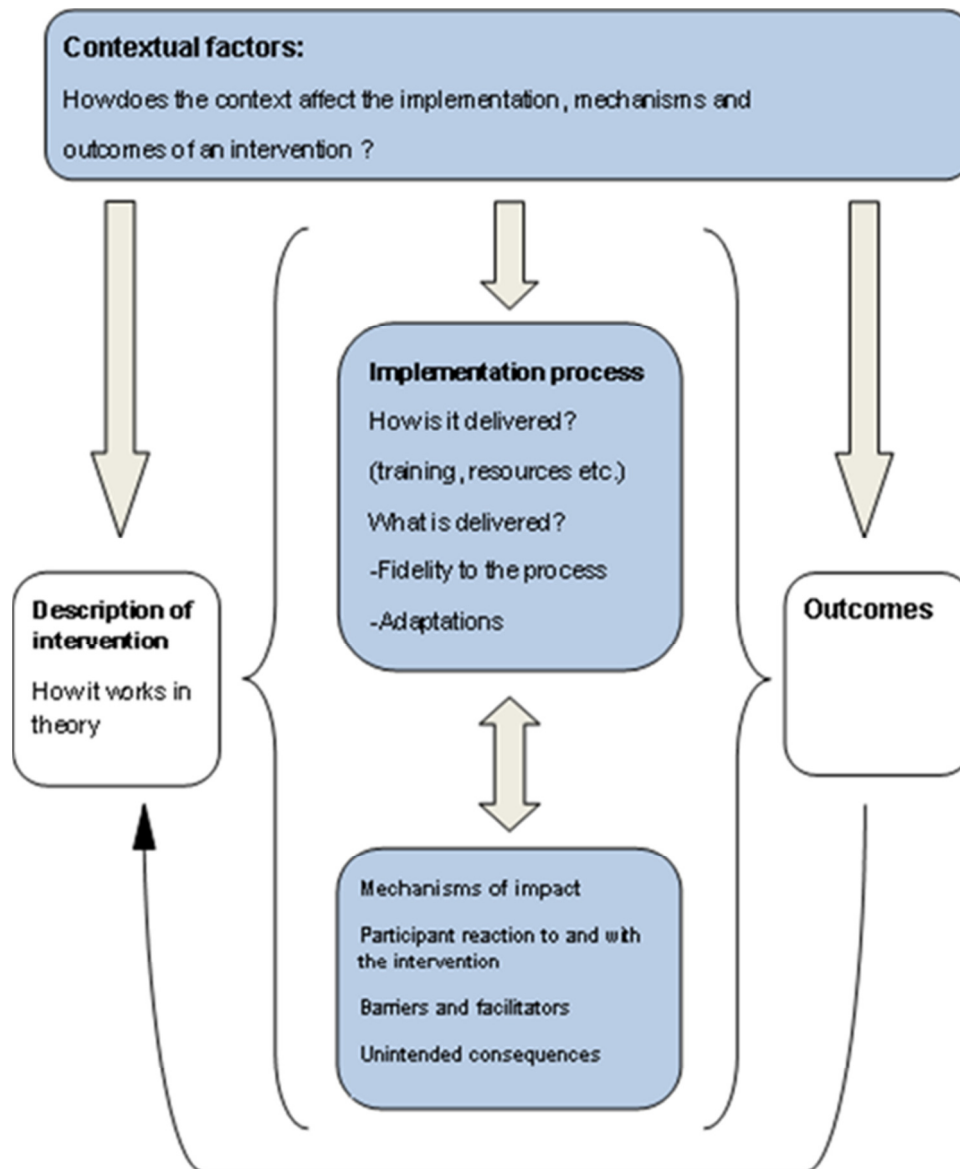


Figure 5.1 The inter-relationship of components within process evaluation - adapted from Moore et al. (2015)

5.3 Context - The EBCD QI project

This study is concerned with exploring stages 2 to 5 of the EBCD project (See Figure 5.3). The background of this QI work was described earlier in Section 4.3.1 with the key activities, outputs and outcomes of the project presented in Table 5.1. Additional information is also provided to contextualise the findings from the thesis which are drawn upon within the discussions (See Sections 4.7 and 5.9).

Table 5.1 Activities, outputs and outcomes during the EBCD process

Key: n=number of people

Activities	Key Outputs	Key Outcomes
Stage 2: Engaging staff and gathering experiences –July to November 2015		
<p>i) Interviews with key staff clinical Individual face-to-face in-depth interviews (n=12) conducted by SM. The interviews were audio-recorded, anonymised and the transcribed by CC (administrative support within the YQSR team). Thematic analysis of semi-structured interviews by LT.</p> <p>ii) Observations in the clinical area Observations conducted by patient volunteers, staff and designers. Observation data collated and summarised by LT and CO.</p> <p>iii) Process mapping exercise Facilitated by the designers with staff members and a patient volunteer. Two hour session to map the process following the patient journey from admission to discharge for an individual being admitted with a heart attack (See Figure 5.2).</p> <p>iv) Summary of findings Findings summarised and written up by LT</p> <p>v) Feedback session delivered to ward staff Verbal feedback session with written report delivered to key ward staff and core team by LT.</p>	<p>*Written summary of staff interviews (See Table 5.2) and observation data (See Table 4.2)</p>	<p>1) The staff interview and observation data was used at the joint co-design meeting to provide the perspective from the staff perspective of delivering care</p> <p>2) The process mapping exercise helped designers and patients to understand the complexity of the pathway and provide an opportunity for staff to reflect on the way care is delivered and could be improved.</p>
Stage 3: Engaging patients and gathering experiences – Sept 2015 to December 2015		
<p>vi) Patient recruitment Ten patients and two carers were recruited by LT using a variety of approaches: hospital volunteer department (n=2), cardiac rehabilitation classes (n=5), local community engagement (n=5), advertising in the cardiac out-patient clinic (n=0). Written consent was taken by LT to ensure patient participants were informed of the possible use of the final trigger film.</p> <p>vii) Filmed patient interviews Individual face-to-face interviews with patients captured on film. Conducted by LT (n=9) and the designers (n=3).</p>	<p>*Creating a patient-centred film to highlight the key 'touch points' of care (See Section 1.5.4)</p>	<p>3) Creating a patient user group for the service</p> <p>4) Patient experience film developed to share at the joint co-design meeting to help with decision making and identification</p>

<p>viii) Creating a trigger film Analysis and editing of patient interviews by designers. During this process the designers watched and listened to the individual films and identified key moments of the patient experience to edit and create the trigger film.</p> <p>ix) Feedback session with patients only Facilitated session by designers. The film was played to the patient group to make any refinements and/or adjustments to ensure the accuracy of the shared story being conveyed. An emotional mapping exercise was conducted to gather a richer picture with regard to the experience of being in hospital and going home.</p> <p>This is where patients rate their experience a long care pathway from positive to negative (See Figure 5.2). This is a highly subjective exercise but aims to reveal the key moments that impact on the patient experience.</p>		<p>of joint serviced priorities</p>
<p>Stage 4: Joint Co-design Meeting – 4 July 2016</p>		
<p>x) Joint meeting with patient volunteers, patients and staff Facilitated session by the two designers with all the stakeholder groups: 3 consultants; head of nursing for the medicine directorate; lead nurse from the ward; a health care assistant; a pharmacist, the Trusts’ patient experience lead, ten patients and two carers.</p> <p>Feedback from the staff perspective was presented verbally by CO. The trigger film was shared with the whole group. Facilitated session to identify the key issues and joint service priority work. Emotional mapping exercise helped to root the focus of the improvement work on the experience of care. Once key areas for improvement were identified, staff and patients were invited to choose an identified issues and join together to make a smaller working group.</p>	<p>*Staff and patient narratives shared about their experiences of delivering and receiving care</p> <p>*Emotional mapping exercise illustrated the key issues during the patient journey</p> <p>*Time and space for a facilitated discussion amongst all stakeholders to identify key priorities for the service at a local level</p>	<p>5) Joint service improvement priorities identified</p> <p>6) Three smaller co-design working groups established:</p> <p>Group A - led by the designers Improving the information given to patients at discharge</p> <p>Group B - led by the designers Transition of care – Managing the patient between the ‘cracks’</p> <p>Group C - led by QI specialist Medicines at discharge - Improving information about medications at discharge.</p>

<p>Stage 5: Individual co-design groups July 2016- to March 2017</p>		
<p>xi) Individual co-design working groups</p> <p>There were three smaller co-design groups working on different priority areas of the patient journey as identified by stage 4.</p> <p>Meetings were convened by LT. Meetings were two hours long. The number of meetings for each group varied from 2 to 5.</p> <p>Group C met on three occasions but stopped co-design work before any outputs were achieved. Staff engagement was challenged owing to a lack of time and resources to enable key members of staff to be taken away from clinical duties.</p> <p>Group A merged with Group B. Adaptations were made to ensure that staff members had an opportunity to feed into the co-design work. This included bespoke ‘micro’ design sessions delivered on the ward by designers to gather feedback from staff on the development of the handbook.</p> <p>The implementation of the handbook into practice was being planned at the time of writing.</p>	<p>*Number of 2 hour meetings held: Group A (n=1) Group B (n=5) Group C (n=3)</p> <p>Group B *Development of a patient held handbook to support the patient through their journey (See Figure 5.3)</p>	<p>7) The co-design work between group A and B were merged as they were addressing the same issue – getting the right information, right people, right time and right format. The designers decided to bring the priorities together.</p> <p>8) Lack of staff engagement affected the tangible outputs from Group C owing to time and resources</p> <p>9) Adaptations were needed to ensure stakeholders had an opportunity to get involved with co-design</p> <p>10) Additional funding applied for to support implementation and evaluation of the patient handbook (on-going - October 2018)</p>
<p>Stage 6: Celebration and review – on-going (2018)</p>		
<p>At the time of writing a celebration event was being planned, to review work to date and thank everyone for their contributions.</p>	<p>*Planning stages of celebration event (on-going - October 2018)</p>	

Table 5.2 Key findings from staff interviews

Themes from staff interviews	Staff interviewed (n=12): Consultant (n=2); Junior Doctor (n=1); Healthcare assistants (n=3); Non-clinical support staff (n=2); Pharmacist (n=1); Sister (n=1); Staff nurse (n=2). [Key n=number of people]
The discharge planning process in practice	There was an acknowledgement by the staff interviewed that discharge planning should start on admission in order to identify issues that could delay going home. Discharge planning appeared to be a staged approach with distinct time points in the patient’s journey; on admission, after diagnostic interventions (angiograms, blood tests etc.) and during ward rounds with the consultant. Discharge planning in practice was also perceived to start at different times by staff. This was owing to factors such as; recognising cardiac patients can rapidly deteriorate in health status after admission making discharge planning difficult, the ease of discharge varied owing to individual patient needs; some patients requiring less support to return home and with those with complex needs. The ward round was a ‘visible’ point for the patient, where staff directly engaged with the patient about their plan of care and being fit/ready for discharge. There have been attempts to standardise discharge care using a checklist by medical staff but it is not applied consistently by all staff.
MDT approach to discharge	The decision to discharge was by initiated by the consultant in discussion with nursing staff, non-clinical support staff and other healthcare professionals. The ward pharmacist’s role was to prepare medication check drug charts and talk to patients about medications before discharge. The pharmacist did not routinely join the ward round. However, once decisions and planned care has been documented by the medical staff , there is an expected chain of events that is expected to occur, with any errors or omissions in medication or planned care picked up at routine follow up appointments by the medical team.
Out of hours discharge care for patients	Nursing staff at the weekend are able to dispense medication from pharmacy out of hours but there was no ‘back-check’ by pharmacists that correct medications was dispensed. Discrepancies and inaccuracies with the discharge summaries were picked up by consultants during routine follow up appointments. The discharge summaries were sometimes delayed because there were errors with the electronic discharge system. Yet, the discharge summaries were seen as vital information for care in the community and were shared with the rehab teams, Clinical Nurse Specialists (CNS) in the

community, the GP practice and for the patient.

Delays to discharge

Waiting for medicines - There appears to be a time lag between being confirmed being fit for discharge and waiting for medicines for patients who are expecting to leave hospital that day. Pharmacy have attempted to speed up the process by preparing routinely prescribed drugs in advance but these may change at the last minute, with the consultant needing to alter medications owing to individual patient needs. Junior doctors have competing priorities when writing up/altering medications to take home and are left until the end of a ward round. However, various 'work-arounds' exist with some patients or relatives returning later in the day to collect medication.

Improving the experience

There was an agreement that the ward environment was fit for purpose with frustrations amongst staff that nothing was ever addressed. It appeared that some staff felt it was important to ensure that the patients were given the correct information about their admissions and what to expect when they went home. Leaflets and information were given to the patients about their condition while in hospital but it was recognised that this was a stressful time in an acute ward setting for patients to remember everything. There were also issues communicating with non-English speaking patients, and delays in providing an interpreting service. There were also suggestions for pharmacy to open longer and for more on call staff across the Trust at the weekends. It was also felt that speeding up the discharge process generally, including medications to take home, would improve the patient experience. This required more forward planning by all staff to ensure a faster transition home with more time to plan thoughtfully about the needs of the patient. Communicating to patients about the day of discharge in order to manage expectations was also important to reduce possible anxiety experienced by patients waiting to go home. This may be achieved by standardising the format so that the process is quicker and clearer between the MDT and community teams, regarding continuity of care.



Figure 5.2 Emotional mapping exercise at the patient feedback session (sticky notes placed above the blue cards indicating a positive experience and below indicating a negative experience).



Figure 5.3 Co-designed patient handbook from Group B

5.4 Study aim and research questions

The aim of this study was to explore the EBCD process from multiple stakeholders' perspective. To understand the possible mechanisms that underpin the EBCD approach that link the process to outcomes. The way the intervention was delivered and the local context play a part in understanding how and why EBCD 'worked' in practice. Using the contextualist approach of IPA can help to make sense of an individual's experience of involvement in the locally situated EBCD project.

Primary research questions within IPA are framed within phenomenological approach with a focus upon exploring and understanding experiences. The following research question was posed:

How do people taking part in an EBCD project make sense of their experience?

The broad and open nature of the primary research question is linked closely to the methodological and epistemological foundations discussed within Chapter 3 and are expanded within the method section that follows. In keeping with IPA methodology, the research question is concerned with 'the detailed examination of the lived experience' (Smith et al., 2009: p47). A useful way to ensure an open research within IPA has been met is to identify objectives, in order to demonstrate that the research questions have been answered (Salmon, 2002, Smith et al. 2009). The following objectives were identified:

- 1) To describe the key features of involvement as understood by participants within the EBCD project.
- 2) To describe any changes and consistencies of involvement as understood by participants within the EBCD project over time.

5.5 Method

5.5.1 Design of the study

A qualitative research design was adopted as an appropriate approach to explore experiential processes and in terms of the research question this study attempted to address underlying epistemological assumptions (See Section 3.2). A qualitative longitudinal IPA methodology was selected as a suitable strategy of inquiry since it allows for a detailed examination of participants' experiences within topics that are complex and ambiguous

(Smith et al., 2009). A longitudinal approach is also well suited to capturing changes and/or consistencies over time owing to data collection at multiple time points (Nielsen and Randall, 2013; Moore et al., 2015; McCoy, 2017). Most longitudinal IPA research has been conducted to explore disease specific experiences over time, and often from one perspective: the patient (Smith and Osborn, 2007; Quinn et al., 2008; Snelgrove et al., 2013; Spiers et al., 2016; Pini et al., 2016; McCoy, 2017). This study design had two layers of complexity i) it adopted a longitudinal IPA approach and ii) sought a multi-perspectival view from staff, patients and designers involved within an EBCD improvement project (See Figure 5.3).

5.5.2 Research Ethics

The study was reviewed and received ethical approval by the University of Leeds, Faculty of Medicine and Health Research Ethics committee (date:15/09/15; Ethics Reference number:15-0153). This research study was deemed as a service evaluation project by the National Research and Ethics Service, therefore, local R&D permissions were sought to ensure governance and checks were in place prior to the study commencing.

5.5.3 Participants

A purposive sampling strategy was used to recruit participants from a local service improvement EBCD project. This was consistent with the aims of the study and the underlying methodological and theoretical assumptions of the study discussed in Chapter 3. Owing to the lack of previously published work using IPA to explore experiences of EBCD, the sampling strategy could not be informed using previous studies which is considered relevant when designing this type of study (Smith et al., 2009). IPA studies usually seek to recruit a largely homogenous sample so that the research question(s) is considered pertinent to those participating (Smith et al., 2009). For the purpose of this study the notion of a 'homogeneity' was defined in terms of all potential participants being involved within the same discrete local EBCD service improvement project: the population was bound by the commonality of a discrete and significant 'event' (the local EBCD project) rather than the experience of a disease or long term condition.

The main recruitment factor that was considered important was in relation to participants having had direct involvement in the EBCD project, rather

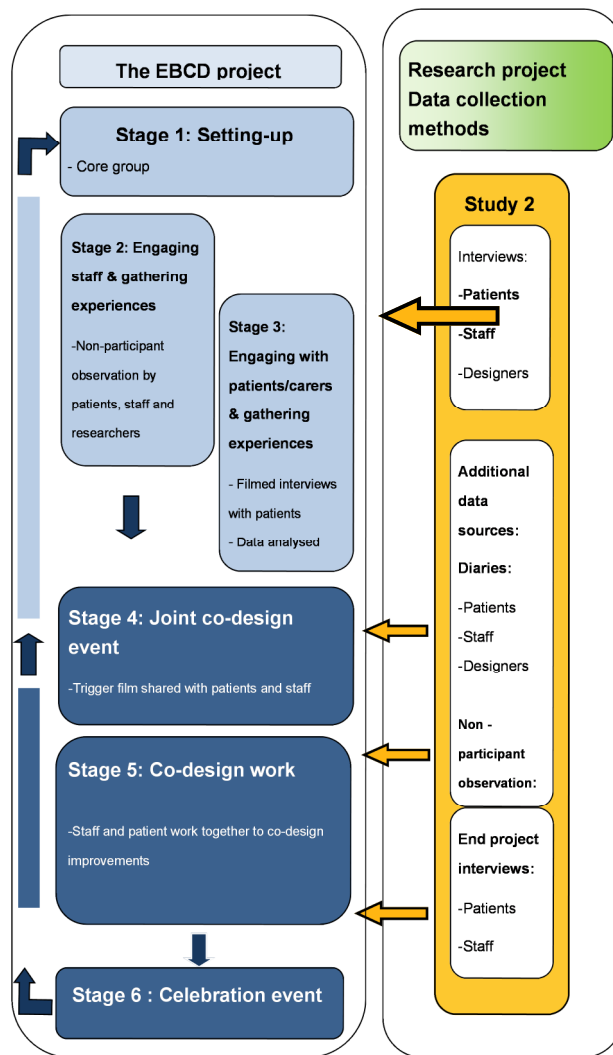


Figure 5.3 EBCD project and study 2 data collection

than trying to recruit a uniform socio-demographic group. Therefore, participants were purposively recruited from four different groups:

- The EBCD project patient group (who were considered to be healthy 'ex-patients' of the service)
- Patient volunteers from the hospital volunteer group who had taken part
- Healthcare staff and non-clinical support staff within the organisation who had been directly involved in the project (this included healthcare professionals within the cardiology service and quality improvement specialists)
- Design engineers in healthcare from a local university that had helped to facilitate the co-design process.

All eligible participants were identified by the main researcher (LT) and were sent a study recruitment letter and participant information sheet by a member of the core improvement team (CO), either by post or email or by hand. The study inclusion criteria were that participants were aged 18 years or older were able to speak English, Urdu or Punjabi, and had been directly involved in the EBCD project.

A total of 25 individuals were eligible to take part in the study (See Table 5.1). This included, ex-patients (n=8), carers (n=2), patient volunteers (n=2), staff (n=10) and design engineers (n=2). Although there were over 100 staff within the service, including non-clinical support staff, only those who had been directly involved in the project were included in the sample population.

Table 5.3 Demographics of the total sample population for study 2

Stakeholder groups	Number of individuals in EBCD project	Gender (n=number)	Ethnicity	
			White British (WB) South Asian (SA)	Ethnicity and gender Female (F) Male (M)
Patients	8	Female (n=3) Male (n=5)	WB (n=4) SA (n=4)	WB F (n=2) WB M (n=2) SA F (n=1) SA M (n=3)
Carers	2	Female (n=1) Male (n=1)	SA (n=2)	
Patient volunteers	2	Female (n=2) Male (n=0)	WB (n=1) SA (n=1)	
Staff	10	Female (n=9) Male (n=1)	WB (n=7) WE (n=2) SA (n=1)	WB M (n=1) WB F (n=6) WE F (n=2) SA F (n=1)
Design engineers	3	Female (n=0) Male (n=3)	WB (n=2) WE (n=1)	
Total number	25			

Previous evaluative EBCD studies that included staff not directly involved in the QI project declined to be interviewed believing that they had little to contribute in evaluation terms (Bowen et al. 2013). Previous QI efforts on the ward also demonstrated the difficulty of asking staff to take part in activities outside normal working hours. Contextual issues relating to staff shortages, the potential negative impact on patient care asking staff to leave clinical duties and placing undue burden on staff were also considered. Therefore, the decision to only include staff involved in the co-design components was based on previous empirical evidence and pragmatic reasons.

Eligible participants were given 72 hours to consider the information before being contacted by the main researcher (LT) via telephone, email or face-to-face contact. Further information was provided verbally to explain what the study would entail with regard to time commitments, activities and remuneration costs offered. At this point a convenient date and time was mutually agreed in order to obtain informed written consent and conduct the first interview. This process was intentionally flexible in order to meet the needs of patients taking part, and fitting in with the busy work schedules of staff and the designers.

A total of 13 of participants were recruited. The participant's characteristics for study 2 are displayed in Table 5.2. This includes the number recruited from the different stakeholder groups, gender and ethnic origin. The reasons that participants gave for not taking part differed as expected by stakeholder groups. Patients and carers explained that they had returned to work or had a complex home life, which precluded them taking part. Staff cited reasons with regard to shortages in staffing, fatigue with QI projects, organisational pressures and feeling they had little to contribute to the process. One of the design engineers left the University during the project and was unable to participate.

Table 5.4 Characteristics of study participants

Participant stakeholder groups	Number recruited	Reasons for not taking part
	White British (WB) South Asian (SA) Female (F) Male (M)	
Patient participants - All had been admitted to hospital for treatment following a heart attack	Total (n=6/8) WB F (n=2) WB M (n=2) SA F (n=1) SA M (n=1)	- Back at work with limited time to take part - Complex home life and main carer for a severely disabled child
Carers	Total (n=0/2)	- Too busy with work, family and community responsibilities
Patient representatives	Total (n=2/2)	- Not applicable
Staff	Total (n=3/10)	- Shortage of nursing staff on the wards and community - Trust wide directive during key times in the project meant all non-clinical meetings were cancelled - staff reached fatigue with regard to concurrent research and QI work within the service - Deferring interview dates and times beyond the time frame for the study - Did not feel they had anything to contribute owing to limited involvement
Nursing staff Medical staff Non-clinical support Quality improvement team Patient Experience team		
Design Engineers	Total (n=2/3)	- Left the University for a new job

Although 13 participants were recruited in total, it is noted that at a sub group level the sample sizes differ, ranging from two to six participants. However, IPA as a methodology is 'committed to the detailed examination of the particular case' (Smith et al., 2009: p3) and so, it was anticipated that the similarities and differences between participants and groups could be explored in depth. The number of participants is normative for IPA studies (Brocki & Wearden, 2006; Smith & Osborn, 2007).

The patient participants were offered reimbursement for their time and travel expenses for this interview at a cost of £20.00 per person guided by the NIHR's policy on payment of fees and expenses for members of the public participating in research (INVOLVE, 2018). Staff members and designers were not reimbursed owing to the fact that this study was seen as an evaluation of a service improvement project and therefore, considered part of normal for their contribution.

In keeping with the theoretical of IPA, idiographic pen portraits are a useful way of bringing context and relevant details about participants into qualitative analysis (King & Horrocks, 2010). Pen portraits for Jean, Sara and Sam were presented previously in Table 4.3. Additional pen portraits are presented in Table 5.3, to included additional participants featured within this study. Pseudonyms have been assigned to participants and to avoid potential identification certain individual experiences have been omitted (identifying characteristics may be removed in formal publications to preserve the anonymity of participants).

Table 5.5 Pen-portraits of participants

Participant	Stakeholder group/ type of involvement	Pen portrait
Robert	Patient / Involved throughout stages 3-5 of the EBCD process	Robert is a retired gentleman in his late sixties, who lives alone but has a close relationship with his sister and nephews. He has travelled around the world having been in the Navy. He was admitted after a routine clinic appointment for treatment that required a heart bypass. This led to a prolonged stay in hospital before being transferred for surgery. Robert suffers from diabetes and has been a long-time advocate of research and improvements for people with diabetes. He is an active member on National board for diabetes and is involved in patient safety patient and public involvement research panel. Robert loves a pub quiz.
Harry	Patient/ Involved throughout stages 3-	Harry is a gentleman in his early fifties, living with his partner and is a policeman. He suffered a heart attack and

	5 of the EBCD process	was recruited from a community cardiac rehabilitation session. Here turned to work during the EBCD project. Harry loves the gym.
Ivy	Patient/ Involved throughout stages 3-5 of the EBCD process	Ivy is a woman in her early seventies, who was married with grown up children living nearby. She has suffered a heart attack that required open heart surgery. Ivy became good friends with Mary.
Mary	Patient/ Involved throughout stages 3-5 of the EBCD process	Mary is a woman in her early seventies. She lives alone but her daughters lived nearby and she spent a lot of time with her grandchildren. During the project she broke her foot palsyng football with her grandson. She had suffered a heart attack and required some intervention but during the EBCD project required further support, having had a pace maker fitted.
Fayza	Patient/ Involved throughout stages 3-5 of the EBCD process	Fayza is a middle aged woman, with a large family and worked four days a week at a local voluntary organisation. She spent a lot of time preparing for celebration and festivals within her local community and loved to cook.
Haseeb	Patient/ Involved throughout stages 3-4 of the EBCD process	Haseeb was a gentleman in his late sixties. He was married and totally devoted to his wife. He did not have any children but had a large extended family that supported his efforts within the project, with his nephew bringing him to numerous sessions. It was with great sadness that Haseeb unexpectedly passed away during the EBCD project.
Esther	Staff/ Involved throughout Stages 1,3,4, 5 of the EBCD process	Esther is a woman in her forties who was part of the QI team. She has a QI background and had been working in the Trust for a couple of years.
Claire	Staff/ Involved throughout Stage 2 and 4 of the EBCD process	Claire is a ward sister and had worked within the service for many years. She had extensive experience and knowledge of caring and treating patients with heart conditions
John	Staff/ Involved throughout Stage 2 and 4 of the EBCD process	John is a Consultant cardiologist in his late forties, who had worked for many years within the Trust.
Frank	Designer/ Involved throughout Stage 3-5 of the EBCD process	Frank is a design engineer, in his late twenties and originally from the continent. He had worked with children designing online activities and games to promote physical exercise. Frank loved carrot cake.

5.5.4 Ethical considerations for recruitment, retention and timing of interviews

There were concerns about the potential attrition rates of the participants for several reasons owing to the specific stakeholder groups. For the patient group there were concerns that patients may deteriorate in health or feel that the study was burdensome on top of the intensive EBCD project,

which demanded multiple sessions within the co-design stage. It was deemed as potentially onerous to ask patient participants to be interviewed before the filmed interviews in Stage 3 and after co-design workshops at the end of stage 5 (See Figure 5.3). Thus, separate interview appointments were arranged at a suitable time for all patient participants. There was also the concern that staff would not be able to commit to interviews owing to competing workload pressures. Thus, the main researcher (LT) presented multiple dates and opportunities for suitable interview times. Informed consent was also checked throughout the duration of the project and before the second interview time point, to ensure participants were still happy to participate.

One member of staff withdrew at the second interview time point owing to clinical workload pressures and unable to schedule in time to be interviewed. One patient also withdrew at the second stage owing to work obligations. Every effort was made to try and accommodate interviews with these participants over a two-month period, however, this proved unsuccessful. Unfortunately, one patient participant died suddenly near completion and so no final interview was conducted. The interview at the first time point was included within the analysis since informed written consent had been obtained and this event (withdrawal from the study) was addressed within the study participant information sheet and discussed verbally at the time of taking consent.

5.6 Procedure

Participants took part in two in-depth semi-structured interviews at the start of their involvement and at the end of the co-design stage (See Figure 5.3). Semi-structured diaries were provided to all participants to use if desired during the EBCD process. Non-participant observations by the main researcher (LT) of the co-design meetings were conducted to capture additional data to assist with contextualising interview data. Thus, using a longitudinal IPA approach to explore multiple perspectives with regard to the mechanisms of change within an EBCD project could be considered an original and novel approach.

5.6.1 Data Collection

There were various methods used to collect data and at different time points during the EBCD project. These included in-depth interviews, participant diaries, non-participatory observations and researcher (LT) field

notes. A chronological time line of events is presented to illustrate when specific activities occurred within the various stages of the EBCD project and when the interviews occurred for this study (See Table 5.1).

5.6.2 In-depth Interviews

The semi-structured in-depth interview schedules were constructed based on the literature reviewed Chapter 2, consideration of the relevant stages of the EBCD process and IPA methodology. This enabled participants to tell their story in their own words (Smith et al., 2009) about their experience taking part in an EBCD project with freedom to describe any moments that were important to the participants. The schedules contained open-ended questions on the stages of the EBCD process at the start (co-discovery stage 2 and 3) and end of the co-discovery stage (Stage 5) (See Figure 5.3). This approach is in keeping with the principles of IPA methodology and also allows the researcher to delve deeper into topics raised that are related to the aims of the study (Smith, 2011).

The interview schedule was reviewed by an independent patient and public research panel to check for relevance, comprehension of the questions and to address any topic that may have been omitted. A hard copy of the interview schedule was sent via post to a total of 10 members of the panel with instructions to carefully read through and return any comments either by email or post with regard to any suggestions. No substantial changes were made at this point and the feedback from the panel members felt it was an acceptable approach to the interview.

Following an introduction by the researcher to explain the purpose of the research project and the aim of the interview, the schedule consisted of the following questions:

Interview 1: At the start of the EBCD project

- Can you tell me why you wanted to take part in the EBCD project?
- Can you tell me about any expectations taking part in the EBCD project, if any?
- How do you think your family and friends feel about you taking part in the EBCD project?

Interview 2: At the end of the project

- So, can you tell me about the different stages that you were involved in the EBCD project?
- Can you tell me how you felt being interviewed and filmed for the project?

- So, can you tell me about the different stages of the co-design work that you took part in? Can you tell me about the service improvements that were designed in your group?
- Can you tell me about how you felt about having group discussions with other patient representatives/members of staff/health researchers?
- How do you think your family and friends feel about you having taken part in the EBCD project?
- How did taking part in the EBCD project make you feel?
- What do you think were the main differences between the patients, staff and health researchers involved in the EBCD project?
- How did you feel about using the diaries?
- Is there anything that could have been done better with regard to the EBCD project, if at all?

Possible prompts and probes:

- Can you tell me a bit more about that?
- What do you mean by '.....'?
- Can you give me an example?

All the interviews were conducted by the main researcher (LT) at the start of the participant's involvement and at the end of stage 5, which was over a ten-month period (February 2016 to November 2016). It was made clear that the contents of the interview were confidential and any reported extracts would be anonymised. It was explained that there were no right or wrong answers to any of the questions and were encouraged to talk openly about their experience. The duration of the interviews at T1 ranged between 10 to 30 minutes and at T2 ranged from 40 to 60 minutes. The interviews were conducted in accordance to the arrangements set out in the ethical review, and were all conducted in a private room and away from the main clinical area. The interviews were audio-recorded and transcribed verbatim by a trained transcriber, based within the University of Leeds, School of Psychology.

Reflexivity point:

I had disclosed my previous background in nursing to the participants and was aware of the rapport that had developed as part of my involvement in the EBCD project. I was therefore concerned that participants would avoid talking about more contentious or difficult aspects of the process as a way of protecting me from any negative comments. In an attempt to mitigate this issue I explained that I was interested about their honest opinions about the experience of taking part. I was attempting to remain as objective as possible to try and uncover participant's true experience: I was more interested in understanding the experience of the process, rather

than taking things to heart either personally or professionally. I felt that this was a real learning opportunity, managing the challenges of the research process. By taking a gentle and transparent approach to the interview process within IPA patient participants appeared to be comfortable talking about more difficult aspects of the process. This led to one participant tearfully recounting her story of being admitted to hospital (she was offered support at this stage as per the study protocol). But, I saw her fragility and her strength. She reminded me of my own mother, she was of a similar age and I felt a connection. Reflecting on this encounter whilst analysing data, I thought about this reaction and how this might colour my interpretation of the participant's experience. Keeping a reflective log helped to manage this process during analysis. This example describes the tensions that arise with a phenomenological commitment to research: attempting to achieve a reductionist view whilst maintaining reflexivity (Finlay, 2008).

5.6.3 Observation of co-design meetings

Non-participant observations of the large joint co-design meeting (stage 4) and smaller co-design meetings (Stage 5) were conducted. An observation sheet was developed using principles of writing up ethnographic field notes and was guided by answering the following questions (Emerson, Fretz & Shaw, 1995; p146);

- What are people doing? What are they trying to accomplish?
- How exactly do they do this?
- How do people characterise and understand what is going on?
- What assumptions do they mean?
- What do I see going on here?
- What did I learn from these notes?
- Why did I include them?

These observation notes assisted with the interpretation of participants' accounts in an attempt to assist with the contextualisation of any interviews and development of the analysis. Participant observation can be a useful way of further understanding specific local contexts and activities (Smith et al, 2009).

Informed written consent was taken by participants with regard to these observations during co-design meetings. It was anticipated that some

participants at the first joint co-design meetings may not have taken part in the study, therefore, in line with good clinical practice (GCP) guidance, informed written consent was obtained by LT on the day of the meeting. No one was identified by name on the observation sheets.

5.6.4 Participant diaries

All participants were provided with a semi-structured paper based diary to capture their thoughts about any EBCD related activities. This was provided at the point of taking informed written consent at T1.

Participants were encouraged to record any thoughts but it was made explicit that this was not a compulsory part of the study. They could be written in either English or Urdu (and translated if required – none were). The data from the diaries was considered as a supplementary source of data and was intended provide additional context to support analysis. Participants' diaries were requested after interviews at T2, with reasons for use or non-use recorded (See Table 5.3).

5.7 Analysis

5.7.1 In-depth interviews

The methodological foundations for IPA were described earlier in Chapter 3. However, the practical application of the approach during the process of analysis for this study is now expounded. This is in order to adhere to the broader principles of transparency and coherence when assessing the quality of qualitative research (Yardley, 2000) and is of particularly relevance for IPA studies (Smith, 2011).

As previously discussed in Chapter 3 the extant literature on analysing data from multiple stakeholder perspectives and at multiple time points using IPA is scant. A method for working with larger samples has been described by Smith et al., (2009) but not in any great detail. This may be partly attributed to the flexible and creative approach to analysis advocated within IPA studies (Smith et al. (2009).

However, Smith et al. (2009) suggest that studies with larger corpus of data, in which this study falls, may mean that analysis of individual cases may not be as detailed, with a shift to highlighting key emergent themes for the group as a whole. Thus, the guidance in developing the analytic approach for this study was drawn from multiple sources. Firstly, previous published IPA studies using either a longitudinal approach (Clare, 2002;

Snelgrove et al., 2013; Snelgrove et al., 2014; Pini et al., 2014) and studies with multiple perspectives (Larkin and Griffiths, 2004; Linmans et al., 2013). Secondly, methodological discussions were held with the supervision team (PG, RL, JOH and AG) and experienced qualitative researchers within the School of Psychology, University of Leeds (AM) and the YSQR group (LS).

In an attempt to avoid duplication within this thesis, the analytical process (stages 1 to 3) was described in detail in Section 4.4.3. Briefly, this consisted of reading and re-reading an individual account followed by coding at a semantic level: describing the content of the account articulated by the participant, paying close attention to the 'things which matter' in their life world (Smith et al., 2009). The second level of exploratory coding at a linguistic level looked at the use of language and how this related to the content and meaning of the account. Attention was paid to the use of metaphors, which helped to make a link between the descriptive codes and the third level of annotation: conceptual coding. The coding was then turned into emergent themes and annotated with key words in order to be able to locate the source of the theme within the original transcript. This process was then repeated for each account at time point one (T1) and at time point two (T2).

Stage 4 of the analysis process differed from the usual approach to analysis with smaller samples (Smith et al., 2009). Having created a set of emergent themes for an individual account, rather than initially mapping connections within an individual account, the process was extended to explore patterns first within participant subgroups, and then across the whole group. This was conducted separately for both time points. This approach is considered an appropriate method when working with a larger corpus of data (Smith et al., 2009). The main technique used to look for connections between themes was abstraction: putting together like with like themes and developing a name for the cluster of themes. Themes were also explored in terms of their function within an account and helped with a deeper interpretation of the data, since the use of language is profoundly connected to participant's interpretations of the event under investigation (Smith et al., 2009). The use of subsumption, where an emergent theme becomes a superordinate theme in its own right, additionally helped to bring together related themes.

A master table of themes was subsequently developed at time point one and time point two. These master tables attempted to represent themes

particular to individual cases whilst recognising higher order concepts shared across all the accounts. It was at this stage a meta-theme table was developed which identified patterns and connections from the two master tables, in order to identify changes and consistencies over time (See Table 5.1).

Reflexivity point:

The analysis was challenging owing to the lack of studies that had used a longitudinal IPA approach to explore mechanism of change within QI interventions. The final sequence of analysis was after much trial and error: mapping themes within cases and across cases. I felt a sense of losing the 'particular' across the whole data set when the process of identifying super-ordinate themes within a case was conducted too early and it was easier to map connections across cases using emergent themes. This concern was articulated within supervision sessions with JoH and additional methodological advice from an experienced qualitative researcher (AM) was sought. This proved to be invaluable when checking the specific analytical approach I had taken, providing assurance and suggestions how to incorporate supplementary data from the analysis (i.e. the 'call-out boxes'). Careful consideration and thinking was given whilst exploring themes and potential super-ordinate themes. However, working with the data, there was a moment when taking a 'birds-eye view' of the data where it became evident that many of the themes within sub-groups were linked by higher order concepts, and resulted in the current analysis presented.

In order to maintain an idiographic stance, central to IPA, the analysis attempted to stay close to the particular claims of the individual participants whilst representing higher order concepts that the cases shared (Smith et al., 2009; Smith, 2011). The measurement of reassurance of themes within larger IPA studies is considered an important element (Smith et al., 2009). Therefore, a matrix of the identified themes cross referenced with the participants was produced (See Table 5.2).

Although the analysis process has been described in a linear fashion, it was a far more iterative process, moving back and forth across the data set. This is conceptualised as the hermeneutic circle, as researchers attempt to make sense of participants making sense of their experiences (Smith et al., 2009).

Table 5.6 Matrix of identified themes cross-referenced by participantsKey: = Theme present, x = Theme not present - = Not interviewed

Theme	'Camps'		Boundary spanners		The empathy scale		Challenges and surprises		Protecting the self		Glimmering hope		Co-design as therapy		Untapped mystery		Frustrated self	
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2
Jean	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Sara	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Robert	<input type="checkbox"/>	<input type="checkbox"/>	x	x	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Harry	<input type="checkbox"/>	-	x	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	x	-
Ivy	<input type="checkbox"/>	<input type="checkbox"/>	x	x	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mary	<input type="checkbox"/>	<input type="checkbox"/>	x	x	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fayza	<input type="checkbox"/>	<input type="checkbox"/>	x	x	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Haseeb	<input type="checkbox"/>	-	x	x	<input type="checkbox"/>	-	<input type="checkbox"/>	-	x	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	x	-
Esther	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Claire	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>
John	<input type="checkbox"/>	-	x	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	<input type="checkbox"/>	-	x	-	x	-	<input type="checkbox"/>	-
Sam	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Frank	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	-	-	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	x	<input type="checkbox"/>
Prevalence of themes	12/12	10/10	5/12	6/12	12/12	10/10	12/12	10/10	8/10	5/10	12/12	10/10	11/12	9/10	11/12	10/10	5/12	10/10

The use of bracketing as a reflexive device (as discussed in section 3.6.1) was beneficial during the analysis of individual accounts. This avoided leaping to conclusions about the data before the analysis was completed and also carrying impressions between cases. However, truly being able to suspend thoughts about the analysis is questionable, and it is argued that being reflexive throughout the approach may be more beneficial when explaining how the researcher arrived at interpretation of the phenomenon (Finlay 2003; Shaw, 2010).

5.7.2 Observational data

Data collected during non-participant observation of co-design meetings by LT (stage 4 and 5 of the EBCD process) was analysed using thematic analysis (Braun & Clarke, 2006). The comments recorded on the observation sheets were read and re-read. Discrete chunks of data were then coded and grouped together by themes. The findings from the observational data were used to assist with the development of the analysis, and have been presented in reflexive 'call out' boxes (See section 3.10).

5.7.3 Participants diaries

Diary entries were read in relation to participant's individual IPA coding framework developed during the IPA process. Detailed reading of the accounts provided additional context when interpreting individual experiences. All diary data was anonymised. Only three diaries were returned, two from patient volunteers and one patient participant.

Table 5.7 Rationale for use and non-use of participant diaries

Stakeholder group	Number of diaries returned	Reasons for use or non-use of diaries
Patients	1 out of 6	Writing about experiences was an unfamiliar activity and was not seen as necessary
Patient volunteers	2 out of 2	Considered a useful way to record thoughts after meetings and activities after EBCD related activities
Staff	0 out of 3	Not used to record any thoughts or comments after EBCD related activities
Designers	0 out of 2	Recording thoughts and reflections in own journal

The reasons given by other participants for not using the diary included; not useful as way of recording thoughts, and not familiar with writing and reflecting on experiences (See Table 5.4).

5.8 Results

The following analysis explored the multi-perspective experience of taking part in an EBCD service improvement project within a cardiology service, to improve the experience of discharge from hospital to home.

Three meta-themes are presented, connecting with others, the idealism and realism of EBCD and solving the mystery (See Table 5.3). The term 'meta-theme' has been used to describe a higher order super-ordinate construct across both time points. This term appeared to be a more accurate description of encapsulating overarching themes within the corpus. The themes within each meta-theme draw upon the similarities and differences within and across participants' accounts.

Table 5.8 Meta-themes and subthemes

Meta-themes	Sub-themes
1. Connecting with others	1a. 'Camps' 1b. Boundary spanners 1c. The empathy scale
2. The idealism and realism of EBCD	2a. Challenges and surprises 2b. Protecting the self 2c. Glimmering hope
3. Solving the mystery	3a. Co-design as therapy 3b. Untapped mystery 3c. Frustrated self

For larger IPA studies (See Section 3.9) indicating the level of recurrence of themes across accounts is also an important feature. This provides a way of enhancing the validity of the results when assessing the quality of the study (Smith et al., 2009). It is suggested that for a theme to be classed as recurrent it should appear between a third and a half of all participants' accounts (Smith et al., 2009). With this in mind, the prevalence of each theme appears to occur for over half of all participants (See Table 5.4). However, when considering the prevalence of themes and in keeping with IPA principles, there is scope for variation within the themes. For instance, the same theme may be represented differently by the participants. Constantly 'negotiating' the importance and relevance of

themes is a feature within more complex IPA studies, with the need to balance similarities and differences within individual accounts and across the group as a whole (Smith et al., 2009: p107). The degree in which the variation occurs is revealed within the narrative account of the findings.

The following sections now present a detailed and discursive narrative of participant's accounts with the use of additional contextual data from observations and participant diaries (See Section 3.10). Extracts from participants are denoted with the time point when data was gathered, T1 (first time point) and T2 (second time point) after participant's pseudonyms. The nature of changes and/or consistencies over time is described within each theme.

5.8.1 Meta-theme 1: Connecting with others

There are three sub-themes that illustrate the main features of connecting with others during the EBCD process. They describe participant's experiences of being involved in an EBCD project from multiple perspectives and explore convergent and divergent accounts over time. The themes that developed during the analytical process were, 'camps', crossing boundaries and the empathy scale. These are presented in the three following sections.

5.8.1.1 Sub-theme 1a: 'Camps'

The theme title 'camps' refers to the way participants identified themselves in terms of group identity and refers to a particular extract from Ivy, a patient participant. This 'secretive gem' (See Section 3.9) helped to elucidate the idea that participants identified with different 'camps' within the EBCD process. For Ivy, the use of a war time analogy helped to describe the spirit of the patient camp:

'I suppose it would be like . . . during the war, people that fought together; there was a lot of camaraderie and er, it felt like that. Um, it gave me um, confidence er, to talk to others about what I'd gone through because I knew they sim-gone through similar. And er, yeah . . . it was good for me.' (Ivy, T2).

The above extract highlights the simultaneous notion of a community coming together to share 'similar' experiences whilst providing a safe place to talk, confident that others in the same situation would understand. Ivy's use of the word 'camaraderie' also underpins the sense of people coming

together at a time of immense adversity and drawing upon each other for support. The phrase 'people that fought together' infers a real sense of being physically under attack and fighting to stay alive which may aptly describe the very real effects of suffering a heart attack, which they all shared as a group. The strong sense of community that developed quickly amongst the patient participants was evident throughout the group's accounts. At the first patient-only event (See Section 1.9) everyone commented how much they had enjoyed meeting each other. Haseeb described his delight in the following extract:

LT: 'How did you find that session?'

Haseeb: 'Oh, very nicely. We share some view for everybody, you know and I, I find something, new thing because so many people come, and I like them, you see.' (Haseeb/patient T1)

Haseeb's pleasure was derived from meeting others that had gone through the same experience but also discovering new things through sharing stories. Fayza also sums up the overall sentiment described by the patient 'camp':

'...it was brilliant. It was really nice meeting them' (Fayza/patient, T1)

The strength of this connection at the first patient only meeting was visible to the designers who had facilitated the session with Sam remarking on the almost instant bond that occurred:

'...the rest of them hadn't met each other but there was immediately a sort of strong sense of um, well, by the end of the session, a very strong community between them.' (Sam/designer, T1)

Initially the patients had come together as apparent strangers but, taking part in the EBCD project appeared to provide an opportunity for participants to find their 'camp'. This was not anticipated by the patient participants at the outset of their involvement. They were not seeking their 'camp'; it was more a sudden realisation that they had found a 'camp'. The extract below from Harry illustrates this realisation that he was not alone, 'You tend to feel that nobody knows what you're going through' (Harry/patient, T1) and the chance to share his experience with others:

'It was interesting because people-people are saying the same things you're saying about, you know being scared and um, not knowing what to expect and I think people had got the same . . . the

same issues that you've got. Um, but it was nice to sort of meet with other people and-and share some of those experiences.'

(Harry/patient, T1)

The sense of others not understanding resonated throughout all the patient participant accounts. The sheer disbelief and feeling frightened on admission were common emotions, as Mary commented 'it can't be happening to me' (T1) and Harry stating, '...you're scared to death about your future...and what's happening with your body' (T1).

Additional data – Non participatory observations

First patient only event

The patient group was a diverse mix of age, gender and ethnic background. Yet, there was a feeling of instant connection between people as they started to chat and listen to each other's stories even before watching the trigger film that had been created from the individual interviews prior to the session. There was almost a palpable buzz of excitement with the meeting feeling very upbeat, despite the at times harrowing descriptions of people's stories within the film. This was seen in terms of head nodding, agreement utterances and smaller break away discussions after the event between the patient participants. This meeting was the first time patients had met and was facilitated by the designers, and at this stage there were no members of staff present at the meeting

However, by being part of the 'patient camp' this appeared to offer a safe space to open up and talk about their experiences which was hard to do with close friends and family members. Mary best embodies this sentiment across the patient accounts when describing her families' reaction to her heart attack:

'Because you can't describe to them what you're going through. And they don't really, you know, you don't want to be wrapped up in cotton wool... but you need to know that they're there.'

(Mary/patient, T1)

The imagery Mary gives of her family wanting to wrap her up in 'cotton wool' infers a sense of others seeing her as fragile. Although, this could be seen as a normal reaction by her family, Mary's actual needs were different. She wanted reassurance that her family were around if she needed them but she wanted to return to a sense of normality. Despite

close friends and family, Mary also found it uncomfortable sharing her experiences with others:

'I've got a couple of really good friends who we can tell each other anything but even then I don't ...keep to myself much to most of the time' (Mary patient, T2)

The interesting thing to note from this extract is the fact that Mary did not want to share *'anything'* about her heart attack even though she would share almost anything else with good friends. This infers a feeling of how isolating illness may be. The following extract from Robert highlights how difficult it is for others to truly appreciate experiences of long term health conditions, when he spoke about his close family:

'So we [his family] don't normally um, discuss things like this, you know we take a, an interest in each other's health obviously as, as you normally would but um, er, I think to a certain extent um, they find it difficult to understand all the complications [having a heart attack] that go along with um, the, the diabetes.' (Robert/Patient T1).

The above extract illustrates the awkwardness that Robert described talking about health issues with his family. The pauses *'um'* before referring to health issues and referring to his heart attack as *'things like this'* and *'complications'* suggests a more pragmatic approach to life. This is further explained by his admission to having a *'stoical'* personality:

'I'm relatively stoical...when I was first diagnosed with diabetes um, and ...the doctor at the time: it must come as a heck of a shock...And I said, 'well, not really. I know that there is a history in the family of, of diabetes so there's a possibility um, I could um, get it. Um, I have, so right, let's get on and get it treated.' (Robert/Patient T1).

However, despite his no-nonsense approach the need to talk about what happened and making sense of the experience within the setting of an EBCD project was seen as invaluable, not just personally but for others too:

'You can get together or you can talk about things and some things, you know may not bother you so much but it may be extremely important to someone else. So again um, there's a good deal of cross-fertilisation that can happen there, where you can um, get ideas from other people and they can pick up ideas from you.' (Robert/Patient T1)

Roberts's expression of 'cross-fertilisation' infers a sense again of the value of having lots of different perspectives contributing to the learning and creation of new ideas. The opportunity to be part of this community appears to be even more significant for the participants despite evidence of other support systems.

Reflexivity point:

Despite a pragmatic attitude to life, Robert during his interview for the EBCD trigger film revealed that he lamented the lack of psychological support he received whilst waiting for a heart by-pass as an in-patient. He saw this as an important aspect of care that had been neglected, and no-one had spoken to him in depth about the procedure but only in terms of keeping him up to date with the transfer status to another hospital. A key moment on the ward was when he met an ex-patient, who was visiting the ward as a volunteer. He spoke to Richard about his successful operation twenty years ago which provided Richard with a strong sense of hope. This made me reflect how peer support had significantly contributed to relieving his anxieties over his impending surgery.

For Fayza, it was a revelation that her own next door neighbour and people from her local community turned up at the patient only meeting, having had no idea they had suffered the same event:

'...well I find it really comfortable cause my . . . the people, another patient was same our, my neighbour! I didn't know that! I didn't come across that he . . . he was here with the group. And I know somebody else; found two people – three people, I think (Fayza/patient T2)

The above extracts reinforce the idea that significant health events (heart attacks) were not discussed with others. The change between 'my' and 'the' indicates a subtle recognition of her cultural perception of the people within the patient group and that Fayza found comfort in familiarity within this setting.

Identifying and belonging to the patient camp remained consistently important for the patient participant group over the duration of the project. This was seen in terms of the following joint co-design event and smaller co-design groups.

Additional data – Non participatory observations

joint co-design meeting

At the joint co-design event all the patients sat together around the table and faced the staff for the start of the meeting. They appeared to be more comfortable sitting together and presenting a united front. This was remarked upon by the patients who were aware that the position looked confrontational but no-one moved to redress the balance.

This connection also extended outside of the EBCD project with Fayza and Haseeb drawing upon each other for support at the start of the project and visiting each other at home:

'...he [Haseeb] did say oh go for it and he did come to visit me and I went to visit him'

Although the patient participants were drawn together over a significant life experience Sara, a patient volunteer, also identified closely with the patient camp. She had direct experience of family members being on the ward having suffered a heart attack. The following extract illustrates the way she perceived her own identity when connecting with other patients during the observational component of the EBCD process:

'I'm just like yourself. I'm not a medic. I'm not academic. I am just the normal person from the street who's talking to you um, about this project... I think when they meet somebody like ourselves and give them that confidence... I think patient's carers speaking to patient's carers makes a big difference. ' (Sara/Patient volunteer, T1)

Sara was very keen to identify with patients and carers that she interacted with in order to gain their confidence and trust. The use of the phrase 'I'm just a normal person from the street' adds to the idea that the healthcare professionals are seen as different, and a subtly suggests a degree of professional hierarchy. By identifying as an ordinary person Sara, is intentionally placing herself in a more comfortable position within her role in the EBCD project. This position exploits the connection within the patient camp to talk about things not routinely shared with healthcare professionals (who are outside their camp). This view remained consistent over time for Sara, with the extract below highlighting the outcomes of the project being framed in terms of benefits for patients and carers:

'I felt a sense of achievement because I could see from, especially from this project, that your project was going to benefit patients and it's gonna benefit carers, and hopefully... will make that patient who's going to be discharged in a better position.' (Sara/patient volunteer, T2)

However, for Jean, her account suggested a more divergent perspective. She perceived her role as more of a 'go-between', occupying the space between the patient and staff camps. Jean's account offered a 'shinning gem' when describing her role in the EBCD process and extended Ivy's wartime metaphor:

'I'm in no-man's land, but, because of the position I'm in, I'm able to see both sides.' (Jean/patient representative T1).

Being able to provide a neutral viewpoint was something that Jean saw as advantageous. Although the idea of no-man's land has connotations of dangerous ground, it conjures images of a white flag being waved; by taking a more neutral position she felt she could adopt a more balanced approach to understanding the issues around improving patient care. Jean's more ambiguous status is expanded within the following theme in order to explore the idea of people as boundary spanners.

The idea of a patient 'camp' helps to make more sense of the invisible boundary that appeared to exist between staff and patients. For staff participants their self-identity was firmly embedded in their professional 'camp'. This influenced the way they interacted with the patient participants in the QI project and was justified in terms of needing to adhere to a professional duty of care and preventing undue harm. Staff wanted to protect patients from difficult conversations and activities as part of the EBCD process, mindful of their long term health conditions:

'...you've got to remember they're patients who have got heart conditions um, and they still remain patients... so we've got to be very careful if we talking about maybe patients are d-dying or patients that suddenly die or expected death, that that will be in their minds that that could happen to them.' (Claire/staff, T2)

There are several issues to note within this extract. Claire's response to the idea of discussing care pathways with patients, within the co-design activities of EBCD was protective and considered, as indicated by the phrase 'we've got to be very careful'. Her professional experience reminds

her of the harsh reality that these patients may still face poor health outcomes owing to their long-term conditions. By keeping the relationship within the professional/patient domain, this may have helped to manage her concerns over sensitive topics but this idea also conveys a sense of power and control. Although the staff were working with people that were considered 'healthy volunteers' Claire defined the patients in terms of their health status: 'they still remain patients'. This extract infers that as a healthcare professional (her camp) she is able to set the agenda about what is talked about. This idea is important when thinking about the role of power and the interpersonal dynamics within the EBCD process. A short extract from John, also subtly suggests this complex interplay between patients and staff;

'I think they'll be delighted and I think it's a very useful thing to have [patient involvement]. Um, they are the end-users at the end of the day: the people most likely to be affected by it.' (John/staff, T1)

John's use of the word 'they' is interesting. It evokes a sense of 'us and them' mentality by not using a more collaborative expression. This infers that he sees patients as a separate entity from staff (different camps). His almost throw away comment at the end of the extract suggests that he may even discount the effects of improving the experience of care may have for staff. Again, the idea of improvement benefiting the 'end-user' infers a professional distance between himself and his patients. John describes his professional role as having a 'nominal touch' to all aspects of care delivery and describes communicating with patients as 'interfacing'. The phrase conjures the image of more perfunctory interactions with patients, in a de-humanised tone. This elicits a sense of being detached from a more personal engagement with patients and supports the idea of professional camps.

Additional data – Non participatory observations from an early co-discovery session with staff, patients and designers (June 2015)

During a session to map out the care pathways for patients admitted to the hospital with chest pains, there was a sense of frustration as the staff member tried to explain the multiple routes through the service. This was evident from the repetition of information relayed to the group and a need to re-emphasise what could or couldn't be changed by the service. It took a long time to explain and explore the care pathway within the group, and

tensions arose between stake holder groups when designers and the patient volunteer challenged accepted ways of doing things and suggested possible changes.

The effects of professionals and patient camps were also evident within an early co-discovery workshop to map the process of care (See Section 1.9). Tacit knowledge about the way care was delivered was not commonly understood by patients and the design team. This caused difficulty for staff, as Claire commented:

'...I don't think that everyone appreciated the different pathways that patients go down. And it's really hard to explain to people that are not based on a ward or don't have medical backgrounds ...'
(Claire/staff, T2)

The tension for Claire was getting others, not within the system, to understand the complexities of providing and delivering care. There is the suggestion here that only people with insider knowledge would understand what happens, that intimate medical knowledge was needed. There appears to be a source of knowledge that is carried by staff but is not routinely shared with others outside the system, and thus, the patients and designers were unaware of the implications of making small changes may have on the larger system. The actual processes and decisions associated with care were not ordinarily visible to others outside the system. The phrase 'I don't think that everyone appreciated the different pathways' evoked a sense for Claire, that even by the end of the meeting others still did not grasp the real complexity behind the care pathway.

Esther also identified as a member of staff, but her 'tribe' was within the specialist professional world of QI. She saw her role as a facilitator to bring about changes to care with patient and staff:

'...it doesn't matter what project it is, it's all about changing culture and, and, and supporting staff, you know, to work differently based on the experience shared by patient[s].' (Esther/Staff T1)

This short extract has several items to note. The word 'shared' suggests a more collaborative sense of patient involvement, which differed from John and Claire's (the clinician camp) professional world. This extract also suggests that Esther sees the value of patient experiences as a lever to change culture. The phrase 'it doesn't matter what project it is' suggests that the hidden outcome for all QI work is really concerned with a higher

ideal of culture change, doing things differently, a sense of a more permanent change in thinking and practice for the better, rather than just the outputs from a specific project. However, interestingly Esther alludes to her professional boundary within this short extract:

'I'm there to support them as much as I can but it's about them taking ownership and there's only so much you can do . . . for staff.'
(Esther/Staff T2)

The extract above illustrates Esther's own boundary with regard to her personal and professional responsibility for the project. By positioning herself in the QI camp, she was able to emphasise her role as a facilitator and thus, not have to take ownership of the project. So, although being a member of staff within the organisation she did not see herself as part of the cardiology service. Esther's ultimate focus about 'changing culture' was something that was not identified as a primary outcome in other staff member accounts; they were concerned with more direct changes to the service to improve the experience of care for patients. When considering Esther's comments, there is a change in tone over time from suggesting a more supportive attitude to help staff to work 'differently' to a more deflated sense of achievement, as suggested by the phrase 'there's only so much you can do...for staff'. This may have been owing to the lack of tangible outputs from the work stream that was led by Esther. The following extract described her frustrations over the modest changes that accompanied the co-design work. By retreating to her tribe, this may have helped to make sense of the experience and provide a mechanism to protect her from the negative connotations of a failing to achieve the desired outcomes.

It was difficult to determine changes or consistencies over time for staff members as they were only interviewed at one time point. However, from Claire's account she remained highly cautious in terms of working with small discrete groups of patients despite theoretically appreciating the value of patient and public involvement:

'I think it's got a massive benefit having patients involved from their perspective. And it's important to actually listen to their perspective...the other thing that I have to wonder is as well is the patients that come in volunteer for these projects are they typical of our patients?..... these tend to be older volunteers um, who are comfortable in life – and this is my experience of the ones that we've got at the moment – they, you know they've got the interest in

coming back to the ward; they've got the motivation to come back to the ward. They want to give something back and those are all brilliant things but it's probably not typical of our standard patient.'
(Claire/staff, T2)

This extract conveys a certain scepticism about the EBCD approach, Claire makes some assumptions about the patients that were involved in the project, yet from their stories, despite some coming from more 'comfortable' backgrounds, the distress and shock was something that was shared by all. Yet, for Claire she is aware that this may not include the 'typical' patient she encounters on the ward. This implies that although their knowledge and experience is valuable it is not enough. The sense of Claire placing herself in the professional camp sends out a strong message about what knowledge she believes is valid in the context of QI efforts.

Sam and Frank, as design engineers, occupied very clearly a self-defined professional camp, within the design sciences. This came with several assumptions about knowledge generation and underpinning professional philosophies. However, the notion of patients and professionals occupying different camps is further reinforced with the following extract from Sam:

'...culture of being a healthcare professional is different to being a patient culture... and the reasons if you ask them are very different to the patient, what they're doing and why they're doing it, are extraordinarily different...' (Sam/designer, T2).

Sam refers to cultural differences that may exist between the different camps. The above extract also alludes to his previous experiences working with healthcare a professional which infers that he brings with him tacit learning from co-design work, aware of different perspectives and life worlds that the patients and staff operate within. The word 'extraordinarily' suggests Sam's surprise about how marked the differences between two camps are.

5.8.1.2 Sub-theme 1b: Boundary spanners

This theme links the previous theme of 'camps' and the idea of certain players acting as 'boundary spanners' between the camps. This role was something that the designers bought explicitly to the process when compared to the others who assumed this position in a more nuanced way. It is noted here that much of the material within this theme draws upon the experiences of the designers, patient volunteers and the QI specialist staff

member. This is owing to the nature of their involvement and their perceived role within the EBCD process.

Sara identified strongly with the patient camp and bridged a gap between patients and staff, in an attempt to access the patient experience. This included a more participatory approach to conducting observations, and making sure the patient voice was incorporated during an early workshop with staff to map out the process of care (See section 1.9). The following extract from Sara, illustrates her understanding of what she brings to the process:

'...if you're an academic or researcher you think . . . in a different mind-setting. As a patient who's involved or carer whose involved they can give you that personal experience that will help you um, to look at it from an eye-from the eyes of actually being through that experience.I've found it um . . . extremely beneficial because it makes not only that um . . . I can speak to patients at their level (Sara/patient volunteer, T1)

There is clearly an indication of wanting to bring the patient voice to the process and awareness that there is a different perspective or 'mind-set' that the professionals bring. Again, Sara alludes to the notion of hierarchy that exists, which infers that it may be difficult for the 'standard' patient (as referred to by Claire in the previous section) to get involved. This notion of hierarchy is explored further within the designer's accounts later within the theme.

Jean describes her boundary spanning position but takes it a step further. She perceived her role in the EBCD process as providing a sense of neutrality, occupying 'no-man's land', which she saw as a benefit for QI efforts. The following diary extract from Jean describing the advantages of not being burdened with clinical work or having to think about competing demands that staff would otherwise have to consider:

Additional data – participant diaries

Jean - 23 June 2016

"As a volunteer I have no specific loyalties, no external demands. I am able to take an entirely neutral position and pragmatic approach to observations. A volunteer has the luxury of concentrating solely on specific observation/interviews with individual patients without any additional demands."

The idea that Jean sees herself as being in a luxurious position recognises the difficulty that clinical staff may face trying to engage in QI work, as well as, the idea of QI work being a luxury. This conundrum is exemplified by Claire:

'...so the piece of work actually um, was very useful. I can see the merits of it, in that if we can make a smoother discharge that would be the icing on top of the, or the cherry on top of the icing... often it does feel like we are just churning patients in and churning patients out. And we haven't, we just haven't the time to do the nursing things that we used to do.' (Claire/staff T2).

The above extract illustrates the simultaneous tensions that QI work brings in the clinical domain, that improving care is an ultimate outcome but difficult to achieve in the existing clinical climate. The notion of QI efforts are seen as the 'cherry on top' signifies the idea of luxury and the best scenario. However the reality suggested here is that staff may not have time to even appreciate the cake. This idea is fundamental to understanding the barriers to connection, that despite the professional and personal drives to improve care, time to connect, to understand needs to be created in order to foster more collaborative ways of working.

The idea of spanning boundaries was evident within the designer's accounts. This was in terms of what the design sciences brought to the EBCD process and what the designers brought as individuals to the process, professionally and personally. In the first instance, the field of design sciences crossed multiple boundaries and searched for a common rubric to bring all sides together:

'so that means co-design stuff and it crosses...the boundary between service design and um, er, technology, health technology, design and innovation...And that's what our approach brings in: is to address those barriers using a kind of tangible language, a creative language that then takes out the science or the professional jargon, and makes it accessible to everyone, and common to everyone.'
(Sam/designer T1)

This notion of a '*creative language*' also suggests a different way of talking to each other across different stakeholder groups which alludes to the need to make the dialogue was meaningful for all. Language used solely between healthcare professionals was recognised as being very different when compared to communicating with patients, as Claire comments:

'...you've got to be very careful how you communicate 'cause as professionals, we're used to talking to each other in a different way. And having patients in the room, they don't always understand um, the banter or the maybe sarcasm or humour professionals use. A- and actually might find something what we say inappropriate.'
(Claire/staff T2)

Healthcare professionals usually interact with patients within a different context: addressing healthcare needs, and not within the context of QI activities. Claire suggests that language normally used between staff may have to be moderated in order not to cause any offence, or have comments misunderstood by patients. Thus, bringing patients, staff and designers together may require a new type of dialogue and set of rules, as suggested by the designers and the need for a creative language.

The designers also had a very different agenda when it came to breaking down barriers and was associated with their professional and personal philosophical assumptions:

'I think there is still a very um, a hu-big hierarchy where there is this view that academic knowledge is superior and knows best, and that it doesn't have to think about and include with the knowledge of other people that, it's, it's because it's un-validated. It's um, it's subjective; it's all these other things that don't fit the scientific description of good quality data. And so therefore it's not given the, the credibility that perhaps it deserves.' (Sam/designer T1).

Sam in the above extract recognises the potential issues with patients' stories being accepted by professionals, as they are steeped in subjectivity and concern the few and not the many. This was alluded to in Claire's earlier extract with regard to accepting contributions from a few highly motivated patients from a comfortable life position. Sam brings with him his own professional socio-political orientation which shapes his perception of patient involvement:

'..how we work, sort of underpinning philosophy, values all participants as experts in that process..' (Sam/designer T1).

His understanding with regard to this type of improvement methodology (EBCD) differs from Claire. He recognises the value of different stakeholder perspectives:

'Because there's value in having it quite small and contained but you've always got to be thinking about the possibility that you might be missing a perspective um, and there is a, a real benefit to, I firmly believe that um, improvement work and design work benefits from a diversity of ideas and views and perspectives, massively.'
(Sam/designer T1).

Sam's extract strongly suggests his assumptions about the co-design process, which is also based of experiential learning, and the constant negotiation between valuing individuals within the process and thinking about who may not be represented at the time.

The way the designers spanned the boundaries between the different stakeholders was also associated with specific and intentional activities used within the co-design process and linked back to the notion of a establishing a connection between others. This included more informal and nuanced aspects of co-design meetings. Rituals like pouring tea and cutting a cake, small talk and banter between the designers all served a very deliberate purpose for Sam. Breaking down the barrier meant developing a more of familial feel, where patients and staff could come together as people, embracing the spirit of co-design:

'...we'll always try and have at least one whole cake that you have to cut into, because there is something about the nature of cutting into a cake to serve everyone a slice of cake; and not one that's pre-cut: one that you cut with everyone, in front of everyone. That's very, very informal. That's very sort of family...it sort of sets a lower level of formality to the whole thing and bonds people more closely'
(Sam/designer T2)

This understated and soft approach to creating a more conducive environment was observed as a part of a suite of tools and techniques used by the designers. This was in contrast to group design meetings led by staff. The following notes were from non-participatory observations of the co-deisgn meetings highlighted this difference:

Additional data – Non participatory observations

Designer led sessions - The designer's demonstrated flexibility and responsiveness to planned activities during the co-design sessions, and though they tried to stay on track, often the discussions between patients, staff and designers took precedence. The importance of small talk and

'banter' between the two designers was seen as a crucial part of building relationships. Designers moved around the room, often crouching down to patient's eye level during discussions, appearing to be mindful of physically reducing hierarchies.

Staff led sessions - There was less conversation at the start of the meeting and little attention was paid to the informalities at the start of the meeting although the same refreshments were provided.

Breaking down barriers was also seen in terms of the types of different activities within the co-design meetings. The designers wanted to bring an air of playfulness to proceedings. This was seen to promote a sense of cohesion within the group and help to engage staff and patients together in order to uncover the issues that needed to be addressed to improve patient experience. Frank commented:

'...because it's role play it's a bit kind of like funny and engaging, even though, well one participant er, [female patient] was like, 'Oh no! oh we're gonna play.' I remember her saying, 'Right guys, we're gonna play. We're gonna do the role-playing today,' and she's like, 'Oh no!' and like cause she probably doesn't like to be on stage or something. But because it's all in a kind of friendly [way] and you build up relationship and you've got [indicates by making knocking sound] physical stuff to kind of you can base yourself onto it all went well and we got, well we gathered some interesting data, even though we didn't have enough time to cover it all!' (Frank/designer, T2)

This extract demonstrates the role of the designers taking people out of their comfort zone in order to explore experience. But, because of the subtle activities that preceded the main focus of the co-design group meetings, relationships developed over time. Jean described the pull of the environment created;

'it was fascinating. It . . . the dynamics were excellent really. Um, I think the facilitators created an inclusive ambiance and adhered to the agenda, and that was good because I felt, I felt drawn in to it.' (Jean, Patient volunteer, T2).

Additional data – Non participatory observations

Designer led sessions - The range of activities varied, from role play with props, to creating 'mood boards' - patients were given 'homework' and

asked to bring in pictures to describe their experience of being in hospital. For example, one patient brought in a picture of a bus (they wanted to signify being hit by the proverbial bus). A mock-up of the patient held handbook was produced in different formats for feedback. These were tangible outcomes from the co-design work, that the group were pleased to see.

Staff led sessions – The meeting was led by the QI member of staff and began with broad introductions and conversations to clarify key issues for the service. This was achieved by round table discussion with staff and the patient with lots of non-verbal signs of agreement during the discussion (nodding heads and sounds of agreement). The staff member leading the session used flip charts and different coloured pens to record the discussion and make sense of what the issues to be addressed were. Discussions moved from the specific to more generalised concerns. There was little input from the patient participant at this meeting and appeared to address the concerns raised by staff. The issues raised by the trigger film were forgotten by the members of staff despite being present at the joint co-design meeting.

The concept of boundary spanning remained consistent for designers but changed over time for Jean. Though initially finding a purpose within the observational work (as revealed within Study 1), Jean commented on a loss of relevance personally within these meetings, and felt unable to contribute meaningfully to the co-design element:

'I had difficulty with, from a, on a personal level, was when it was um, about the patient's experience because . . . I-I didn't feel able to participate. I could've said all sorts of thing about being a patient in hospital because I've been in hospital several times but, but that wouldn't have been relevant. So um, I suppose . . . I wondered if I should've been there at that point. I didn't mind because I found it interesting but I was disappointed that I couldn't make a contribution; but . . . in the other meetings I felt able, the issues were more general and I felt able to participate and that was fine. Um, but it was . . . I think the patients needed to talk and there was a fair bit of repetition because they're obviously still in a . . . in a state of disarray about their conditions, aren't they really.' (Jean/patient volunteer, T2).

Jean highlights the nature of these smaller co-design groups, which appeared to support a therapeutic function for the patients within the meetings. She comments upon the 'repetition' of stories from patients and recognises that they are still making sense of their experience of suffering a heart attack. Where she did feel able to contribute, was when issues were more generic, but there is a sense of not being totally part of this 'inner community' of patients. Jean also comments on her 'disappointment' at not being able to meaningfully contribute to the session, but this was not identified by others as an issue.

Esther, within her role as a QI specialist also sought to span the boundary between staff and patients bringing her knowledge and expertise with regard to change management:

'...so one of the key things that are challenges which are across the board er, around I think I mentioned before, behaviour change, culture um, support, support for staff around the expertise required to change behaviour and culture.... so there's a bit of training, there's a bit of capability building, there's a bit of um, expertise and support and culture into working differently to achieve change.' (Esther/staff, T1)

However, with regard to the EBCD approach Esther appeared to take a far more distal approach to the change process and really saw herself as a facilitator. This implied that much of the work needs to be driven by staff and without their input she was powerless to make or lead changes, as the extract below suggests:

'But we didn't have the staff representative with the knowledge; you know expertise to kind of give some direction on what needed to happen.' (Esther/staff, T2)

The issue of staff being able to be consistently involved in the smaller co-design meetings was a constant source of tension. Whereas, the designers persevered often only working with patients in the co-design meetings, they also sought ways to adapt the process. However, for the Esther, without the availability of staff the co-design sessions halted with outputs left on hold.

Reflexivity point:

The designers ran bespoke ward based sessions for staff to share the on-going development on a patient held handbook. Early prototypes were left

in the ward office and senior staff was asked to encourage all ward staff to look through the handbook and add comments on post it notes. These could be anonymous if desired. These were collected from the ward after two weeks and the feedback was reviewed by the designers. This was a way of interacting with staff whilst addressing the issue of staff availability.

5.8.1.3 Sub-theme 1c: The empathy scale

This theme refers to the importance of empathy within the EBCD process. The title includes the word scale, and as this term suggests there was at times a wide degree of variation with regard to the empathy expressed within and towards the different camps. The way in which empathy developed and was shaped by the interactions during co-design activities was an important feature when considering how and why people connected during the EBCD project.

For all the patients and patient volunteers the primary reason for taking part in the EBCD project was expressed as an outwardly altruistic concern: they genuinely wanted to make a difference for other patients in similar situations. Fayza (T2) stated, 'I got the experience, why not share it?' and Haseeb (T1) wanted to ensure the experience of care was the best:

'well, I like about it is er, in the hospital patient, how they suffering, you know so everybody want to come one day in this hospital so we want to bring in, in Yorkshire, this hospital, you want to bring in the top grade, you know.'

This is also illustrated by Harry reflecting upon his reasons for taking part:

'I don't think, I don't think I were looking for myself to get things out of it.....I think er, I were more thinking about . . . it might help somebody else in the future. (Harry/patient, T1).

The psychological toll of the experience of being a patient was also something that they did wish other people to go through, as Ivy said:

'It left me quite emotional. Um . . . and I-I saw so much, experienced so much during the time I was in hospital. Um, now I'm very keen to . . . improve things if I can, or take part in anything that would improve the experience for future patient.' (Ivy/patient, T2)

Additional data – Non participatory observations

Ivy's emotional recall of experiences in hospital

Ivy's extract here, contains a couple of nuanced pauses. Whilst, recalling her experiences, whether about her time in hospital or taking part in EBCD events, she would often look out in a trance, almost appearing to visually replay moments. This was something that was remarked upon by the design team, and made them more acutely aware of how emotive it was, thinking about these events, and often made her tearful during co-design sessions.

The sense of altruism was a main motivating factor for patient involvement in the project and remained consistent throughout the duration of the project. Understanding and improving the service was also seen as a primary concern for staff. They realised patients were brought into an unfamiliar world and anything that staff could do to ameliorate the situation for the better was considered an optimal aim. The extract below illuminates this particular issue as John comments on his perception of patient centred care within the service:

'Did you genuinely feel that your- my health was the most important thing to you?' because I often think we let patients down on that' (John/ staff, T1).

This short extract highlights the reflective nature of John, as a healthcare professional. The use of 'we' infers a collective responsibility for care delivered but this self-awareness feels brutally honest and evokes a sense of sadness, that staff feel that they 'let patients down'. However, despite the empathetic feelings for patients this did not translate into any personal direct action with regard to the smaller design group work. Interestingly, John saw 'health' as the ultimate outcome for patients and links to the idea of being positioned within the clinician camp. He was focussed on improving health outcomes rather than focussing on the experience of care.

Additional data – Non participatory observations

During the joint co-design event John attended the meeting but placed himself physically outside the main group. There was almost a sense that he was observing the observer, who was observing the group. He did not join in with the group discussions but at the end of the event spoke to me about the issues that had been identified by patients and staff. John commented that the issues that the patients had raised with regard to improving the experience, such as, more information and reassurance, he thought that the service already provided all the information they wanted. It

was at this point that I suggested that the timing and the way the service delivered this information could be revisited, as there appeared to a disconnection between the information being sent and the information being received. This was an awkward moment for me. I was aware that I was there as a non-participatory capacity, but not to verbalise my observation felt as if it would have been a lost opportunity. However, it made me think about John's lack of engagement after this event with the project and whether I had jeopardised his involvement or whether his actions were unaffected by my comments.

A key factor in developing and maintaining connections related to the emotional and personal effect of patients' stories on stakeholder groups. This effect differed between groups and remained consistent over time. The trigger film appeared to be one way in which the designers first developed a connection with the patients involved within the EBCD project. Sam and Frank were closely linked with the development of the trigger film, Sam had conducted some interviews and both were directly involved in creating the final film. This activity provided a way of developing a deeper level of understanding for the designers about the reality of suffering a heart attack:

'...there's plenty of things that have been entertaining. Some surprises umm, it, it's very revealing as well the to get a real insight into people's um, their kind of well views um, but also the kind of impact that . . . things that happen to them have on a um, sort of fundamental level in terms of their identity and their relationships., it's just intriguing. It's a strange kind of voyeurism in a way um, but it's, it . . . it's fan-fantastic cause it's just such a raw human qualities, which are incredible...so you get the shocks like um, the lady that cut her hair off. Um, and then you get the sort of er, sort of loving conflicts between the husband and wife, where she's obviously spotting things about him that are very different and very changed. But he can't see them about himself and they're trying to, there's obviously a deep love between the two of them; it's not a conflict in that sense. But she was trying to get him to see things from a different way, different perspective. And he's stubbornly refusing!' (Sam/Designer, T2)

Sam describes his reaction to the viewing the filmed interviews as 'intriguing'. It infers that Sam first connected with the patients through their

visceral stories before meeting the group in person. These stories were far more holistic in nature and revealed issues that were important to patients, such as changes in relationships with family and friends. Again, Sam also refers to the idea of voyeurism (discussed previously in Study 1) which reveals his awkwardness at watching such emotive and personal narratives. Interestingly, Sam also mentions the word 'entertaining' which implies a real sense of engagement with the filmed interviews, and the whole extract above gives the sense of the highs and lows, the more intimate moments between husband and wife that have been captured in such a 'raw' way. This in fact is not a 'movie' but the real world experiences in which participants have willingly shared highly personal moments, perhaps this is what Sam is trying to portray, *'to get a real insight'* into the life worlds of the patient participants. There is a sense that the filmed interviews provided a level of insight that went beyond describing the process of hospital care.

The effect of the trigger film also changed Frank's perspective over time. Frank's focus initially was on the global aim of the EBCD project, to improving the patient experience of discharge care (See Section 1.9). But, this was in terms of understanding the process of care rather than the experience of care

'But then there is like a whole process that you go through, and especially afterwards when you are actually leaving the hospital and things should be . . . empathic and simpler....so as a designer coming in, joining in, it feels like um . . . we should improve and, and feel er, yeah, improve like the overall experience, and, yeah. So that's, that's er, my driver in a way, my motivation.'(Frank/designer, T1)

However, Frank's reaction after watching the patient interviews and prior to making the trigger film revealed a deeper level of understanding:

'The patient's story /overview was, I thought that was quite . . . a powerful thing...the emotions of the patients...for instance, crying, like well you can't be indifferent to that...Yeah, it was like 'Fuck [pauses] well, when I was listening to ...[a patient's] story when she went back home and cut her hair, I was like pffww!' (Frank/designer, T2)

Frank's use of strong language, followed by a pause (taking in the enormity of the actions by a patient) and verbal utterance at the end of the extract

'pffww', helps to emphasise the impact that one patient story had upon him. Frank was shocked, by the description and actions of Ivy retelling her story. This developed a connection to the patient group as he describes, 'well you can't be indifferent to that'. This extract highlights a greater level of understanding what the experience was like rather than understanding the process through the system.

Reflexivity point:

Conducting interviews for the EBCD trigger film

As part of my project facilitation role I conducted nine out of eleven face-to-face interviews (See Section 4.3). My field notes from these interviews remarked how emotive and intimate some of the narratives were. The interview schedule was loosely based on the process of care delivered but patients were given as much time as they needed to tell their story and trying not to impose too much structure. My experience as a qualified nurse and clinical work with cardiology patients may have helped to develop a rapport with participants I remember vividly the patient's account of cutting her hair off when she got home from hospital, almost in act of defiance, anger and 'bloodletting'. This act appeared to provide some short-term relief and may have been a way of signifying outwardly her inward altered state that she could not verbalise to family and friends. The effect that it had upon me was equally emotive. I questioned how as health care professionals we had somehow failed this person – how could they have been left to go home clearly distressed and having not been given the support they clearly needed. Another patient I found myself feeling protective over and quickly developed a strong rapport. She reminded me of my own mother, and at times had to consciously make note of these feelings especially when analysing subsequent interview data for this study.

After watching the trigger film at the joint co-design event, Esther commented on the profound effect of the film upon her:

'it was very emotive um, and but also insightful to hear their own perspective around, you know their story and erm, how, you know how they all reacted when they got to hear that, you know that this is now something that they have to live with for the rest of their lives and um, how most of them had to kind of come round to the issue of 'Okay, this is what I've got now so how do I manage this going forward.' And um, the perspective it kind of highlighted kind of, or it

made it clear that sometimes you kind of blind staff to what the patients sees, or what the patient experience is' (Esther/Staff T2).

There are several issues to highlight within this extract. Esher's reaction to the film was not only at an emotional level but made her consider the wider long term health implications, projecting forward to what life will be like in the future for these individuals. The phrase 'you kind of blind staff' that Esther uses, considers the possible hidden aspects of patient experience that may not be ordinarily accessible to staff. However, the effect of the film on other staff members is less clear. Claire did not attend the joint co-design meeting and John declined to be interviewed at T2 (the ramifications of missing data are discussed in Section 5.6). But, participant diary extracts below reveal some of the divergent feelings about the joint co-design meeting and illustrate the degree of empathy that fluctuated between patients and staff.

Additional data – participant diaries

1. Sara - 04/07/2016

'The room was awkward. Could not see everyone.'

'Not nice that 80% staff left after the break.'

'Unable to express thoughts with staff and those high up'

2. Jean - 04/07/2016

'The duration of the meeting was approx. 21/2 hours long, including a short comfort break. Given the weight of the agenda, it could have run to 3 hrs at a push. The facilitators were effective in eliciting pertinent information from participants. They facilitated a group discussion that led to the identification of group priorities be taken forward to smaller co-design working groups...The facilitators created an inclusive ambience and adhered to the agenda, whilst also picking up queries/comments that arose during group discussion. Commitment to this experience based co-design project and enthusiasm for it, was very much in evidence.'

3. Ivy - 04/07/2016

It helped me that this time the subject of psychological trauma on patients after surgery was raised (I thought I was the only one until now). I think I expected more discussion and information from the people who do the actual surgery and pre-surgical activities. They appeared to speak only to each other rather than the group and it was disappointing when they had to

leave before the meeting was over. Busy, important people in much demand should be aware that a smile and words of reassurance take up little time yet contribute so much towards putting patients at ease whatever stage of treatment they are at.

Sara and Ivy were indignant that some staff prematurely left the meeting. Ivy comments on the small niceties that can have a big impact upon patients, 'a smile' and 'words of reassurance'. Staff leaving early only confirmed previous poor experiences that she had encountered as an in-patient, which focussed around communication. Ivy also infers a sense of hierarchy and power in terms of the patients and healthcare personal dynamics. Sara also comments that she felt unable to comfortably contribute at this meeting despite the apparent efforts of the designers. However, Jean commented upon the feeling of the commitment taking the EBCD project forward and did not raise any the issue of staff leaving early. This may be owing to her self-identity, occupation of a neutral territory, in the context of being involved in QI efforts (as discussed earlier). Conversely, the other patient volunteer Sara appeared to identify more closely with the patient perspective which may account for her more pointed comment on staff leaving.

These extract also suggests that despite the emotive film, this device was possibly insufficient to hold staff at a pre-planned meeting. What became evident over time was that in order to maintain connections between the stakeholder groups, the immediate effect of the trigger film was not enough. The designers felt that it was through face-to-face group work that connections were developed and maintained:

'It's the more of a connection you can have with the real person sat opposite you in the co-design team the better...I think creating that bond between patients and staff is really key. If you don't kind of create that at the earliest opportunity then um [pauses] and it doesn't, the trigger film itself isn't enough to create that bond. There's something that . . . that [sighs / pauses] you can create empathy for sure in some members of staff, not in others. But even empathy isn't necessarily a bond; you can empathise with someone without actually saying.....15 people sat round the table just watching the screen for half-an-hour. And that's not an engaging, an engagement between people. That's an engagement between individuals and a screen [pauses] and that I think, yeah I-I . . . I think

it's a bit of a red herring that or . . . not red herring [pauses] it's the wrong foot' (Sam/Designer, T2)

Sam's audible pause and sigh infers disappointment and frustration over the effect of trying to trigger an emotional response in all the staff. He makes a distinction between the more immediate emotional responses and the difference of creating a bond between stakeholders. This is a subtle difference but a sense of community and bonding is needed to ensure co-design happens. Ivy's diary extract also commented on discussions happening within groups and not between groups. The idioms used, 'red-herring' and 'wrong-foot', both summarise the feeling that the trigger film may not be the influencing factor that the EBCD process suggests. This sentiment is consistent for Sam over the duration of the project and may be partly explained by his previous experiences with clinicians within other co-design projects:

'It was a sharp reminder that actually there can be a, a coldness and pragmatism to decision making from the professional side.'
(Sam/Designer, T1)

The function of empathy is questioned here within the EBCD process. Sam believes that a direct connection and relationship building is the important aspect of the EBCD process. The notion of empathy fluctuates throughout the duration of the project and appears to be contingent upon context. At the start of the project there was a general sense of collaboration and desire for patients and staff to work together to improve the experience of discharge and care within the service.

Prior to the meeting Frank commented about how the trigger film might be received:

'Frank:...I'm curious of seeing how staff and patients might react. How staff might react to the video that we are going to show them about the experience of a patient. And how the patient might react from the staff reaction. Um, maybe we should provide, should-shouldn't provide any sharp pens or [laughs] um, but I, I, I'm sure it can, it can be like a, and it will be a really fruitful like er, event. You're probably gonna be tired because you want again . . .

LT: Why do you think you'll be tired'?

Frank: because there will be a lot of emotions and a lot of, and probably some conflicts but er, but . . . people going to an event all

going there for the same reason. So there is no reason why it shouldn't go well. (Frank/designer, T1).

This extract highlights the possible tensions that Frank was anticipating at this event. He uses humour to deflect the possible consequences of things not going well by suggesting removing sharp objects from the meeting. But this may indicate the strong emotions behind the experience of care for the patient participants, and at this stage is unsure of the reactions that the trigger film will elicit. He assumes that staff are there for the same reasons as the patients and therefore, sees no issue that may negatively affect the joint event. However, the joint co-design event appeared to be a pivotal moment in the EBCD project and appeared to show dramatic changes with regard to empathy displayed between staff and the patients and designers. This was concerning the attitudes, non-verbal cues (falling asleep during the film) and leaving before the end of the session by some senior members of clinical staff. Whilst the joint event has been discussed in terms of developing and keeping connections the emotional impact upon the patients and the designers was blistering. Sam, when asked about the event commented,

'well, very angry internally. It was, you know [sighs] deeply, deeply frustrated. And I think for me and sort of dragging in um . . . my own . . . erm, subjective personal baggage political things and class-related things and all sorts of stuff like that, I-I felt deeply kind of um, a-annoyed that someone who was obviously so intelligent um, and obviously so erm . . . so well off – not-not not financially but through the choices and opportunities that they had had available and they had probably made for themselves as well. Um, that they could just be so dismissive...I know that they work long hours. I, you know I realised and accepted that that person could've been on duty from 5am in the morning and this was the one chance that they'd had to sit down. So there is that at the-I think sort of a warring thing inside me about, about those. But I just felt he could've a bit of respect would've-so even if he'd had to sit on some drawing pins to keep yourself awake should have been there for the patients who'd all turned up and were all there.' (Sam/Designer, T2)

There are several things of note within this passage. In the context of a specific event, Sam was profoundly irritated witnessing a clinical member of staff 'nodding off to sleep' when watching the trigger film, which was

exaggerated with his sigh and repetition of the word 'deeply'. His personal social values and beliefs are also raised in terms of what he expected from the clinician, that despite understanding that they may have had a challenging day, he firmly felt that he should have shown courtesy and respect to the people that had turned up. This also illustrates Sam's underlying professional philosophy with regard to the contribution of design sciences within co-design, breaking down boundaries (as discussed earlier) and championing the patient perspective. His empathy was extended to the patients but not to the clinician in this scenario, suggesting that they should do anything to remain connected to what was being shared, even if it meant self-inflicted pain to stay awake, 'sit on some drawing pins to keep yourself awake'. This may have seen an extreme reaction by Sam but may be explained by a deeper level of connection to the patients that had developed through creating the trigger film and spending time with the group at a face-to-face patient only event. He also had a vested interest in the film:

'I felt quite a deep sense of responsibility . . . because we had edited this . . . trigger film, but it was representing the experiences and views of other people that were there in the room. Now although we'd kind of run it past them, umm....So if it didn't achieve that, there was this, for me, there was a sense that I might have let them down.' (Sam/Designer, T2)

This feeling of responsibility may have made the reactions by staff feel more acute, that he felt responsible for the reactions or actions as a result of the film. In this case this was not the desired effect of the film. Mary also commented on the reactions of a certain clinician:

'It made you feel like you were worthless and of no account to anybody ... as he did when he did my angiogram...I wanted to get off that table and slap him ...how difficult is it to say good morning? Instead of just this is just a piece of meat...I thought those days had gone, I really did, I thought obviously some people still need to go to charm school. And it's no good, he wasn't interested at all I don't think ,well he wasn't no.. I think everyone could say that, he couldn't have cared less... and then he actually had the cheek to sit there and say 'well its communication isn't it ...we'll have to do that 'and I'm looking and I'm thinking....' (Mary./ T2)

For Mary, the reaction to a seemingly uninterested clinician at the joint event, immediately transported her to a moment of care that had a negative emotional impact. The strength of feeling was highlighted by the notion of wanting to 'slap' him. The actions of a single clinician had a detrimental effect on the patient, at the time of treatment and again within the meeting. This confirmed her first impressions and affected the collaborative nature of the event for her. It clearly bought back the feeling of being treated inhumanely, that she was not worthy or that she did not feel she had a legitimate place at the table. In this context, the actions of the staff played an enormous part with regard to possible losing connections between staff, patients and designers. This was also evident within the smaller co-design groups, the lack of staff being present, physical or emotional, spoke volumes to the patients and designers.

Additional data – Non participatory observations

Joint co-design meeting

When some senior members of clinical staff left the meeting early other staff made their feelings known to the rest of the group. One member of nursing staff was visible and audibly angry and frustrated at the way they had been left and recognised the impact on the remaining patient participants.

5.8.2 Meta-theme 2: The Idealism and realism of EBCD

This meta-theme describes the challenges that EBCD project bought in terms of what the ideal scenario should be and the reality of conducting a co-design QI project within a busy acute ward based service. The themes that relate to this meta-theme are challenges and surprises, protecting the self and 'glimmering' hope.

5.8.2.1 Sub-theme 2a: Challenges and surprises

A key limiting factor that was anticipated by staff and the designers at the outset of the EBCD project was time and available resources, which remained consistent over the duration of the project. Staff were aware of the time and input that was required for such a project and intentions were honourable in order to dedicate time. However, the reality meant that staff found it incredibly difficult to leave the clinical area during pressurised and demanding times within the service:

'It's sad to say that it's to be expected; it's expected in the current climate and what's happening. But um, and-and we have no control on addressing that...' (Esther/ staff, T2)

However staff displayed a certain sense of cynicism to QI efforts that were founded on previous experiences. John described other QI projects that despite being well received by staff and patients failed to be sustained in the long term, with incentives 'running out of steam' and new practices 'dropped' which he found frustrating. However, he felt that EBCD had something novel to offer and had a 'better potential' to succeed. A main challenge was seen in terms of improvements from the frontline being supported by senior managers, which from bitter experience was something that John attributed to the reason good ideas came and went:

'Well within management, within directorates, it doesn't get picked up and become – I mean they're very quick at saying: you must all wash your hands. You must all roll your sleeves up. And they're very quick at enforcing that. Um, but something like this, they-they-they won't actually able to take any further forward...' (John/staff, T1)

This infers a sense that improvements have previously been enforced from the top down but it was more difficult to pursue improvements from the bottom up approach. There is also a sense of a lack of agency for John, that despite his best efforts, if he did not have the support from senior colleagues and manager's improvement efforts, and the changes were not seen as important as an organisational level, then initiatives would ultimately be side-lined.

For the designers there was an understanding of the pressures that were being experienced by staff. However, Sam in the extract below demonstrates his frustration at an organisational level, in a similar vein to John:

'I think in that current climate, my sympathy was completely with the-the . . . ward staff. There is no way based on the shortages that they were experiencing, that they could have had people to come to these events. It just, they didn't have the staff available to do it. Erm, and I-I, you know, most of my frustration was directed towards [pauses] political . . . powers-that-be. And specifically one of them um, and-and, you know [pauses] if that individual dropped dead I wouldn't [chuckles] I wouldn't shed a tear. Um, but I think it . . . it's not, it wasn't ideal for what we were trying to do but I was aware of .

. . . the constraints, and I was very, very sympathetic to those for the staff. Um , so we did, we did what we could and I think we, we negotiated it with patients in such a way that um, they didn't . . . they never ever came across as um, sort of being demanding of where staff were or, you know frustrated that staff weren't there'
(Sam/designer, T2).

This extract highlights several issues. Sam expressed his sympathy with staff, describing that trying to co-design in the context of service demands at the time of the project was virtually impossible. The sense of disappointment and frustration that staff could not maintain involvement is evident and this was never raised overtly within the meetings by patients. But linking back to the previous theme and the empathy scale, Sam directs his anger at senior staff and the '*political powers that be*' that the importance of the co-design work was not taken in the way it was intended to be. The sheer anger over this situation is directed towards a senior member of staff and refers to the incident at the joint co-design meeting. The phrase '*if that individual dropped dead I wouldn't [chuckles] I wouldn't shed a tear*' highlights the depth of his frustration and demonstrates how empathetic responses waxed and waned during the process (as discussed earlier). This response was also in stark contrast to the emotive response from the patient films. The feeling of being powerless in the face of anticipated challenges was also illustrated by Claire:

'We're chronically understaffed; we're using lots of agency nursesthe Trust has changed that now so staff work a 12-hour shift through so there's not the extra time.' (Claire/staff, T2)

This also suggests that issues of time and resource lay at an organisational level. Frank also commented on his frustration with the lack of staff involvement:

'I felt disappointed a bit that they couldn't turn up at least like, you know even like 20 minutes or one workshop; like I can understand and, you know that's how things are...I think it would have been worth to have them on board straightaway from the start so that, well, they can kind of . . . approve the viability of an idea.'
(Frank/designer, T2)

Frank was willing for any level of involvement but it is interesting to note that he felt that he needed staff there to validate ideas generated. This

suggests that the designers perceived themselves as an outside group and lacked the legitimacy to make decisions without staff.

Anticipated challenges for patients were in terms of having their interviews filmed. Ivy commented:

'I didn't fancy the idea of being filmed. And er, I wasn't really looking forward to it but . . . I didn't er . . . once I'd got into it, I forgot the camera was there.' (Ivy/patient, T2)

This was a similar experience for Robert:

'... I quite enjoyed [being filmed]... Hmm, I'm not saying I enjoy being on the, on the ward sort of thing but er, you know er, talking about it and discussing it. Um, and trying to umm . . . sort of improve er, things. Er, it's something I'm interested in so, yes, you know the interview um, was quite good... you just completely forget that the cameras are there so you just act normally.'

For Fayza, she was initially anxious about being filmed but found that the experience pleasantly surprised her:

'[I was] A bit nervous at first, but then I got, I mean I . . . I open up a lot. I think I, I got everything off my chest and think, 'Yeah, why not?' At first I didn't know. I wa'a [were a] bit nervous about it.' (Fayza, T1)

This extract provides an insight into the experience of being able to tell her story. The idea of getting 'everything off my chest' infers that she still had unresolved thoughts about her experience of her heart attack that she may have not been able to articulate before. Although initially uneasy about being filmed, it was a way of being able to tell her story without fear of being challenged. This positive experience led to her feeling enabled to openly share her story in the patient only event and saw the similar effect that it had upon fellow patients:

'It was really enjoyable. I think we open up a lot. We open up a lot and it was a good work and we had all these idea coming in. so, yeah, yeah, that was . . . that's what we're going to do this, you know like the group work was really good. I enjoyed it...I feel proud of myself! [Chuckles]' (Fayza, T1)

Fayza describes a sense of pride that she felt she was able to contribute to the group and was pleased with herself that she had the courage to get involved in this way. It is also evident that by sharing stories and feeling

part of a community this may have helped her overcome her initial reservations of taking part in the co-design work.

The sense of sharing stories also had a dynamic effect on the group which produced ideas about making positive changes to the way care was delivered, as Harry and Haseeb both commented:

'...it kinda provoked er, thought and conversation between the people within that room; so I think that, that were a definite, a definite plus.' (Harry/patient, T1).

'We share some view for everybody, you know and I, I find something, new thing because so many people come, and I like them, you see...We can put more idea, some new idea. So I like them, you see' (Haseeb/ patient T1).

Haseeb clearly enjoyed the interactions with others and infers a sense of the value of many people contributing to the re-design of the service. However, Mary had slightly different concerns about being filmed and worried that things may be taken out of context and potentially cause an upset with staff:

'You get anxious and you don't know, you don't always say what you mean to say. So therefore you're not in control, basically: feather-legged! Huh! Got that from my mother! [chuckles] so long as they don't, I'm a bit anxious that they might think I'm having a go.'

The idiom 'feather-legged' aptly describes her anxiety, accompanied with a nervous chuckle. The effect of the situation provoked enough worry that it made her legs feel weak, but this related to what she might say and how this would come across to others rather than a fear of being filmed.

5.8.2.2 Sub-theme 2b: Protecting the self

The reality of being involved in the EBCD project demonstrated layers of vulnerability for all stakeholder groups. This changed over time and had multiple effects on the project. For Sara, as a patient volunteer, repeated exposure to the ward in her role within a simultaneous QI project was too much to bear:

'I've had a lot of personal experience. I think that's why I asked to be moved away from ward 22 because I had family friends who'd passed away from ward 22. So . . . it was a bit more emotional for

me to keep going back to the same ward. Um, so I asked um . . . [staff from another QI project] to move me to another ward.'

The interesting thing to note here is that Sara decided to remain on the EBCD project but changed her involvement in another QI project. The emotive nature of the co-discovery phase may have been overwhelming for Sara, which resulted in her finding it traumatic to keep revisiting this ward. This on the surface has not affected the involvement with the EBCD project but it does have ramifications for concurrent QI efforts within the same clinical area.

Another device consistently used to protect the self from being vulnerable amongst staff was the concept of detachment. This involved distancing themselves from the challenges that EBCD brings. John's extract below illustrates the reality and the idealism associated with QI work,

'I think the focus in the hospital is, is very much based around the idealism is there, you know ideally everyone knows and would aspire to change things to a certain level but there seems to be very much just a day-to-day fire-fighting er, ethos now, doesn't there, you know your energy's . . . certainly management energy, and that's not a criticism of them 'cause they're trying to do their best. It's purely that they seem to stagger from one crisis to another, and all these other things literally just have to sit and wait, which is a shame.'
(John/staff , T1)

The notion that without the support of senior management, making improvements are impossible when their energy is consumed with 'fire-fighting' on a daily basis meant it was hard to conduct any other sort of work. This infers a sense that for John attempting QI activities is pointless, as previous experiences have shown and that appropriating the blame to the system, dissolves his responsibility and protects him from personally failing. The idea of letting patients down in a QI setting may have been influenced by John's concern that he was letting patients down with the clinical environment (as discussed earlier). By keeping to his professional boundaries, this may have protected him from potential failures. Esther also distanced herself over time from the project, with the focus of her involvement shifting from being an integral part of the project:

'It's appropriate for me to be part of this, how it gets run...behaviour change, support staff around expertise' (Esther/staff, T1)

to perceiving her role as a facilitator:

'I'm there to support them as much as I can but it's about them taking ownership and there's only so much you can do . . . for staff'
(Esther/staff, T2)

This shift meant that any perceived failures of the project were owing to staff, and not the QI team. This was in relation to the small co-design group that she led, that trailed to an end without any tangible outcomes. However, Esther recognised this was owing to the issues of time and resources,

'But we didn't have the staff representative with the knowledge; you know expertise to kind of give some direction on what needed to happen. So we had a pharmacist representative but we didn't have a ward staff representative.' (Esther/staff, T2)

For patients feeling vulnerable was associated with watching the trigger film at the joint event. Mary commented upon how people had bared their souls,

'people on that film people are opening their hearts to it, pardon the pun, you know...

Her jovial manner lightens the tone but the sentiment that patients were sharing really intimate aspects of their lives is not lost. Watching the film was a challenge for Mary,

'(Laughter) it's difficult because it's not ..it's so far out of your comfort zone that you don't really know how to handle it, but, we did it I suppose, all of us did and some were more emotional than others and that made it hard to watch sometimes, you know.. not particularly me, I hated seeing myself (laughter) on the screen but there you go that's how I am!' (Mary/patient, T2).

Again the nervous laughter added to the sense of her embarrassment viewing her on the film in the presence of staff. This contrasted with Fayza's experience, 'I find it all right. It was nice. It was really good '. This may have been owing to her sense of achievement of being filmed and was proud of her involvement as discussed earlier.

Ivy was concerned that her filmed interview would reveal too much but was pleased that the final film represented her views without making her appear as if she was a 'blubbering wreck'. ,

'...I didn't want to say anything that might frighten anybody in the future um, I wanted to be positive and that, and I found I couldn't be. So . . . I felt like a bit of a failure.' (Ivy/patient, T2)

Despite all the anxieties about watching the film at the joint co-design event the patients felt protected as they were together when the film was shown, and may have added to their sense of camaraderie.

Additional data – Non participatory observations

When the trigger film was being played the patients took it in terms to smile, nervously laugh and cover their faces when they appeared on the screen. This was accompanied by whispers amongst themselves. This did not appear to distract others watching but the awkwardness at some of the clips was palpable.

5.8.2.3 Sub-theme 2c: Glimmering hope

The idea that EBCD appeared to elicit an air of excitement amongst staff members was evident at the start of the process. There were several other quality improvement interventions that were taking place concurrently on the ward but the notion of EBCD genuinely intrigued staff. EBCD appeared to offer something different. The idea of novelty was concerned with the working actively with patients throughout the process of service improvement with staff clearly expressed their enthusiasm:

'I'm really excited about this 'cause it's a big thing to be able to say that you are engaging patients in a quality improvement project'
(Esther, staff, T1)

'... it was massively interesting. It's probably first time that I've been involved with something um . . . in . . . in that area' (Claire, Staff, T2)

Esther alludes to the importance of being able to demonstrate active patient involvement in terms to the wider improvement and PPI agenda for the organisation. The comment 'it's a big thing to say' suggests the enormity of this opportunity compared to other QI approaches that Esther has experienced in the past. They recognise the significance of this type of improvement approach, which is seen as beneficial for patients. However, interestingly they focus on the impact for patients, service and organisation, rather than considering benefits of the process from staff: the drive for change appears to be orientated to patient needs not their needs.

For Claire the luxury of having the time and space to reflect about care delivery in order try to understand what it is like to be a patient was invaluable:

'I had time to think and engage with the other ...researchers and volunteers and patients um, and, and it were really a good session. I could see the definite merits of . . . going forward with the work.'
(Claire/Staff, T2).

This was an opportunity not usually afforded to nursing staff. The time to discuss issues with colleagues was routinely challenged, 'we don't have any time for um, maybe reflection or feedback' which made this session such a golden moment for Claire. She was able to see the initial output from the designer led project, which provided a 'glimmer' of hope:

'I can see the value of, I really can see the value of it [pauses] and it's a shame that it's gone on for such a long time ...you know the booklets that I saw, I can see um, a glimmer in them where you think that's really good.' (Claire, Staff, T2)

However, the fact there was a lot she 'didn't like' adds to feeling of loss of an opportunity by staff not consistently attending the smaller co-design groups. The staff perspective was missing, and though additional input from staff was added in subsequent separate meetings, this only served to lengthen the process. The idea of the 'possible, impossible, possible' trajectory of the EBCD project was shaped by a moment within Claire's account; that despite all the barriers to implementation she still saw that it was possible to improve the service, having seen evidence and the creation of something tangible; a patient handbook.

Across all the patients and patient participants accounts there was also the anticipation of something tangible that would be created to improve the patient experience. Sara sums this sentiment up with the following extract:

'I think the expectation is it'd be nice to see what [pauses] to actually see it work. So it's not just gonna be a tick-box exercise...it's great to see that you're gonna go back on ward and pilot this with the patients to see that it's going-it's going to make a difference....And what attracted me to this project was the actual reality; because discharge and what happens at discharge is reality, is a problem and the project hopefully will bring some improvement in that.'
(Sara/patient volunteer, T2)

This extract infers a sense of hope with the outcomes of the project, that the patient stories are able to make real changes to real problems being faced by patients. The phrase, '*So it's not just gonna be a tick-box exercise*' alludes to the notion that patient involvement is often seen in tokenistic terms. But the nature of the EBCD process offered something different.

5.8.3 Meta-theme 3: Solving the mystery

The final meta-theme relates to way that the EBCD co-design affected participants taking part. This was different for different stakeholder groups and changed over time. The first theme refers to the therapeutic nature of the process for the patient participants, which was observed across the accounts. The second theme describes the idea of patient experience as an untapped mystery and the final theme considers the frustration experienced by participants over the course of the project.

5.8.3.1 Sub-theme 3a: Co-design as therapy

This sub-theme addresses the therapeutic aspect of EBCD. Although all the patients had cited altruistic desires to be involved there was evidence that the process provided a unique time and space to talk. For patients, EBCD provided an opportunity to make sense of what had happened from their own patient perspective. Mary perhaps best embodied this sentiment:

'I: How did you find talking about it [your experience of having a heart attack]?

Mary: Erm...not too bad actually, because by that time it had been and gone , if you like, er...and I didn't feel as fragile then as I did straight afterwards because that is the thing...you just think ' I'm shattered into bits' and I don't really know if they understand that part of it , that you're trying to pull these bits back together and you just feel like, you know, you've just been like an egg's that's cracked and you've gone...and you're laid in bed, you know you're laid in bed but it's a scary time.' (Mary/ patient, T2)

This appears to suggest that Mary found talking about her heart attack for the purposes of the project as acceptable, when compared to her initial memories. Mary compares herself to being like an eggshell being smashed into pieces, which emphasises her feelings at the time of having her heart attack of fragility and a fractured self-identity. The sense of trying to 'pull' these pieces of shell back together feels like an impossible task.

The sense of being scared and staff not understanding how she feels add to a sense of vulnerability. In an effort to regain a sense of wholeness, Mary found the interview process co-design activities useful:

'I think it relieved a lot of ... not stress but pointed out a lot of things that you were feeling and remembering that you really weren't taking any notice of but they were going on under the surface, if you like, because I don't know whether you...you can't be frail if you are a woman...because that's not me speaking that's people in general. You have to pick yourself up ... and you don't realise that you're not letting that feeling come out, you're just floating along and being ok now, you know and you're not really.' (Mary/ patient, T2)

This extract also illustrates the need to revisit what happened, to provide time and space to remember, as Mary infers that there is a feeling that she was 'just floating along' dealing with the practicalities of getting back to normal and day to day activities, but below the surface, there are a lots of feelings that remained suppressed which has a deleterious effect on the 'self' long term. It is interesting to note, her notion of fragility as a woman, that she thought she could not be seen to be weak by others. This may be owing to her idea of remaining strong and independent despite challenges in life as the following extract highlights:

'I mean I've bought my daughter up on my own so you get a bit toughened but there's no need to be as tough as I was.' (Mary/ patient, T2)

However, during EBCD activities Mary's attitude changed. When talking about the emotional mapping exercise within the patient only meeting (See Section 1.9) she describes her initial nervousness opening up and sharing her inner frightening thoughts not previously shared with anyone.

'It was a bit scary at first but it was good, if you can call it that, because it made me realise I'm not invincible and I can't do it all and I can't protect myself as I am have been erm...to a certain extent I was pushing people away not realising I was doing that , 'I can do it, I can do it..' but you don't want to have that weakness that you can't manage on your own, that's scary, really scary, I don't want to have someone come in and wash and dress me. It wouldn't ever get to that stage I hope. But then it comes to you and you can let go you don't have to managing everything.' (Mary/ patient, T2).

Being able to share these feelings with the patient group may have been facilitated by the sense of camaraderie and rapport that developed quickly between patients (as discussed earlier). This extract illustrates the realisation that her fears were not realised and that by sharing and talking about her experience it provided a new insight that she can accept help without losing her independence.

The notion of fragility was also referred to by Ivy in terms of the way she felt her well-meaning family treated her:

'...Mum, you take on far too much. Now you've been through this...Don't do any more. Take it easy.' Treat me like a china doll and that's not what I want. I'm me. I'll do what I need to do.' (Ivy/patient, T2)

It is clear from Ivy's perspective that she fiercely wanted to assert her independence, her free will, her choice. Thus, by actively choosing to participate in the EBCD project she was defying her family's suggestions and expectations and looking to gain control of her life again,

'I just . . . lost all my confidence and everything. But I think taking part in this project has improved that for me.' (Ivy/patient, T2)

A key change for Robert was that through his involvement with the project he had started a new dialogue with family and friends about his experience being in hospital. EBCD gave him a medium through which to talk about previously awkward discussions about his health. Using the EBCD project as a focus, this allowed Robert to engage in conversations indirectly about his health, and the effect upon his family and reduced any previous awkwardness suggested:

'And talking to other people, you know friends and family and what they er, thought about it [the EBCD project] um, when they came to visit, you know did they see that there were any, any problems and anything. And I-I found that um, they didn't, you know they found that everything was running er, pretty smoothly and they were quite happy with it.' (Robert/patient, T2)

Harry also commented on the process of being involved,

'I don't think, I don't think I were looking for myself to get things out of it....I think er, I were more thinking about . . . it might help somebody else in the future. So I guess that's my only expectations about what the, what the outcome'd be. And I guess . . . through

those expectations umm, it, I have got something out of it. So, huh! It kind of, it worked both ways, I guess...I'd never really sort of broken it down and in that way analysed what we'd been through – or what I'd been through. Umm, and put it into, into some sort of order.'
(Harry/patient, T21)

The above extract highlights that for Harry, the personal benefits of taking part were only realised during his interview, with the expression 'So, huh! It kind of, it worked both ways' suggesting a 'light bulb' moment. The EBCD co-discovery phase included, being interviewed, an emotional mapping exercise and the trigger film provided a structured approach for Harry to make sense things in an ordered fashion, something that he had not done outside of the meeting. For Haseeb, the benefit of taking part was in terms of his relationship with his wife:

'...mostly my wife, she likes [me] to involve in this project, you know. She say, you can learn something ; you can tell any, anything, you know what's happened to you in the hospital; what's the hospital want improve, you see; you should be taking part because you are the patient; you are staying in the hospital. Do you know the other people, you know because you pass this situation, you know. So you know these things; so best thing you can, you can go the meeting and improve some-something, you know.' (Haseeb/ patient, T1)

This extract highlights the level of conversation with his wife and thought that had gone into taking part. The benefit of taking part was seen in terms of benefits for others, which a consistent view for patients throughout the project. The value of having direct experience of care was recognised by the patients and his wife, and the value of sharing that knowledge more formally to improve the experience of care.

5.8.3.2 Sub-theme 3b: Untapped mystery

This theme refers to a 'suggestive gem' from Mary when talking about the patient experience and underlying tensions between staff and patients understanding each other's perspectives:

'And it made me think there's a whole thing of untapped mystery if you like that they don't seem to either want to know or understand that's going on.' (Mary/ patient, T2)

This short extract underpins the importance of developing deeper connections between staff and patients during the EBCD process. The

idea of an 'untapped mystery' suggests a missed opportunity for staff to recognise what really happens to patients during the process of care. This idea of hierarchy is again displayed with the concept of gods (doctors) and mortals (patients):

'People on that film people are opening their hearts...they are telling you how they felt ...and he couldn't have cared less, now I thought that kind of attitude went out in the stone age, I mean , we've all had consultants that think they're gods and behave like gods and the nurses and matrons runs around after them, treating them like gods but that's gone, I've no doubt he's a very intelligent man and very good at his jobs but his charisma (laughs) is pffttt...but that's part of his job to make his patients comfortable and at home if you like.'

Reflexivity point:

The concept of gods and mortals and the traditional relationship between patients and healthcare professional's links with Jean's ideas of how de-humanising healthcare institutions were perceived in the past (see section 4.5.1.2). However, through Jean's experience of conducting observations this myth was somewhat dispelled, having observed the interactions between patients and doctors in the clinical setting.

This extracts describes the way patients are prepared to be vulnerable, and though challenging are willing to share their intimate fears. However, it is disheartening for them to see this openness met with apparent disinterest by staff. This is in direct conflict to the assumptions that Mary holds with regard to staff being caring and compassionate, *'that's part of his job to make his patients comfortable and at home if you like'*. There also appears to be a lack of understanding about the staff perspective for patients, so that in a sense the untapped mystery can be extended both ways. Claire when interviewed talked about an especially busy time for the service:

'the patients flow; the patient bed crisis at the moment; the hospital is under immense pressure, and now this has been one of the worse weeks we-we've experienced um, for a long, long time, in terms of bed crisis and breaches in A&E.'

This extract suggests not only the system under a great strain, but this has a direct impact for staff on the ward. This may be understood by the designers and patients but the real effect on the constant pressure for staff on a day to day basis may be not fully appreciated. As discussed earlier,

patients and the designers were largely unaware of the complexities associated with the potential care pathway for patients admitted with a suspected heart attack. The mystery of how services operate remains hidden to key stakeholder groups, if they are unable to come together, and fully see the picture from both sides. Jean felt she was able to see both sides, from her unique no-man's land position but was unable to affect changes that were needed.

The idea of an untapped mystery also refers to staff being confused with the different QI initiatives running simultaneously. This is alluded to by Claire:

'I think because they're so, they're both running um, aside each other; and they're both actually looking at similar things – I know [name] very much about patient safety and yours is about discharge. But they do tend to muddle a little bit' (Claire/Staff, T2)

The sense of things becoming jumbled with regard to project aims; outputs and outcomes have the potential to become confusing for busy staff on the ward. This may also make it difficult to determine why and how QI initiatives 'work' if there are multiple projects. Jean also got muddled with the projects when recalling her experience on the ward during observation activity and her work with another patient safety project, *'It's really finding out about the patient's experience, which is exactly what you're doing really.'* (Jean, T2). However, from the additional work that she was involved in she was able to bring a further insight into the experiences of the patient participants. She interestingly commented on the far more positive experiences voiced by patients on the ward compared to the 'ex' patients. She noticed an almost euphoric like state, which was in direct contrast from the more sober reflections from the patients within the EBCD project:

'They've come through it and they're still at a phase of being grateful to staff because they've come through it. Um, and as I see it, the patients who are being interviewed for the experience based co-design workshops um . . . have come through it. They've left what I've seen as a bit of a euphoric state . . . and they're remembering things that were quite worrying for them. It's as if they've come down to earth with a bump. I-I I found that quite, quite fascinating cause if we hadn't been doing PRASE I wouldn't have had that, that

observation, but it's there so it's in my mind and it's, I find it interesting.' (Jean, T2).

This comparison that Jean has made between the different patient cohorts signifies a great deal of reflections and thought about interactions with patients on the ward. Jean has the skills, experience and an inquisitive nature that means that she is able to provide a nuanced insight into patient experience that may be beneficial to both projects.

5.8.3.3 Sub-theme 3c: Frustrated self

Staff recognised the value of listening to patient's stories and experiences, as illustrated by the extracts below:

'I think it's got a massive benefit having patients involved from their perspective. And it's important to actually listen to their perspective' (Claire/staff, T2)

'...we actually wanting to understand and kind of trying to use that knowledge er, to-to steer everything else towards that outcome. Er, I think that was important and-and fantastic' (Esther/staff, T2)

This sentiment did not translate into tangible outcomes for some of the patients involved. They were frustrated with the pace of work, and perceptions changed over the course of the project:

'I try to help as much as and get more information, and try to do things quicker but what else can you do . . . frustration, innit' (Fayza/patient, T2)

'I thought it was wonderful that er . . . that so many came. And er, I felt that [pauses] yes, people are gonna take notice of this because it's gonna be professional input as well. Er, but it didn't, didn't seem to turn out that way. Umm [pauses] there was a couple of them that just talked to each other. They didn't really have much to say in the meeting' (Ivy/patient, T2)

The expectations by the designers were also challenged. Trying to solve the problems thinking about using new creative ways was difficult. It involved a change in mind set; a culture change from the usual way that staff approached problems but the extract below suggests from Sam, this was incredibly hard to achieve:

'Oh, we already do that' [repeating the response from staff] *erm, there seemed to be a bit of a barrier to accepting there was a*

problem with that. Erm [pauses] and that [pauses] I think-I think it was . . . I think . . . it might have been yourself or myself who did kind of intervene in that face-off moment to say, to explain that kind of difference about it's not . . . the giving information. It's the understanding of it that's important'.

Reflexivity point:

Sam in this above extract is referring to a point during the joint co-design meeting, where despite patients claiming that they did not understand their follow-up care at discharge, or had issues with their medications, the staff were steadfast in their view that they provided the information at discharge and therefore, there was nothing further they could do. It was at this point that Sam asked me to explain further about 'co-designing' experiences. I explained to the group that despite the information being given, verbally and in a written format, this was not being 'received' in the way intended by staff. There was a fundamental misunderstanding that just because they provided the information this did not necessarily equate to the information being digested and understood. Many of the patients talked about being in shock and had only spent a few days in hospital before being discharged. Trying to absorb complex information about massive changes to their life world may have been too much at this point. Jean also commented on the euphoric state of patients on the ward compared to the patient participants in the EBCD project.

Sam uses the phrase 'face-off' to describes a confrontational moment during the joint co-design event. It suggests that time is needed for staff to reflect and digest information from the trigger film and explore what they real issues are for the service. As discussed earlier the designers were able to draw upon many tools and techniques to support meaningful changes.

This aim of this study was to make sense of participant's experience being involved in a local EBCD service improvement project over time with a view to exploring the key issues regarding how, why and under what circumstance EBCD 'works' (as indicated in the main aim of the thesis; See Section 2.9). The following discussion explores the findings drawing upon relevant literature.

5.9 Discussion

This thesis aims to explore the experience of participation for people involved within an EBCD quality improvement project in the health care setting. The aim of this study was to make sense of individual experiences of taking part in a locally situated EBCD project. It was anticipated that this may enhance our understanding about the mechanisms within the EBCD process that may help to bring about change. The main objectives of this study included, describing the key features of involvement, any barriers to involvement, any changes and consistencies of involvement over time and to identify any possible mechanisms within the EBCD that may assist with the change process. These objectives are now discussed in detail in relation to the results from the study.

The apparent role that participants played in the EBCD project was largely dependent on their self and group identity. Smith et al. (2004) have commented that the notion of identity frequently appears to be a key organising construct within qualitative research. However, the concept of tribalism may go some way to understand how and why the stakeholder groups occupied different social spaces.

A tribe may be defined as an 'in-group exhibiting strong bonds with tendencies towards inward social loyalty and conformity across the membership' (Braithwaite, Clay-Williams, Vecellio, Marks & Hooper, 2016). The strength of the instant bonds that occurred within the patient camp was evident to those outside, and appeared to transcend age, gender and ethnicity. By sharing stories about a life changing experience this appeared to foster a unique relationship. The opportunity for others to truly understand what each other had experienced was something not shared with others outside the group. This included family and friends. It could be argued that being part of a patient tribe provided a sense of social and symbolic capital. These two forms of capital or social power, as conceptualised by Bourdieu (1987), refer to capital in the sense of 'material and symbolic qualities' that provide a social standing within a specific social setting (Locock et al., 2017: p838). The idea of social capital draws upon the value of a new network of relationships; people sharing a common experience (suffering a heart attack). Symbolic capital considers the legitimacy possessed by individuals, in terms of 'status, prestige and respect' within and beyond a social network (Locock et al., 2017:p838). There is a strong sense of legitimacy within the patient tribe with social

capital seen as a collective response; it is embedded in relationships between individuals (Plunkett, Leipert & Olson, 2016). The value of social capital for patient and public involvement may be in terms of accessing resources and achieving goals that may be otherwise impossible to reach (Plunkett, Leipert & Olson, 2016). The designers attempted to span this boundary wanting to capture the raw experience and communicate this to staff. The intentional interactions by the designers also served to reinforce this bond, creating a strong sense of community through direct and indirect contact and purposeful activities. This may have helped to develop the bonds and develop a greater sense of loyalty within the group. Although the designers saw themselves as boundary spanners between patients and staff camps, being so closely involved with key components of the EBCD process (such as, creating the trigger film, interviewing patients and running the emotional mapping exercise) also appears to have strengthened the bond between the patients participants and the designers. This was seen in terms of a mixed empathetic response to the staff even though they had a stressful time delivering care in very demanding circumstances.

The notion of tribalism may also explain the source of tension that often occur between professional groups owing to differing expectations 'how things should be done' (Hudson, 2002; Weller et al., 2012: p2). This was evident from the staff narrative, where tension arose between staff and people 'outside' the system (outside their camp) who could not apparently appreciate the complexity of care delivery and that this was difficult to communicate. Social identity theory may also help to explain the tribalism that is exhibited between professional groups (Weller et al., 2012). This means that professional groups, such as nurses, doctors and allied healthcare professionals, view their own attributes more favourably compared to other groups. These groups will usually refer to colleagues within their profession when solving problems, asking for professional advice, as well as, interacting socially (Creswick et al., 2009). Using the idea that patients were seen as a separate group (or camp) the side discussions between staff during the joint co-design meeting, made patients feel excluded. There was also evidence that the social side of meetings was absent from the smaller co-design meetings, when not facilitated by the designers (no symbolic cutting cake, or small talk).

Whilst exploring the notion of social identity it is also noted that the staff level of engagement significantly decreased over time within the EBCD

project when compared to patient involvement. There are several possible reasons for this key finding. The staff members talked about the difficult working conditions that occurred during the project. There was an unprecedented shortage of nursing staff, with bed capacity running extremely high over a prolonged period with winter bed pressures. Clinical responsibilities and duties appeared to take precedent over immediate QI efforts, with senior management within the organisation often ordering meetings not directly related to clinical in-patient care to be cancelled. This may have been a contributory factor to the smaller co-design group C, led by staff, folding before any tangible outputs or changes to the service were put into practice (See Table 5.1). The length of time that the project ran may have also contributed to the loss of engagement overtime by staff, as keeping the momentum going for projects also appears to be a factor for success (Tollyfield, 2014). The lack of input from the designers may have also contributed to challenges faced by staff when thinking about re-designing the experience of care, rather than thinking about the process and outcome. This approach requires a subtle shift in thinking and without specific tools and techniques may have been a reason why staff found it hard to remain focussed on the experience. The need for more tools and techniques within the EBCD process has been previously recognised by Donetto et al. (2014) and an attempt has now been made to provide more online support for teams/services using EBCD (Point of Care Foundation, 2018b).

The lack of staff engagement made it very difficult to successfully achieve the aims of the QI project. EBCD when applied in a more consistent manner appears to foster a greater sense of empowerment for staff, taking ownership of implementing changes to the service (Farr, 2011). Staff within the study wanted to take part but were all too aware of the limitations that this type of QI effort required. Paradoxically, the very approach needed to bring staff and patients together to co-design meaningful changes to the service appeared to be confounded by the need to deliver care, with staff having little dedicated time to actively improve care. The challenges NHS staff face trying to deliver high quality and safe care are affected by organisational culture, pressures at work, risk management culture, communication and resources (Hignett, Lang, Pickup, Ives and Fray, 2018). It would suggest that conducting quality improvement projects without additional support, resources and time may become more elusive with the continued pressure upon the NHS.

Thinking about the origins of EBCD and the underpinning theory of user-centred design, central hypothesised processes within participatory design underpinning EBCD (Robert, 2013) are:

- Direct patient and staff participation in a face-to-face collaborative effort to co-design (or re-design) services
- An emphasis on improving the experience rather than the process of care

The findings from this study suggest that direct participation with staff and patients encountered a number of obstacles. Firstly, this was in pragmatic terms with staff finding it increasingly difficult to dedicate time to the improvement process owing to the burden of work and staff shortages. Adaptations were made during the process, but this meant that a fundamental premise of user-centred design was foregone: face-to-face meetings between staff and patients were sparse and relied on the groups working separately. The effect of a closer working relationship between the designers and patients was evident and produced a tangible outcome which addressed the experience of care. However, it is noted that the latter pairing had the time and resources to meet in a collaborative setting. Whilst sympathy was extended to the staff who at short notice could not attend co-design workshops, it was a source of frustration for the designers and patients. The staff presence was seen as an important part of the process, in terms of providing legitimacy and accuracy to the patient handbook being developed. The visibility of the system in which staff operated was largely invisible to the designers and patients taking part. The findings suggest that before developing solutions together a shared and wider understanding of the problems being faced by all is needed. This in turn, may be an active ingredient with the EBCD process.

The second major issue concerning face-to-face collaboration was concerned with the traditional hierarchical structure that exists within healthcare (Weller, 2012; Weller, Boyd & Cumin, 2014; Braithwaite et al., 2016). Despite the movement to meaningfully involve patients and the public in health service development and research (Department for Health, 2010a; Department for Health, 2015) it appears that healthcare professionals prefer patients take a consultative role (Gagliardi, Lemieux-Charles, Brown, Sullivan & Goel 2008). Power gradients have also been seen to affect communication between junior and senior staff, in terms of not seeing contributions as valuable and requiring a degree of courage

when challenging or disagreeing with colleagues (Brindley & Reynolds, 2011). This results in potentially sub-optimal care decisions and provides a source of stress and conflict (Brindley & Reynolds, 2011). Thus, the difficulty for patients to overcome this barrier could be seen as even greater. Although, there is little empirical evidence that describes the way PPI impacts upon service development and research (Mockford et al., 2012), this study did highlight the experience of patients feeling unable to challenge staff within the joint co-design meetings. The issue concerning hierarchical structures in this setting was explicitly recognised by the designers. The foundations of user-centred design rely upon equal contribution and mutual respect from both staff and patients, although it is suggested this remains hard to achieve within the healthcare setting where traditional roles are deeply entrenched (Donetto, Pierri, Tsianakas & Robert, 2015). This is despite recognising the knowledge and expertise that a lay perspective brings in a collaborative effort may create a greater understanding of complicated and complex healthcare issues (Gibson, Welsman & Britten al., 2017). The designers used specific tools and techniques in order to reduce the effects of hierarchy between the staff and patients. However, it is recognised that designers are armed with 'designerly' tools and techniques not commonly used by non-designers (Robert & Macdonald, 2017:p125). They suggested the need for a common creative language that both patients and staff could understand. However, it was evident at face-to-face meeting tensions arose when staff where challenged over the delivery of care. The example of the 'face-off' incident where a senior member of staff could not see the more nuanced concept of giving patient information that was received as intended, illustrates the degree of difficulty trying to understand the experience of care through the patient lens.

This example also raises a contentious issue with a primary concept of EBCD: the focus upon improving 'patient experience' rather than the process of care. This may be a subtle distinction but something unintentionally difficult to maintain. For example, within the smaller co-design groups patient touch points appeared to be lost in translation within staff led groups. There was a tendency for staff to revisit the process of care, re-deciding what mattered most for the service which translated into action plans for staff with little involvement from patients at the meetings. Yet, when staff worked alongside the designers they were prompted to reflect on the process and experience of care with more value ascribed to

the work by staff and appeared a way to engage staff going forward. The results from this study suggest that a combination of remembering patient touch points and time and space to reflect and engage with others that for staff is not routinely resourced, may be needed to bring about change within the EBCD process.

The designers were firmly wedded to idea of experience and spent time exploring the heart of patient experience in order to understand further what was needed at critical touch points. The skills and expertise exhibited by the designers was in direct contrast to the staff led sessions, However, it is noted that some EBCD projects have lamented not having adequate tools and techniques to co-design solutions and require more understanding in how to make a co-design event 'work' (Donetto et al., 2015). Therefore, the use of designers within the process could be an important part of implementing the approach. Reaching the desired outcomes to improve the experience of care appears to be enhanced using the specific skills and knowledge that designers bring to the collaborative approach. The designer acting as a boundary spanner is also able to manipulate the interactions between staff and patients, trying to reduce the hierarchy in order to produce solutions that are meaningful to both. These skills, knowledge and experience can be taught, so that the spread and sustainability of EBCD becomes easier, as evidence suggest that for health care professionals the process can appear to be very 'messy' (Donetto et al, 2015:p238). This suggests that the 'design' in co-design could be conceptualised in terms of the people leading the design process. Robert and Macdonald (2017: p117) have described two forms of designing, 'designerly', that is it is led by designers and is embedded within the principles of user-centred design and 'design-like', led by non-designers and employs the idea of PAR approach to design. They posit that QI efforts require combining both approaches.

There is evidence to suggest that EBCD is successful without the use of designers (Macdonald, 2017). However, what is argued here is that the designers bring more to the process than just a unique set of tools and techniques peculiar to the field of design science. Owing to their philosophical orientation, and an explicit understanding of user centred design means they actively seek to address the issues inherently associated with the development of complex healthcare interventions, that is, social processes - culture, language and cognition, identity and citizenship (Greenhalgh, Howick & Maskrey, 2014). An example from the

EBCD project illustrates the use of pictures and diagrams by designers to capture the complexities of social interactions (See Figure 4.1). Evidence suggests that the value of a designer's 'creative practice' within a collaborative partnership to design interventions may help to build upon patients' contributions towards the development process (Bowen, Durrant, Nissen, Bowers & Wright, 2016). Although the systematic review in Chapter 2 revealed the role of a facilitator as an essential element of the implementation of the EBCD process, the value of a designer within the process has not been previously reported upon. Thus, this finding may be important when understanding the best approach to implementing EBCD.

A second important theoretical strand within EBCD is the idea of a narrative based approach to change. Stories and telling stories are the cornerstone of the EBCD process, as they contain a rich insight, 'wisdom and intelligence' that are waiting to be 'tapped' (Bate and Robert, 2007a: p65, 66; Robert, 2013). These stories are located in a 'subjective and socially constructed world' with the assumption that these will resonate with others and develop broader and more permanent meanings (Bate and Robert, 2007a: p65). The trigger film is seen as a 'catalyst for improvement' by providing a mechanism for staff to connect and acting as 'a persuasive starting point for change' (Bate et al., 2015: p1). Viewing the trigger film and the ensuing discussion is considered an essential mechanism for engaging patients and staff in a collaborative manner (Locock et al., 2014). To this end, the trigger film was seen as a useful way to develop connections but the intended effects were not uniformly experienced by all: the connection was keenly seen between patients and the designers but less so with staff. It has been argued that the use of co-production to improve health outcomes require a profound cultural shift at an individual and systemic level (Morris, O'Neill, Armitage, Lane & Symons, 2007). Patients creating their own stories can help to consolidate their experiential knowledge' and 'deepen' their sense of 'contribution' to the process of improvement (Morris et al., 2007:p7). One patient participant referred to the useful way that the interview and emotional mapping exercises helped to 'order' and make sense the experience. Within the academic literature of medical education, using a patient lens to reframe patient safety initiatives (rather than a healthcare professional view) is an approach that is gaining momentum (Entwistle et al. 2010). In one study, a patient led teaching intervention was piloted with newly qualified doctors (Jha, Winterbottom, Symons, Thompson & Quinton, 2013) patient narratives

were used as way to explore patient safety issues with a facilitated discussion. A key finding suggested that patient stories that had a clear structure, with a focus on the learning objective (patient safety) and 'take-home' message appeared to work better. This could apply to the trigger film so that an ordered and systematic approach with clear learning points are taken away and 'kept' by staff for use at subsequent co-design events.

The difficulty of trying to establish a connection between patients and staff using the film was beset with problems. Since the films captured such personal and emotive accounts, the visible reaction and actions by some staff (leaving the joint co-design meeting early before identifying service priorities) within this EBCD project appeared to have a detrimental effect with on-going relationships between staff and patient participants. The reasons for leaving were not established within this study, since staff declined to be interviewed, citing time pressures and corporate imperatives (any meetings not concerned with care delivery had to be cancelled). The reason for staff leaving could also been owing to a degree of discomfort watching the film with the 'actors' sitting directly opposite. However, it has been suggested from previous empirical work that in order to get the most out of co-design 'a certain amount of unsettlement among staff can be productive' (Locock et al, 2014:p34). The use of national patient narratives has been suggested as a feasible and acceptable alternative to using local narratives and may make staff feeling more comfortable when listening to patient stories (Locock et al. 2014). However, the range of narratives that were available at the time of the project did not represent the local population and therefore, may have missed more nuanced aspects of care experience. But, by using a more generic approach this may have reduced such emotive responses to the way the trigger film was received by staff. The discussion that occurred after the summary of staff findings and the film did produce joint priorities by the service but this was again facilitated by the designers who focussed upon improvements to the patient experience.

Story sharing within the EBCD process is also seen as a way of 'deriving concrete knowledge' to inform change. This relies on others listening and trying to see the world from a different perspective. It is assumed that the mechanism for change relies on a key ingredient – empathy - both in terms of the 'technique', that is, consciously taking on the 'role' of the 'stranger' and the mind-set (Bate and Robert, 2009; p43). However, this study revealed the challenges in trying to establish and maintain an empathetic

viewpoint. For staff the factor of time appeared to be crucial. Without having the time to think and discuss the experience through the patient lens, the underlying mechanism of empathy did not have a chance to flourish. Time as a resource was in short supply. This was seen not only from the joint co-design meeting but filtered through to the smaller so-design workshops, as those run by staff petered out. However, the lack of engagement by staff may have also been explained by previous QI experiences. For the staff members there was an air of scepticism that changes would not be maintained long term, and that without support from senior managers projects would fall flat. For the designers the notion of empathy was extended to the patients and mixed attitude towards staff. The effect of the trigger film as an emotional hook was seen more intensely within the designer's experiences, but this may have been to do with the repeated watching and creation of the film. This was then reinforced with face to face interactions with the patients, with relationships developing over time. The designers spent far less time with staff and the issue of face-to-face collaboration as a mechanism for co-design became more apparent, not only in terms of outputs but in terms of building alliances, an essential principle of participatory action research underpinning EBCD (McIntyre, 2007; Robert, 2013). The most successful group in terms of project outputs consisted of the designers and patients. They had the time to develop this relationship compared to staff that consistently faced insurmountable problems to create time to engage with EBCD activities over a prolonged time scale (staffing shortages, emergency meetings to address bed management crisis, changes in patient conditions, organisational directives stopping all non-clinical meetings). There was a rare moment for staff, who were able to reflect back at the opportunity of having been given dedicated time and space to become involved, but this was short lived. Although, the setting for the EBCD project was localised and highly contextual, the unprecedented pressures being faced by other NHS services and organisations are seen as a common issue (Ham, 2017; Iacobacci, 2017).

The issue of time as a barrier also brings the notion of learning theory, as a key theoretical strand within EBCD, to the forefront. Another hypothesised process within EBCD is the development of staff as reflective practitioners. This requires staff to be able to 'pause and reflect' on information gathered. This study revealed there appeared to be little time and space dedicated to reflection for staff. Improving patient experiences within EBCD is supposed

to focus on the needs from both staff and patients. However, within the early co-design phase there appeared to be an emphasis on the patient voice, with staff concerns appearing less significant at the joint event.

The Patient Feedback Response Framework (PFRF) may be one way to further explore and explain the results within this study (Sheard, O'Hara, Armitage, Wright & Cocks, 2017). This framework was developed by combining three concepts derived from theoretical literature on organisational change and sociological constructs (See Table 5.6).

Table 5.9 Applied theoretical definitions within the PFRF

Theoretical concept	normative legitimacy (NL)	structural legitimacy (SL)	organisational readiness (OR)
Definition	The 'moral orientation' of persuading others to do the right thing (Lockett, Currie, Waring, Finn & Martin, 2012).	The formal institutional structures and 'the power that emanates from professional hierarchy and jurisdiction' (Lockett et al, 2012).	A shared "resolve to pursue the courses of action involved in change implementation" at the organisational level (Weiner, 2009).
Applied definition by Sheard et al. (2017)	At an individual level staff believe in the importance of 'responding to patient feedback and the desire to act' (Sheard et al., (2017: p21)	Staff believe that they have sufficient autonomy, ownership and resources to establish a plan of action to address patient feedback.	<u>Macro level</u> –the ability of 'senior hospital management and the high level systems of the organisations support and facilitate ward staff to work on improvement <u>Meso level</u> – the ability of inter-departmental collaboration to achieve improvements

These concepts were used to make sense of empirical data gathered as part of a process evaluation of an RCT of a patient safety intervention (Lawton, O'Hara, Sheard, Armitage, & Cocks, 2017). These concepts were seen as a way of understanding change efforts at an individual level and the ability to generate action. It is noted by the authors however, that the use of these concepts to interpret their findings should be treated with caution. This is especially when considering the way SL has been applied to the empirical findings from this qualitative study: Lockett et al., (2012) state that SL is dependent on the professional and hierarchal position

within an institution. Whereas, Sheard et al. (2017: p21) interpreted SL as the notion of the ‘availability of autonomy, ownership and resource’.

The framework proposes a theoretical model of the necessary conditions to effectively respond to patient feedback (See Figure 5.4). It is posited that NL and SL are both needed to respond and act to patient feedback. If there are high levels of SL, changes can be made without external input and the need for OR. Some changes however, would require OR to support actions (Sheard et al., 2017).

When looking at the empirical results from this study NL was present across all the participants’ accounts and remained a consistent finding (See circle 1 in Figure 5.4). There was no doubt that improving the patient experience of care was the global aim. However, some of the observational data also indicated that not all staff appeared receptive to the feedback, which may have weakened the NL within the core group of participants within the EBCD project.

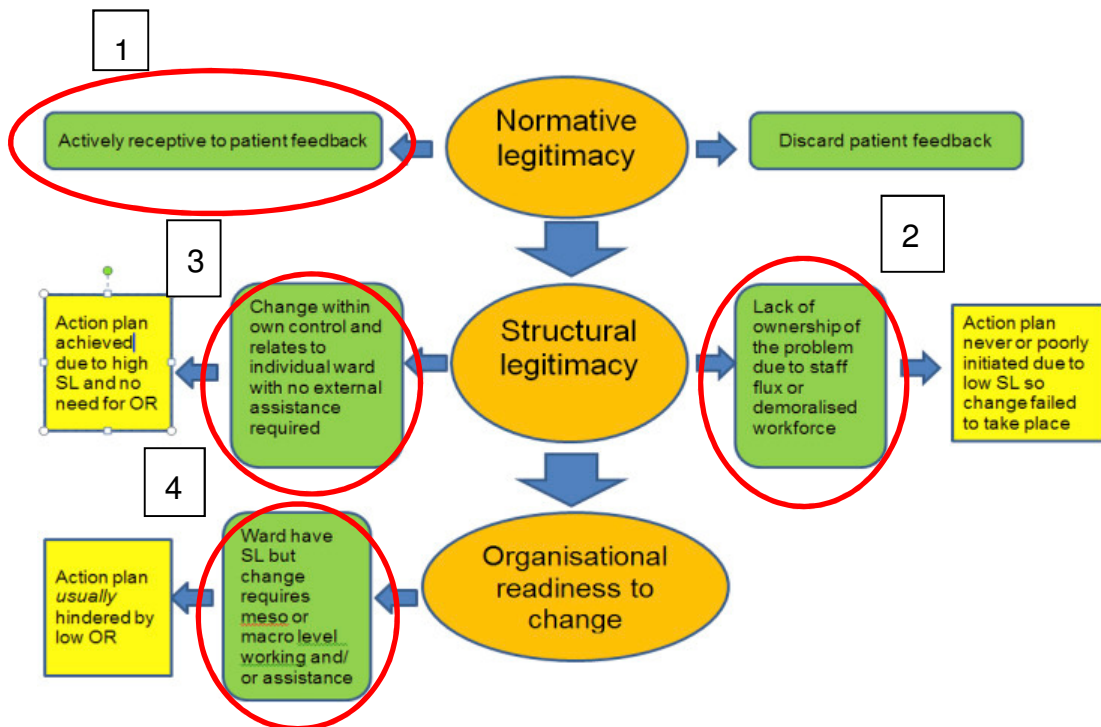


Figure 5.4 The Patient Feedback Response Framework (PFRF) – Making sense of stakeholders experiences within the EBCD project. (Adapted from Sheard et al. 2017 – kindly reproduced with author’s permission)

In terms of SL, there appeared to be a lack of ownership of the project (See circle 2 in Figure 5.4). The QI specialist appeared to distance themselves over time and staff appeared to be increasingly less engaged as the project continued. It is at this point that level of recruitment of staff to the study is noted. The core staff members of the team at the outset of the EBCD project were research fatigued when it came to accepting invitations to be interviewed. This was owing to multiple QI and research projects that were being run concurrently on the ward. The challenges that staff faced also suggested a low morale, in terms of achieving realistic outcomes and experience of previous QI efforts.

The result of low SL for staff meant that they had little chance to get involved in the co-design work. However, for the designers and patients they occupied the left hand side of the domain (See circle 3 in Figure 5.4) they had SL but needed OR to formally legitimise the work they had done and implement changes into practice (See circle 4 in Figure 5.4). Although, similar issues with regard to implementation that have been reported in evaluative EBCD studies (Bowen et al., 2010; Piper et al., 2010; Piper et al., 2012; Bowen et al., 2013) this framework helps to understand additional mechanisms that are needed to ensure the success of the EBCD project.

Finally, the notion that EBCD had a therapeutic effect for patients and the designers also affected the way EBCD worked. There is some empirical evidence that suggest previously that EBCD may have a personal therapeutic benefit (Locock et al, 2014). This was clearly demonstrated across all patient accounts and to some degree for the designers. This was seen in terms of having a unique opportunity to share their stories, which on reflection helped them to make sense of what had happened as in-patients. There was also the therapeutic benefit of finding their 'camp' which they drew strength from and in turn, helped them to have confidence in taking part in the EBCD project. The therapeutic benefits may have also assisted with their continued interest and involvement with the project, despite the decreasing lack of engagement with staff over time. The role of the designers appeared to act as the social glue, they created a collaborative atmosphere which was underpinned by their professional and personal philosophies, a desire to engage in activities that 'leads to a useful solution that benefits the people involved' (McIntyre, 2007: p1).

In summary, this study has explored the experiences of multiple stakeholders involved in a local EBCD project, to improve the experience of discharge following a heart attack. The mechanisms of change that underpinned the process within this specific context were complex and multi-faceted. They rely upon several key factors:

- a collaborative approach with all stakeholders having a shared vision
- Face-to-face interactions in a safe setting
- Reducing traditional hierarchies and creating an empathetic atmosphere
- High levels of normative and structural legitimacy for all stakeholders
- Designers to closely facilitate the process and encourage learning and reflective practices
- Protected time for staff to engage with the project
- High levels of OR support
- Using a creative language to help patients and staff
- Valuing the patient perspective as viewed from outside the organisation

These findings link closely with the broader elements of co-design within EBCD; participation, development, ownership and power and outcomes and intent (Donetto et al., 2015). It is anticipated that the findings from this study will help to further understand how EBCD works and under what circumstances.

5.10 Limitations of the study

Limitations of this study refer to issues relating to LQR methods (see Section 3.8.1). Not all participants were interviewed at both time points. The most important issue to note was the lack of staff interviews, despite making every effort to accommodate the needs of staff taking part. The main reasons for staff not taking part was owing to a lack of time and the demanding pressures of work. There were also competing factors, with multiple service improvement interventions and research studies running concurrently. This appeared to have a negative effect on participation with this study with staff only feeling that they commit to one research project. There was also the sense of avoidance, with staff not returning emails, or

not following up invitations to be interviewed after face to face meetings. The need to balance the amount of pressure placed on staff to be interviewed, was considered an ethical implication, and owing to a time limit in which data could be collected, a decision was made to stop recruitment at the end of December 2016. The study findings are also highly contextualised, having followed the events of an EBCD service improvement project within a localised setting. However, owing the concept of theoretical generalisability it is anticipated that these findings will have a wider application within the NHS and for health care organisations generally.

Chapter 6: Analysis part 2a

6.1 Chapter summary

This chapter presents the sub-analysis of data collected as part of study 2 in the previous analysis chapter. The aim of the secondary research question was to explore the experiences of South Asian and White British patients taking part in and a local EBCD project within a cardiology service, in an Acute NHS Hospital Trust in West Yorkshire. The analysis focusses on similarities and differences across the accounts over time. The results are discussed within the framework of psychological empowerment in order to make sense of experiences and explore possible mechanisms of change within the EBCD approach.

6.2 Background

Black and minority ethnic (BME) groups in the UK often experience poorer health and have difficulty accessing healthcare services (Bécares, 2013; Ocloo & Matthews, 2016). Within the primary care setting, large scale patient experience surveys report that South Asian patients and those with poor self-rated health are more likely to have a more negative experience of care (Lyrtatzopoulos et al., 2012).

Evidence also suggests issues such as, language and communication (Murphy & Macleod-Clark, 1993) and poor cultural competence amongst nursing staff (Vydelingum, 2006) may affect the quality of service provision. Cultural competency within the health care has been defined as;

'one that acknowledges and incorporates—at all levels—the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs.'

(Betancourt, Green, Carrillo, Ananeh-Firempong, 2016).

Addressing the social context has emerged as a critical component of cultural competence. This requires understanding how social and cultural issues influence patients' health beliefs and behaviours (Betancourt et al., 2016).

Whilst improvements in patient experience within secondary care have been detected (Elliott, Cohea, Lehrman, Goldstein, Cleary, 2015) the use of large scale survey data is less useful when understanding why and how these changes have occurred. Recognising cultural differences is important when developing services in the healthcare setting and national policies strongly support the need to provide equitable and inclusive healthcare (Stone et al., 2008; Department of Health, 2003). However, ethnic minority populations are often under-represented in health care research (Hussain-Gambles et al., 2004; Dilworth-Anderson et al., 2002; Mason, Hussain-Gambles, Leese, Atkin & Brown, 2003) and it is considered 'unacceptable' for researchers not to address multi-ethnicity of modern day society (Papadopoulos & Lees, 2002).

A key criticism of PPI in healthcare improvement is that people are often hand selected to take part in projects and thus, usually consists of a narrow band of individuals, who are picked for their 'acquiescent' nature (Ocloo & Matthews, 2016). Evidence supports that fact that patients from BME groups are less frequently included in QI efforts (Boote, Wong & Booth, 2015). One of the consequences of this approach is that the people and populations that may have the most to gain are excluded from the process of QI and possibly limits ideas to improve care and experiences and reinforcing the 'cycle of suboptimal care and services' (Ocloo & Matthews, 2016:p4). It has also been suggested that further exploration is required to explore the way organisations support patients to participate in QI efforts (Renedo et al., 2105: Cornish, 2006).

There appears to be little evidence relating specifically to the experiences of South Asian patients within quality improvement efforts. The systematic review within this thesis identified little empirical evidence that has explored the experiences of patient participants from different ethnic backgrounds taking part in EBCD projects. The EBCD project in which this study is embedded within is based in an Acute NHS hospital Trust within Bradford Metropolitan District. Bradford has an ethnically diverse population with the largest proportion of people of Pakistani ethnic origin (20.3%) in England (ONS, 2017). Within the cardiology service approximately 25% patients that are admitted to the ward are of South Asian origin. The context in which this research study was set appeared to be an opportunity to explore experiences of South Asian patients involved in QI efforts.

6.3 Study aim and research question

The aim of this study is to explore the experiences of South Asian and White British patients taking part in an EBCD quality improvement project using a longitudinal IPA approach. The principle objective was to identify any similarities and/or differences between the experiences of South Asian and White British patient participants. It is anticipated that this may increase our understanding how EBCD works in practice for ethnic minorities by exploring similarities and differences in patient participant experiences.

Secondary research question:

How do South Asian and White British patients make sense of their experience of taking part in a local quality improvement project using EBCD?

6.4 Method

6.4.1 Study design

A qualitative longitudinal IPA methodology was selected as a suitable strategy of inquiry since it allows for a detailed examination of participants' experiences within topics that are complex and ambiguous (Smith et al., 2009) and is suited to capturing changes and/or consistencies over time (Nielson and Randall, 2013; Moore et al., 2015; McCoy, 2017). Further details of the rationale and purpose of the study design were expounded upon in the previous analysis chapter (See Section 5.5.1). This study design had two layers of complexity, multiple data points and the number of participants taking part (discussed earlier in Section 3.7.2).

6.4.2 Research Ethics

The study was reviewed and received ethical approval by the University of Leeds, Faculty of Medicine and Health Research Ethics committee (date:15/09/15; Ethics Reference number:15-0153). Further ethical consideration regarding a longitudinal approach and ensuring informed consent was maintained over the duration of the study was previously discussed in Section 5.3.4.

6.4.3 Participants

A purposive sampling strategy was used to recruit participants, consistent with the aims of the study and the underlying methodological discussed in

detail in section 5.3.3. Eligible participants were identified by the main researcher (LT). A study recruitment letter and participant information sheet was sent by a member of the core improvement team (CO), by post or email. The study inclusion criteria were, participants aged 18 years or older, able to speak English, Urdu or Punjabi, and been directly involved in the EBCD project.

Pen portraits of the participants in this study have presented previously (See Table 5.3) with additional details of participant's self-identified ethnicity are presented in Table 6.1.

In order to prevent the identification of participants within this study, the categories for ethnicity were identified at a broad level and did not include sub populations distinctions within the South Asian population.

Table 6.1 Characteristics of participants

Participant	Participant role	Gender	Ethnic Origin
			White British (WB) South Asian (SA)
Jean	Patient volunteer	Female	WB
Sara	Patient volunteer	Female	SA
Fayza	Patient	Female	SA
Harry	Patient	Male	WB
Ivy	Patient	Female	WB
Robert	Patient	Male	WB
Haseeb	Patient	Male	SA
Mary	Patient	Female	WB

6.5 Procedure

Informed written consent was obtained prior to interview. Participants took part in-depth semi-structured interviews at the start of their involvement and at the end of the co-design stage (See Table 6.2). Semi-structured diaries were provided to all participants to use if desired during the EBCD project.

6.5.1 Data collection

Participants were interviewed at different time points (TP) during the EBCD project. TP 1 was after the observation activity, TP 2 was at the start of stage 3 and T2 was at the end of the co-design phase, stage 5 (See Table

6.2). There were only two interviews conducted at TP 1. This was owing to both participants being involved in the observation component of the EBCD process, and were interviewed post involvement. The remaining patients were not involved at this stage and thus, were not interviewed.

Methods used to collect data included, in-depth interviews and participant diaries. A chronological time line for data collection are presented in Figure 6.1.

Table 6.2 Data collection points for study participants

	Time point 1 - Post observation activity interview	Time point 2 - Start of Stage 3 Interview	Time point 3 - End of Stage 5 Interviews	Diary (returned)
Jean	✓	✓	✓	✓
Sara	✓	✓	✓	✓
Fayza	X	✓	✓	/
Harry	X	✓	X	/
Ivy	X	✓	✓	✓
Robert	X	✓	✓	/
Haseeb	X	✓	x	/
Mary	X	✓	✓	/

Key: ✓ = interviewed X = not interviewed / = not completed

6.5.1.1 In-depth Interviews

The semi-structured in-depth interview schedule was informed by EBCD literature and IPA methodology, in order to let the participant tell their story in their own words (Smith et al., 2009) about their experience taking part in an EBCD project with freedom to describe any moments that were important to the participants. All the interviews were conducted by the main researcher (LT) at the start of the participant's involvement and at the end of stage 5, which was over a ten-month period (February 2016 to November 2016). The duration of the interviews at T1 ranged between 10 to 30 minutes and at T2 ranged from 40 to 60 minutes. The interviews were conducted in accordance to the arrangements set out in the ethical review, and were all conducted in a private room and away from the main clinical area. The interviews were audio-recorded and transcribed verbatim

by a trained transcriber, based within the University of Leeds, School of Psychology

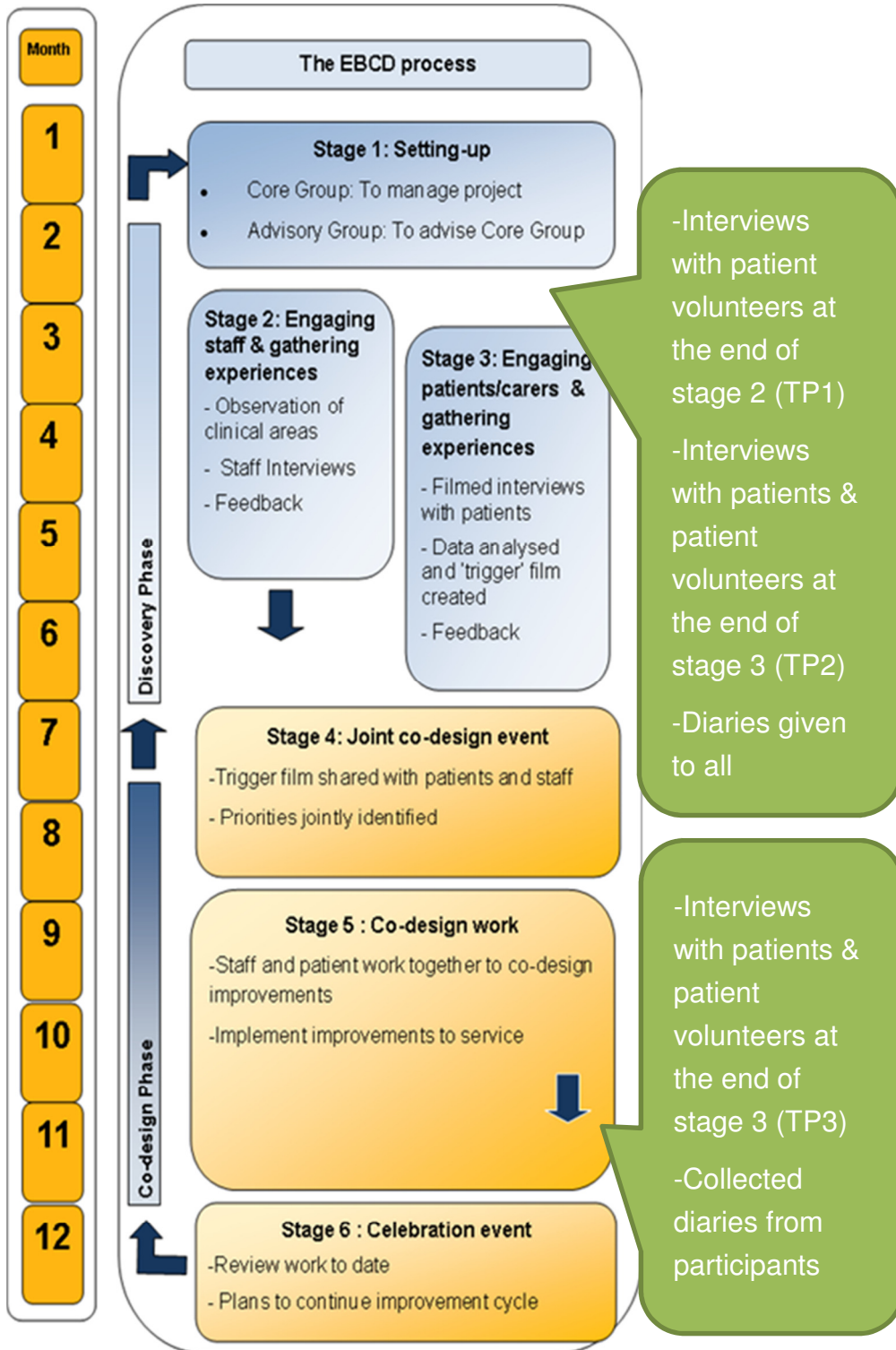


Figure 6.1 Data collection and EBCD timeline

6.5.1.2 Participant diaries

All participants were provided with a semi-structured paper based diary to capture their thoughts about any EBCD related activities. This was provided at the point of taking informed written consent at T1. Participants were encouraged to record any thoughts but it was made explicit that this was not a compulsory part of the study. They could be written in either English or Urdu (and translated if required – none were). The data from the diaries was considered as a supplementary source of data and was intended provide additional context to support analysis. Participants' diaries were requested after interviews at T2, with reasons for use or non-use recorded (See Table 5.3).

6.6 Data Analysis

Reflexivity point:

Before starting analysis I was aware that I may have had some prior assumptions having already handled the data in Study 2. Therefore, I attempted to look at the data with a fresh perspective and try to look for any different patterns or connections across the data set. This refers back to the idea of 'bracketing' in IPA. The reality was that unconsciously I may have been influenced by previous interpretations.

6.6.1 In-depth interviews

The analytical process for IPA has been previously described in detail (See Section 3.9). For the purposes of this study the following analytical approach was taken, reading and re-reading an individual account followed by developing codes to describe the content of the account articulated by the participant, the use of language and how this related to the content and meaning of the account in order to identify any conceptual meanings (Smith et al., 2009). This process was then repeated for each participants account for each time point. Mapping connections within an individual account was conducted before looking for patterns across cases. This was conducted for each time point. A master table of themes was developed for each time point with meta-theme developed to identified patterns and connections from the two master tables, in order to identify changes and consistencies over time. Although the analysis process has been described in a linear fashion, it was a far more iterative process, moving

back and forth across the data set. This is conceptualised as the hermeneutic circle, as researchers attempt to make sense of participants making sense of their experiences (Smith et al., 2009).

The analysis also involved comparing South Asian and White British patient participants accounts involved in the EBCD project. This was an important feature of the analysis in order to explore divergent account across the groups, in order to focus on any specific finds that were unique to either group. Understanding in more detail the way patients are supported to participation in QI efforts is vital to help inform staff and healthcare organisations, especially when considering objectives such as diversity and inclusivity (Renedo et al., 2105: Cornish, 2006).

6.6.2 Participant diaries

Diary entries were read in relation to participant's individual IPA coding framework developed during the IPA process. Detailed reading of the accounts provided additional context when interpreting individual experiences. All diary data was anonymised. Only three diaries were returned, two from patient volunteers and one patient participant. The reasons given by other participants for not using the diary included; not useful as way of recording thoughts, and not familiar with writing and reflecting on experiences (See Table 5.4).

6.7 Results

The analysis detailed a number of recurrent and common themes across all the participants' accounts. These included, a strong social group identity, recognising the value of peer support, a sense of legitimacy owing to the direct experience of care from the service and shared frustration over the lack of staff involvement during the co-design phase. There were also differences between all the participants with regard to their perspective on the interactions within the meetings, with divergent views on how well co-design meetings had gone or not. Divergent views were unrelated to the ethnic group. Group dynamics between patients and staff appears to be a real concern for the all the patient participants, which without an honest, transparent and considered approach appeared to hinder relationships developing. Without that connection it appeared that co-design work lost its potency and staff either were fearful of being vulnerable or protected themselves behind an organisational barrier.

The focus of the analysis turns to the differences between South Asian and White British patient participants. The following themes were identified from across South Asian participant accounts and were not revealed from the analysis of the White British participant's accounts. Therefore, the material within the following meta and sub themes draws upon the accounts of South Asian patients. There was one key meta-theme, being empowered, with the following sub-themes, community support, being deviant and the power of language, which are presented below (See Table 6.3).

Table 6.3 Meta-theme and sub-themes

Meta-theme	Themes
1. Being Empowered	1a. Community support 1b. Being deviant 1c. The power of language

6.7.1 Meta-theme 1: Being Empowered

This meta-theme relates to how South Asian patients participants described their feelings of empowerment through their involvement in the EBCD project. There are three smaller sub-themes, community support, being deviant and the power of language

6.7.1.1 Sub-theme 1a: Community support

One difference between the two group accounts was the amount of external support and encouragement that the South Asian participants received from their extended families. For Sara, Fayza and Haseeb part of their motivation for taking part was the desire to improve things for others and that they felt that they could speak from a place of authority.

Haseeb was the only patient participant that spoke about a close family member, who actively promoted the need to get involved:

'...mostly my wife, she likes [me] to involve in this project, you know. She say, you can learn something ; you can tell any, anything, you know what's happened to you in the hospital; what's the hospital want improve, you see; you should be taking part because you are the patient; you are staying in the hospital. Do you know, the other people, you know because you pass this situation, you know. So you know these things; so best thing you can, you can go the meeting and improve some-something, you know.' (Haseeb, T2)

This extract may also suggest a strong sense of his wife's determination that he should be take part. There is a feeling of a moral imperative that his involvement is essential. We know this by the context of the word '*should*' in this extract. This extract also tells us that he has had a conversation about taking part. The phrase '*you can tell any, anything*' firstly infers that Haseeb is able to be honest and truthful about his care, and that he is able to capitalise on this unique opportunity. He has a chance to have his voice heard and that it might make a difference to other people in the future. The idea that Haseeb may learn something too is also suggested by his wife. So, despite his wife not being present, her voice and the effect of her encouragement are felt through Haseeb's involvement in the project.

For Fayza, her original altruistic motives were concerned with improving the service for others, and she brought invaluable experiential knowledge to the EBCD process. Although, this was not a unique finding, as all participants expressed similar desires over the duration of the project, the effects of temporality in her account suggests a shift from improving the service to importing things back out in the community. Taking part in the EBCD project appeared to give her the confidence and impetus to reach out to other South Asian women in her community:

'I know some ladies who's having a heart attack. I would know that in my community [I] would go and help her as much as I can 'cause they probably know that ...men have a heart attack because of smoking, drinking or whatever. But woman don't do [smoke or drink].' Fayza (T2)

This extract illustrates Fayza's understanding of how South Asian women react to this type of health event and the unfairness of illness compared to the apparent less healthy lifestyle of South Asian men. But, with renewed exploration of her experience it made her realise that there are other South Asian women who may feel equally alone. This idea of peer support was thus extended to other women in her community and that she felt empowered to do something that could directly impact on other South Asian women's lives.

The idea of reaching out was also seen in Ivy's account. After her emotive story on the film, the wife of a South Asian patient independently approached her outside of the meeting:

'And one of the ladies, the Indian lady, er, I think she and her husband were there together. And she talked to me outside in the car park and gave me, I think she works for some care organisation, she gave me a leaflet and said, if I ever wanted to talk about anything, you know er, to feel free to contact her; which I thought was very nice.'

This illustrates the extent to which people were happy to support each other. This interaction was only captured from an interview, and was not observed within the co-design meeting. Yet, the feeling of mutual support and care amongst the group was extended across the patient groups, with Ivy equally touched that someone cared enough to go out of their way to help. This event occurred after the patient only feedback session. They had just watched the trigger film together as a group for the first time. It is suggested that the effect of storytelling may have had precipitated this event. Ivy's story was very emotive, Frank (a designer) in Study 2, commented on the powerful effect it had upon him when creating the trigger film. He connected empathetically to her reaction on leaving hospital when she dramatically cut off all her hair, is some form of cathartic release. For one of the participant's wives to then reach out after independently of the meeting, infers a sense that she recognised that she may want extra support and that she was offering to help her.

6.7.1.2 Being deviant

This sub-theme refers to the idea of South Asian patients going against the perceived societal norms. For Sarah, this was conceptualised in terms of being directly challenged by staff during the observation activity but having the self-confidence and her own sense of legitimacy to defend her position successfully:

'It was a difficult thing to say but then I didn't feel that I had to show her my notes because they were personal to this research. And I think it wasn't fair for her to say that when she knew fully well why I was there.' (Sara, T1)

Sarah was the only participant to be challenged in this way, but she felt empowered and she also directly challenged a level of authority not usually seen within this context.

Fayza, in her account alludes to her own self-belief that South Asian people don't usually get involved in this type of project:

'I think it will be nice because meeting somebody who's in the same situation as me, doing the same helping with the research and I think it's a good experience....I feel all right cause I . . . I always mix in. I don't know why somebody Asian! [Chuckles] because I-I-I always work so I know how it . . . how to work with them and that's it!
(Fayza, T2)

There is a sense within this extract that Fayza sees herself as different within her community. She says *'I always mix in'* which suggests that she usually mixes with other people from other ethnic backgrounds, and with the exclamation of *'I don't know why somebody Asian!'* inferring this is not typical behaviour of a South Asian person. This may be down to her personality traits, *'always'* mixing in and owing to her life world experiences of work:

'so I knowhow to work with them...' (Fayza, T2)

This phrase is also interesting in the way she refers to people at work as *'them'*, subtly suggesting that other colleagues are different from her.

Reflexivity point:

Fayza revealed in conversations with me outside her interview that she worked with predominantly with White British colleagues. This was recorded as a field note, with the thought that it may be useful at the stage of analysis.

This final extract from Fayza within this sub-theme, describes her desire to be more involved and included with QI efforts. This is important here as Fayza recognises the value of the patient perspective in term of broadening the minds of staff, something that was not articulated by the White British participants:

'I think I find it really useful. I think there should be more meeting going on and . . . participating; it's like [pauses] it's why their minds are broader, you know like . . . it was nice. I liked it.' (Fayza, T2)

The idea of minds being *'broader'* infers a real sense of capturing the whole experience for staff and patients and getting staff to think in wider terms of patient experience. Fayza relished being part of the EBCD group and saw the merit of real patient participation.

6.7.1.3 The power of language

Accessing experiences from South Asian patients that were not fluent in English was seen as an important part of the project, and something that Sara felt she could uniquely contribute as patient volunteer within the co-discovery process;

'I was able to speak to patients because I was able to speak the language...I was able to give 'em that comfort and, and they were more than willing to participate....They don't want to complain So there's a big cultural um . . . understanding as well. Which is nice that we can bring and give that patient the comfort saying that, 'No, actually, this is what there is researchers here for because we want to take views of the – 'cause when you, you discharge it's really important um, that you have that . . . support.' I think you have been restricted but I think I've been fortunate 'cause I can speak different languages...I think with me being able to get involved, I was able to help' (Sara, T2).

Sara talks about her ability to bring reassurance and comfort to South Asian patients she spoke to during the observation activity. She understands the apparent cultural concern of South Asian patients not wanting to complain about care. But, being multi-lingual was seen by Sara as an advantage, and a way of reducing the limitations of gathering patient experience data associated with language barriers. Fayza in her account describes the difficulty other patients had with the language on the ward:

'I think because I was all right because I can speak English. But I think there was a lot of people struggling there' (Fayza, T2)

'I think my [pauses] experience was because I can speak English I could get on. And some of them which were there who couldn't... And some of them which were there who couldn't. But then they feel isolated...it's like when we talking our language it's like comforting.'
(Fayza, T3)

The sense that Fayza saw other people 'struggling' on the ward, in terms of language makes her realise that she was in a fortunate position that she altruistically wanted to help others. The following extract describes her pleasure at being able to comfort another South Asian female patient:

'I feel really good. I feel helping somebody! And they're taking my advice! [Laughs] which I thought it wouldn't be right but it

was!...don't worry it will be all right there you're in good hand. And she was saying she's er, she was frightened and you know it's like isolated, if it's the language as well. So it's like you're reassurance' (Fayza, T3).

This extract infers a sense of empathy from Fayza, understanding how the other patient was feeling and offering her peer support. The idea that language here is 'isolating' suggests the real effect of not being able to effectively communicate, but also that she felt able to bridge this gap. Importantly, Fayza was able to bring this experience of helping others into the EBCD project. She describes in her account how difficult it is for South Asian women to talk about intimate aspects of their health, '...some Asian ladies are shy to talk with...' (Fayza, T3). But owing to her self-identity, which she considers to be atypical, she was willing to share her experience on film, albeit unsure at first:

'I open up a lot. I think I, I got everything off my chest and think, 'Yeah, why not?' At first I didn't know. I wa'a bit nervous about it.' (Fayza, T2)

One issue to note from both Sara and Fayza's accounts, is the idea of language being comforting. This infers the idea that speaking in a familiar language provides more than just effective communication. It provides reassurance and reduces the idea of being cut off or being 'isolated' during a time which is frightening for even native speakers, as Harry sums up,

'...you're scared to death about your future. Um, your future prospects and what's happening with your body'. (Harry, T2)

Sara comments on an interaction with an elderly South Asian patient during her observation activity, he wanted to query something about his care and addressed Sara:

'...he couldn't speak English and he spoke to me and he said to me, 'This is what? you know daughter . . .' he calls me daughter 'cause they see somebody young.' (Sara, T2)

This extract reinforces the idea of language breeding familiarity and comfort. The cultural exchange between the two, evokes a sense of family, the use of the word 'daughter' though translated and interpreted by Sara to refer to someone younger, still conveys a sense of family and community. In contrast, in English, the expression 'daughter' would not be used to gain the attention of someone. This sense of familiarity may have also helped

with the patient speaking up about a concern that he had about his care, something that Sara alludes to within her account that is hard for older South Asian people to do:

'I think that the more elderly generation you have from the South Asian background they tend not to try and speak up because they feel that if they speak up or they've got a concern, the nurse might hold it against them and do something wrong to them. That's their mind set in [city], this community um . . . and they-they think that if we speak up they might h-harm us or they may not look after us properly. The younger generation like myself we're total opposite.'
(Sara, T2)

This extract also illustrates a difference in attitudes between older and younger generations within the South Asian communities. But as Sara suggests in her account, her ability and her acceptability appear to be an important factor when understanding what is like to be a South Asian patient within the service.

The idea of enabling others was described in terms of actively involving a wider patient population in gathering experiences and feeding this back for the purposes of improvement efforts. Sara actively engaged with patients during the observation activity and Fayza drew upon a more holistic picture of her experience being on the ward.

6.8 Discussion

This study has attempted to explore the experiences of South Asian and White British patients involved in a local EBCD project. The sub-analysis demonstrated commonalities and differences within and across the group.

It is interesting to note the degree of similarity with regard to participants' experiences. The sense of a strong social group identity was seen across all participants' accounts with the idea of social and symbolic capital bringing these people together as discussed in the main findings of the primary study (See Section 5.9). Everyone appeared to equally be frustrated over the lack of staff engagement over time. This similarity suggests broader inferences and generalisability about the findings: that ethnicity may not play a part when understanding patient and public involvement within EBCD, since the motivations and expectations of taking part were very similar.

The key findings relating to the differences between the White British and South Asian patients' experiences are discussed in relation to the middle range theory of psychological empowerment (PE) (Thomas and Velthouse, 1990). Psychological empowerment has been theoretically applied within the domain of organisational research (Spreitzer, 1995), investigation of the effects on work place engagement in healthcare (Kuokkanen, Suominen, Rankinen, Kukkurainen & Savikko, 2000; Wagner et al., 2010; Wang & Liu, 2015), more recently patient participation with regard to managing health (Sak, Rothenfluh, & Schulz, 2017; Eskildsen et al., 2017) and as a framework to explore organisational change processes (Morin, Meyer, Bélanger, Boudrias & Gagné, 2016). Therefore, it would appear to be a relevant framework to discuss some of the findings from this sub-analysis since EBCD requires patients to step into the working world of health care professionals.

PE is broadly defined as a sense of internal motivation that reflects an individual's perception of their work via four strands of thought: meaning; competence; self-determination and impact (Thomas & Velthouse, 1990; Spreitzer, 1995) and are defined more broadly below:

- Meaning is seen as the value of a work purpose and is judged by a personal set of standards (Thomas & Velthouse, 1990).
- The idea of competence or self-efficacy relates to a person's own ability to carry out activities with associated skills.
- Self-determination is where an individual has a sense of having a choice in starting and continuing work behaviours.
- Impact is seen as the level to which a person can influence 'strategic, administrative, or operating outcomes' within the context of the work environment (Spreitzer, 1995:p1444).

In terms of 'meaning' all the patient participants saw the value of the improvement project in terms of improving things for others, with an altruistic motivation. For South Asian participants there also a stronger sense of wanting to actively reach out to others within their community and to others within the patient group. It is suggested that PE has the ability to address the issues of 'powerless and devalued people' and thus, may have additional relevance to individuals within ethnic minority groups (Molex & Bettencourt, 2010: p515). Having the opportunity to be involved in a QI project using EBCD may mean that individuals are able bring their voice to improvement efforts. Although, the value of the work as described by the

two patient groups was the same, it potentially differed for the South Asian participants in the sense that improvement efforts wanted to be readily shared and spread to others in their communities outside of the project setting.

The results may indicate that the cognition of 'meaning' within PE appears to play an important role within the EBCD process, especially in terms of legitimacy for South Asian participants. One South Asian participant described in some detail how she was directly challenged by staff. This may indicate a more entrenched concept of professional hierarchy that exists within the healthcare system (DiPalma, 2004) but it is interesting to note that her counterpart, who was White British was not confronted. This may have been owing to the novel nature of the EBCD process. Staff are not routinely used to patient volunteers collecting observational data and may have felt threatened. Looking at the way these interactions were placed in time the South Asian participant spent more time on the ward and therefore, may have been exposed to more interactions with staff.

Impact within the PE framework considers the level of influence an individual may have on strategic, operational or administrative outcomes within the workplace. Thinking about a key theory underpinning the EBCD process, user-centred design relies upon face-to-face collaboration in order to co-design (Bate & Robert, 2007a). The opportunity to collaborate in this way was really valued by the South Asian patients, with a desire for more meetings.

The effects of group dynamics with staff were also seen in terms of the role of impact in PE. Patient participants formed closed ties over a shared common experience, they had the opportunity to listen and watch each other's stories. However, the experience for some during group co-design meetings also demonstrated the power and control exerted by some staff which may have affected their sense of being able to 'master' the social situation.

The idea of self-determination within the PE framework is seen as the choice of an individual in starting and continuing work behaviours. Though all the accounts highlighted the fact that participants actively choose to get involved, it would appear that the South Asian participants demonstrated a greater sense of wanting to help others outside the confines of the group. This was seen in terms of individual actions inside and outside the EBCD process.

The idea of enabling others was seen largely in terms of South Asian participants enabling others to find their voice, being limited by language. This was associated with a sense of competence within PE; they had the language skills to engage with others, something that the white British participants could not offer. Linguistic barriers to effective communication with patients is well documented (Scouten & Meeuwesen, 2006; Astin, Atkin & Darr, 2008) and specifically for South Asian patient population (Atkin, 2004). The use of family members as interpreters has been criticised owing to often highly sensitive information being translated, leading to information sometimes being withheld (Scouten & Meeuwesen, 2006). However, this study also illustrates the use of a familiar language did more than act as a reliable way to communicate, the function of language here was seen in terms of providing comfort and reassurance during a frightening time.

This study has revealed similarities and differences across the participant's accounts. The use of the PE framework was a useful approach to explain and explore the findings. This could be considered a novel approach but has relied on conceptualising patients as part of the work environment. Indeed, they are not considered to be patients in the true definition, but bring the patient perspective to the EBCD process.

There is no other published literature known to the author (LT) that has evaluated the experiences of South patients taking part within an EBCD project. Although this study was small, the findings may be considered novel and important when understanding how and why and under what circumstances EBCD 'works'. and contributes to the empirical evidence about ethnic minority populations with health care research.

6.9 Limitations

A potential limitation of this study related to the loss of participants from the study during the course of the study, which is associated with an issue of LQR methods (see Section 3.8.1). The issues associated with the methodology of a longitudinal approach are discussed in Chapter 7 (See Section 7.2).

There were only three diaries returned from participants and although the reasons for not using the diary were discussed in section 5. 4.4, this still represents a loss of data. The diary was not an implicit part of the study

requirements and participants were given the express choice of using or not using the device.

IPA often uses metaphors to help elucidate central themes within and across accounts, it was noted that there were fewer metaphors used within the accounts of South Asian patients. This may have been owing to the fact that for Fayza and Haseeb English was a second language with the use of idiomatic phrases not part of their vernacular. If they had been interviewed in their native language, which had been reliably translated and transcribed this may have uncovered additional phrases to aid interpretation of their experiences.

Chapter 7: General discussion: thesis summary, critique of methodology, and directions for future research and practice

7.1 Chapter Summary

This chapter provides an overall summary of the aim of the thesis, the research questions addressed and the key findings from the qualitative studies conducted. The results are discussed in relation to extant literature about EBCD, and what the findings from the research studies add to our current understanding how, why and under what circumstances EBCD ‘works’. The limitations of the thesis are considered, including an assessment of the quality of the IPA studies conducted. Finally, the implications for practice and possible directions for future research are offered.

7.2 Background and thesis aim

The impetus for large scale change to improve the delivery and receipt of care worldwide has been largely attributed to the IOM’s report: *‘To Err is Human: Building a Safer Health System’* (Kohn et al., 1999; Vincent, 2010; Department of Health, 2013a). The key dimensions of quality within the NHS are defined in terms of patient safety, clinical effectiveness and patient experience, which are enshrined within English law (Department of Health, 2008; Health and Social Care Act, 2012).

Patient experience can be defined as,

‘the sum of all interactions, shaped by an organization’s culture that influences patient perceptions across the continuum of care’ (Wolf, 2014).

The emphasis on improving patient experience in the NHS, has been informed by numerous national healthcare reviews and policy changes (Donaldson, 2000; Department of Health, 2008; Department of Health, 2010; The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013; Department of Health, 2013b; Department of Health 2014b; The King’s Fund, 2015) with increasing evidence to suggest that a better patient experience is a vital element of high quality and safe care (Sequist et al.

2008, Meterko et al. 2010, Fenton et al. 2012; Doyle et al., 2013; Price et al., 2014).

There are various ways in which patient experience data is gathered and used to enhance care, from large scale questionnaires to patient stories, complaints and compliments (Coulter et al., 2009; The Health Foundation, 2013). However, it is suggested that existing approaches do not help to inform change at a local level (Robert, 2013; Coulter, 2014). In an attempt to address this gap, experience based co-design (EBCD) was developed and tested within and for the NHS (Bate & Robert, 2007a). EBCD is a theoretically informed complex intervention that uses qualitative methods to capture and understand the patient experience with the express aim of improving the 'experience'. It has been applied to a wide range of clinical settings, nationally and internationally over the last decade. Evidence suggests that EBCD is considered an acceptable and feasible approach to improve the quality of care (Donetto et al, 2014; Locock et al., 2014; Macdonald, 2017). However, it is argued that the ways in which the approach brings about change in practice are unclear (Rohde et al., 2016).

To this end, the initial aim of this thesis was to explore the mechanisms of change through the lens of improvement science. It was anticipated that the qualitative research studies, reported within this thesis would generate new knowledge about the EBCD process, further our understanding about the mechanisms of change and contribute towards the evidence base of the science of improvement. However, it became apparent over the duration of the longitudinal qualitative study that staff participants became disengaged from the QI project. As a result the overall aim of the thesis changed to explore the experience of participants taking part in an EBCD project. The research questions addressed within this thesis were as follows:

- 1) How has EBCD been implemented and its effectiveness assessed within the healthcare setting?
- 2) How do patients, staff and designers experience non-participant observations, as part of an EBCD project?
- 3) How do people taking part in an EBCD project make sense of their experience?
- 4) How do South Asian and White British patients make sense of their experience of taking part in a local quality improvement project using EBCD?

To address these questions, four studies were conducted, a systematic review and three qualitative studies, exploring the lived experience of the EBCD process from multiple perspectives, patients, staff and health care design engineers. Chapter 2 presented the findings of a systematic review, undertaken to assess the implementation and the effectiveness of existing EBCD projects published in peer-reviewed literature. Study 1 (Chapter 4) explored the experiences of staff, patient volunteers and designers conducting non-participatory observations in the clinical area (stage 2 of the EBCD process (See Figure 1.1)). Chapters 5 and 6 presented the analysis of data collected to explore the experience of participants within a local EBCD project using a qualitative longitudinal approach to capture experiences over time. The key results from all four studies are summarised below.

7.3 Summary of key findings

7.3.1 Systematic review: How has EBCD been implemented and its effectiveness assessed within the healthcare setting?

The aim of the review was to assess the implementation and effectiveness of the EBCD approach using existing published empirical evidence. This focussed approach was taken in order to reliably inform research questions and was guided by the principles of improvement science, that efforts to improve care should be based on the highest quality evidence (The Health Foundation, 2011; Davidoff et al., 2014).

The first key finding was the degree of adaptation that took place during the co-discovery and co-design phases of the process (See Section 2.6.2.2). Using different approaches to gather patient experiences appeared to have little effect on reported outcomes, with all projects identifying joint service priorities which resulted in local changes. Complex interventions, like EBCD, are often subject to adaptations for contextual reasons (Hawe, Shiell and Riley, 2004) with positive outcomes being achieved even though an intervention was not delivered as planned (Moore et al., 2013). But, it is argued that some components of the EBCD process are essential, such as, non-participatory observations within the co-discovery phase (Bate & Robert, 2007a; Donetto et al., 2014). However, this element was consistently omitted in the studies identified within the review with little justification for the decision. It is, therefore difficult to determine how it

contributes to the process and what happens during observations and what the experience is like for those conducting them.

The main limitations with regard to the evaluative studies were the study designs which were unable to explore changes over time (Bowen et al., 2012; Iedema et al., 2010; Piper et al., 2012). The ethnographic evaluation of the accelerated version of EBCD (AEBCD) did capture data over time but was not conducted in a uniform manner for all stakeholders (Locock et al., 2014). Although the methods selected were appropriate to explore the experience of participants, it was argued that the evaluation was concerned with understanding the acceptability of AEBCD and not the EBCD process per se. A longitudinal approach may be better suited to capturing changes and/or consistencies over time owing to data collection at multiple time points (Nielson and Randall, 2013; Moore et al., 2015).

One interesting finding was that despite the heterogeneity of clinical settings and patient populations, there appeared to be a set of common touch points identified during the 'gathering patient experiences' stage. The recurrent theme of enhancing communication between patients and the service was evident within all of the EBCD projects. But in order for teams to address specific concerns, it is argued that more careful measurement, documentation and interpretation of patients' subjective experiences are required (Coulter et al., 2014).

Another key finding raised questions about understanding the mechanisms underpinning the activities employed to bring about change. The theory underpinning EBCD suggests that change happens not only at service level but at a personal level, especially for staff to re-engage with patients and the whole journey (Bate and Robert, 2007a). Whilst some evidence may support this theory (Locock et al., 2014), there is little reported evidence from stakeholders exploring their experiences in-depth and how power relations can be managed during the process (Bowen et al., 2013). Where complex interventions may fail to produce long-lasting effects, changing the organisational culture (staff thinking differently about patient experience) combined with small fixes, may be more sustainable and desirable in the long run, than large sweeping changes to the delivery care. However, there was very little detail about what exactly happened during the co-design meetings, and how patient touch points helped to inform changes within the service. Therefore, without fully understanding the essential

elements of the approach, it is argued the theory underpinning EBCD under-investigated.

Finally, a key evidence gap raised from the review was the total lack of evaluative or research studies exploring the experiences of patients from different ethnic origins. Acknowledging cultural differences in order to provide equitable and inclusive healthcare is essential when developing services (Stone et al., 2008; Department of Health, 2003). Patients of South Asian origin are sometimes more dissatisfied with their experience of care (Lyrtzopoulos et al, 2012, Department of Health, 2009) and are an under represented group within healthcare research. The reasons cited for this issue have been in terms of perceived language barriers and passive exclusion by researchers as a result of cultural stereotyping (Hussain-Gambles et al., 2004). There has been to date very little investigation of cultural differences of patients involved in EBCD projects (G. Robert, personal communication, 28 November, 2014).

Therefore, in order to further understand how and why EBCD works, further research was required. Capturing the experience of participants over time may assist with unpacking how this approach may or may not work in practice, and what the barriers and/or facilitators are with regard to a project's success. The review findings helped to inform the three research studies that follow.

7.3.2 Analysis Part 1: How do patients, staff and designers experience non-participant observations, as part of an EBCD project?

This study explored the experiences of patient volunteers, staff members and designers undertaking participant observations as part of an EBD project on an acute cardiology ward. The analysis described the experiences of participants conducting observations whilst also discussing any similarities and differences within and between the different stakeholder groups.

The discomfort described by participants illustrated the difficulty of the 'outsider' and 'insider' perspective assumed during observation (Hume & Mulcock, 2004). This proved to be extremely challenging for staff, concerned about the negative impact on relationships with colleagues and doubting the usefulness of a 'snap shot' of ward life. Although challenged in different ways, the patient volunteers felt empowered, with the idea of social legitimacy (Munduate & Gravenhorst, 2003) possibly playing a key

role in the process by reducing constraints often associated with PPI in improvement efforts (Beresford, 1994; Martin, 2008). Yet, it has been mooted that collaborative partnerships between staff and patient are fraught with challenges (Martin & Finn 2011) with healthcare professionals often sceptical of PPI in QI efforts (Renedo et al. 2015).

The therapeutic aspect of the observation activity was seen in terms of being a cathartic mechanism for patients and for the observers. However, this element for patients on the ward was only recognised by the patient volunteers because they had taken an unprompted 'participatory' approach towards observation and had chosen to engage with others. They may have detected touch points that were hidden to both staff and patients: the need for patients just to talk, without a specific agenda was something that appeared to provide a cathartic release for patients being observed and for the patient volunteers and designers observing life on the ward.

Returning to the theory underpinning EBCD, possessing an empathetic stance is seen as a key factor in trying to understand another person's experience. Empathy has a dual aspect within the EBCD approach in terms of a 'technique' as well as a 'frame of mind' (Bate and Robert, 2007a: p43). It was evident from the accounts, that by talking to patients, a wider understanding was gained of the potential touch points for patients and specific patient safety concerns at a local level. It is argued therefore, that by using a more collaborative and multi-disciplinary approach to observation, that is, actively involving patient volunteers and the designers during the co-discovery phase that a more of a complete picture of patient experience could be gathered. It is also suggested that the role of the design engineers in the process of co-discovery contributed to a more sophisticated interpretation of the patient experience. Evidence suggests that the value of a designer's 'creative practice' within a collaborative partnership, to design interventions to improve health, may help to build upon the patient contribution towards the development process (Bowen et al., 2016). Although the systematic review in Chapter 2 revealed the role of a facilitator as an essential element of the implementation of the EBCD process, the value of a designer within the process has not been previously reported upon. Thus, this finding may be important when understanding how and why and under what circumstance EBCD may 'work' in practice.

7.3.3 Analysis Part 2: How do people taking part in an EBCD project make sense of their experience?

Using a qualitative longitudinal IPA methodology a detailed examination of participants' experiences within the EBCD project was presented.

A key finding was the notion of social group identity within the project, conceptualised as 'tribalism' (Braithwaite et al., 2016). The strength of the bonds within the patient 'tribe' was evident to those outside, appeared to transcend age, gender and ethnicity and was maintained over the duration of the project. By sharing stories about a life changing experience this appeared to foster a unique relationship. It could be argued that being part of a tribe provided a sense of social and symbolic capital referring to the value attributed by the group through forming a new network of relationships, bound by a common experience (suffering a heart attack) (Locock et al. 2017). The intentional interactions by the designers also served to reinforce this bond, creating a strong sense of community through direct and indirect contact and purposeful activities. This may have helped to further develop the bonds and develop a greater sense of loyalty within the group. Although the designers saw themselves as boundary spanners between patients and staff tribes, being so closely involved with key components of the EBCD process, (such as creating the trigger film, interviewing patients and running the emotional mapping exercise) also appears to have strengthened the bond between the patients participants and the designers. This was seen in terms of the mixed empathetic response to the staff involved in the project. The value of this social power was also seen in terms of accessing resources and achieving goals that could have been otherwise impossible to reach (Plunkett, Leipert & Olson, 2016). The smaller co-design group led by the designers was the only group that produced a patient-centred tangible outcome, a patient handbook designed to address key touch points of patient experience, such as, providing reassurance and explaining steps in the care.

The sources of tension that arose between people inside and outside of the system could also be attributed to social identity theory (Creswick et al. 2009; Weller et al., 2012). Patients could be seen to have crossed over into the professional world. They were part of an improvement team, rather than occupying the space of a patient, in the truest sense. Yet, the side discussions between staff during the joint co-design meeting, was an example of patients feeling excluded. There was also evidence that the

social side of meetings was absent from the smaller co-design meetings, when not facilitated by the designers (no symbolic cutting cake, or small talk).

Returning to the theory of user-centred design within the EBCD approach, two hypothesised processes are:

- i) Direct patient and staff participation in a face-to-face collaborative effort to co-design (or re-design) services
- ii) An emphasis on improving the experience rather than the process of care (Robert, 2013)

The findings from this study suggest that direct participation with staff and patients encountered a number of obstacles. Pragmatic issues such as the burden of work and staff shortages made it impossible to meet face-to-face. The effect of a closer working relationship between the designers and patients was evident. Whilst sympathy was extended to the staff who at short notice could not attend co-design workshops, it was a source of frustration for the designers and patients. The staff presence was seen as an important part of the process, in terms of providing legitimacy and accuracy to the content of the patient handbook being developed. It is suggested that the principles of user-centred design may be an active ingredient with the EBCD process.

Another major issue concerning face-to-face interactions between staff and patient was the notion of professional hierarchy. The designers used specific tools and techniques in order to reduce the effects of hierarchy and suggested the need for a common creative language that both patients and staff could understand.

A contentious issue that was identified within the analysis was the difficulty for staff in maintaining the focus upon improving 'patient experience' rather than the process of care. Yet, when staff worked alongside the designers they were prompted to reflect on the experience of care which also appeared a way to engage staff going forward.

The results from this study suggest that a combination of providing staff sufficient time and space to reflect and engage with others, an activity not routinely resourced, may be needed to bring about change within the EBCD process. The use of designers within the process could also be an important part of implementing the approach. Reaching the desired outcomes to improve the experience of care appears to be enhanced using

the specific skills and knowledge that designers bring to the collaborative approach. The 'design' in co-design has been described as either 'designerly' (led by designers) or 'design-like' (led by non-designers) (Robert and Macdonald, 2017: p117) and posit that QI efforts require combining both approaches. Evidence suggests that EBCD is successful without the use of designers (Macdonald, 2017) but, what is argued here is that the designers bring more to the process than just a facilitator role or a unique set of tools and techniques peculiar to field of design science. Owing to their philosophical orientation, and an explicit understanding of user centred design means they actively seek to address the issues inherently associated with the development of complex healthcare interventions, that is, social processes - culture, language and cognition, identity and citizenship (Greenhalgh, 2014).

A second important theoretical strand within EBCD is the idea of a narrative-based approach to change. The trigger film is seen as a 'catalyst for improvement' by providing a mechanism for staff to connect and acting as 'a persuasive starting point for change' (Bate et al., 2015: p1). Although the trigger film was seen as a useful way to develop connections and generate discussions, the hypothesised effects were not uniformly experienced by all. The trigger film also has the power to cause detrimental effects to relationships between staff and patients. The challenges trying to establish and maintain an empathetic viewpoint and an emotional connection via the film were evident within the participant accounts.

The issue of face-to-face collaboration as a mechanism for change for co-design became even more apparent, not only in terms of outputs, but in relation to building alliances, an essential principle of participatory action research underpinning EBCD (McIntyre, 2007; Robert, 2013). The most successful group in terms of project outputs consisted of the designers and patients. They had the time to develop this relationship compared to staff that consistently faced insurmountable problems to create time to engage with EBCD activities over a prolonged time scale. Although, the setting for the EBCD project was highly contextual, the commonalities faced by other NHS services and organisations with regard to unprecedented pressures are recognised more widely (Ham, 2017; Iacobacci, 2017).

The issue of time as a barrier also brings the notion of learning theory, as a key theoretical strand within EBCD, to the forefront. Another hypothesised

process within EBCD is the development of staff as reflective practitioners. This requires staff to be able to 'pause and reflect' on information gathered. This study revealed there appeared to be little time and space dedicated to reflection for staff.

The Patient Feedback Response Framework (PFRF) was used as a way to further explore and explain the results within this study (Sheard et al. 2017). It is comprised of three key concepts, normative legitimacy (NL), structural legitimacy (SL) and organisational readiness (OR) to explain how staff react and address patient feedback. Normative legitimacy (NL) refers to the 'moral orientation' of persuading others to do the right thing (Lockett, et al, 2012), structural legitimacy (SL) refers to the formal institutional structures and 'the power that emanates from professional hierarchy and jurisdiction' (Lockett et al, 2012) and organisational readiness (OR), defined as a shared "resolve to pursue the courses of action involved in change implementation" at the organisational level (Weiner, 2009) (See Figure 5.4).

When looking at the empirical results from this study, NL was present across all the participants' accounts and remained a consistent finding (See Figure 5.4). However, some of the observational data also indicated that not all staff appeared receptive to the feedback, which may have weakened the NL within the core group of participants within the EBCD project. In terms of SL, there appeared to be a lack of ownership of the project (Figure 5.3). The QI specialist appeared to distance themselves over time and staff appeared to be increasingly less engaged as the project continued. The result of low SL for staff meant that they had little chance to get involved in the co-design work. However, for the designers and patients they had high SL but needed OR to formally legitimise the work they had done together and implement changes into practice (See Section 5.9). Similar issues with regard to implementation have been reported in other evaluative EBCD studies (Bowen et al., 2010; Piper et al., 2010; Piper et al., 2012; Bowen et al., 2013) but this framework helps to understand additional mechanisms that are needed to ensure the success of the EBCD project.

Finally, the notion that EBCD had a therapeutic effect for patients and the designers also affected the way EBCD worked. There is some empirical evidence that EBCD may have a personal therapeutic benefit for patient participants (Locock et al, 2014). This was clearly demonstrated across all patient accounts and to some degree for the designers. This was seen in

terms of having a unique opportunity to share their stories, which on reflection helped them to make sense of what had happened as in-patients. There was also the therapeutic benefit of finding their tribe, which they drew strength from and in turn, helped them to have confidence in taking part in the EBCD project. The therapeutic benefits may have also assisted with patients continued interest and involvement with the project, despite the decreasing lack of engagement with staff over time. The designers appeared to act as the social glue, they created a collaborative atmosphere which was underpinned by their professional and personal philosophies, a desire to engage in activities that 'leads to a useful solution that benefits the people involved' (McIntyre, 2007: p1).

In summary, this study explored the experiences of multiple stakeholders involved in a local EBCD project, to improve the experience of discharge following a heart attack. The mechanisms of change that underpinned the process within this specific context were complex and multi-faceted.

7.3.4 Analysis Part 2a: How do South Asian patients make sense of their experience of taking part in a local quality improvement project using EBCD?

This study explored the differences between the experiences of South Asian and White British patients involved in a local EBCD project. The analysis demonstrated commonalities and differences within and across the accounts. There were common themes across all the accounts, such as, the sense of a strong social group identity, recognising the value of peer support, a sense of legitimacy and a shared frustration over the lack of staff involvement during the co-design phase.

The key findings that revealed divergences between the South Asian and White British patients were related to the different way they sensed being empowered within the EBCD project. Psychological empowerment (PE) has been applied within the domain of organisational research (Spreitzer, 1995) but, appeared to be highly relevant as a framework to understand patient participation in QI efforts and EBCD where patients have stepped into the world of work.

In terms of 'meaning' the value of the purpose of the EBCD project was seen not only from the individual perspective but a family and community responsibility for South Asian patients. It is suggested that PE has the ability to address the issues of 'powerless and devalued people' (Molix & Bettencourt, 2010: p515) and thus, it is suggested that EBCD may be even

more relevant and useful as a way of engaging people from marginalised groups. For South Asian patients there was an equal desire to be actively involved, but this requires adopting an inclusive approach when recruiting people to EBCD projects.

Impact within the PE framework considers the level of influence an individual may have on strategic, operational or administrative outcomes within the workplace. The opportunity to collaborate face-to-face was really valued by the South Asian patients with the desire for more opportunities to engage in this way. This is a key mechanism within the EBCD process. It appears that EBCD may offer a way for patients from ethnic minority groups to increase their impact when improving service and delivery and the quality of care meaningfully at a local level.

The idea of self-determination within the PE framework is seen as the choice of an individual in starting and continuing work behaviours. Though all the accounts highlighted the fact that participants actively choose to get involved, it would appear that the South Asian participants demonstrated a greater sense of wanting to help others outside the confines of the group. This was seen in terms of individual actions inside and outside the EBCD process.

Enabling others was seen in terms of South Asian participants helping others to find their voice, often being limited by language. This was associated with a sense of competence; they had the language skills to engage with others, something that the white British participants could not offer. Linguistic barriers to effective communication with patients is well documented (Scouten and Meeuwesen, 2006; Astin et al., 2008) and specifically for South Asian patient population (Atkin, 2004). However, this study also illustrated the use of a familiar language did more than act as a reliable way to communicate, the function of language here was seen in terms of providing comfort and reassurance during a frightening time.

This study has revealed similarities and differences across the participant's accounts. The use of the PE framework was a useful approach to explain and explore the findings. This could be considered a novel approach but has relied on conceptualising patients as part of the work environment. Indeed, they are not considered to be patients in the true definition, but bring the patient perspective to the EBCD process.

7.4 Thesis contributions to understanding further the theory and practice of EBCD: a summary

This thesis aimed to explore how, why and under what circumstances EBCD 'works' in order to generate new knowledge about the EBCD process, to further our understanding about the mechanisms of change and to contribute towards the evidence base of the science of improvement. As the research progressed it was evident that owing to the level of staff engagement over the duration of the EBCD project and lack of staff participation within the research studies it became difficult to fully explore the mechanisms of change. This led to the modification of the original aim of thesis and thus has explored the experience of participation for people involved within an EBCD quality improvement project in the health care setting.

It is at this point the four key features of EBCD are re-examined in view of the analysis reported within this thesis. As discussed in chapter 1, EBCD brings together four strands of thought: PAR; user-centred design; learning theory and a narrative-based approach to change (See Section 1.5.2). Each of these strands will now be discussed in relation to findings reported in the subsequent analysis chapters with Chapter 4 presenting an in-depth analysis of patients volunteers, staff and designers' experiences of conducting observations (as part of stage 2 of the EBCD process). Chapters 5 and 6 present the findings from a qualitative longitudinal study that explored participant's experiences of the EBCD process over time which included stage 2 to stage 5.

- Participatory Action Research

The key principles of PAR underpinning EBCD refer to the development of a democratic partnership between patients, that data are created from the direct experiences of participants and that improvement efforts are seen as an agent of change (McNiff & Whitehead, 2011; Robert, Cornwell, Locock, Purushotham and Sturmeay, 2015). The theory is applied during the EBCD process using specific tools and techniques. For example, collecting qualitative data from staff and patients about the experience of delivering and receiving care, the creation and use of trigger films and patients and staff working together to co-design changes.

When considering the findings from analysis Chapter 4 in relation to the theory of PAR, it was evident that all participants faced challenges carrying

out the observation activity. However, participants brought different insights into understanding the experience of care from both the designer, patient and staff perspective and contributed to a more complete picture of ward life. Traditionally observations have not been conducted by patients, with the suggestion that that the discovery phase is led by the core improvement team. The idea of involving patients more actively within the discovery phase maybe contribute towards a more democratic partnership, as long as there is a recognised legitimacy to being part of this stage.

From the analysis in Chapter 5 it was evident that patients and staff occupied different social spaces, which was related to an individual's perceived self and group's identity. Whilst the trigger films were created using data gathered directly from patient experience, suggesting the underpinning principles of PAR, the notion of a democratic partnership was harder to develop and maintain. This may have been explained by a strong sense of tribalism that appeared to exist amongst staff and patients. The level and type of interactions that occurred at the joint meeting and following smaller co-design groups between staff and patients also impacted upon the idea of democratic partnership. There are without doubt some deeply ingrained behaviours, values and beliefs about the patient and doctor relationship and the hierarchical nature of the way healthcare is delivered and received. However, a key factor that appeared to suggest successful outputs and outcomes from the process could be attributed to the role of the design engineers within the process. They were aware of the potential barriers and sought to readdress the balance of power between patients and staff. This was in terms of activities and social rituals to foster a more egalitarian approach to tackling improvement efforts.

- User-centred design

User-centred design is concerned with designing the 'experience' of care rather than the addressing the 'systems' of care (Robert, 2013). It relies on face-to-face collaboration between the provider and user. However, analysis Chapter 5 highlighted the known challenges involved bringing staff and patients together (Martin & Finn, 2011). What the findings contribute to our understanding about EBCD however, lie in the potential risks of the approach not working as theorised. The purpose of the joint co-design event is to allow patients and staff to share their experiences and identify service priorities together. However, the behaviour and actions exhibited by some staff appeared to have a deleterious effect on the relationships

and the level of empathy towards staff from the designers and patients taking part. This experience could potentially cast staff as uncaring and indifferent in the way care is delivered. It is also suggested that it is very difficult to maintain the concept of co-design if staff are unable to physically meet face-to-face with patients. It appears that the findings also suggest the use of designers within the EBCD enhance the process by spanning boundaries between staff and patients to reduce an imbalance of power. The 'designerly' approach also brings many tools and techniques to facilitate the process which are in fact embedded within professional philosophy of the design sciences. Using this expert skill and knowledge may help to bring about meaningful change at a local level.

- Learning theory

Within EBCD it is intended that the process enables staff to 'pause, reflect and gather information' in order to produce new insights into experiences of care. Bate and Robert (2007a) suggest that to improve the patient experience of healthcare staff need an environment to practice different ways of thinking, feeling, doing and relating. What was evident throughout the accounts of the participants in analysis Chapters 5 and 6 (and the contextual information from the EBCD project) was the importance of time to implement EBCD as intended. There was a rare moment for staff, who were able to reflect back at the opportunity of having been given dedicated time and space to become involved, but this was short lived. It is evident that without the time to be able to reflect on feedback it is impossible for staff to address aspects of the patient experience that require improvement using EBCD.

- A narrative-based approach to change

Story sharing is a cornerstone of the EBCD process. The trigger film is perceived as a catalyst for improvement efforts (Bate and Robert, 2007a). However, the intended effects were not uniformly experienced by all. A key issue was the negative effect of staff reactions during the joint co-design event upon patients and designers. The films captured such emotive accounts which had been edited by the designers, that the personal investment may have not been so keenly felt by staff. The challenge to establish and maintain an empathetic viewpoint did not appear to have been supported with the use of the trigger film. This may have been owing to a more sceptical impression of QI work by staff with disappointing experiences in the past, where changes were not recognised as important

by senior managers and any improvements made were not sustained. The most successful group in terms of project outputs consisted of the designers and patients. It is recognised that neither group had time pressures and could plan working sessions. It is with caution that these findings are discussed as the limitations of the study made it difficult to explore fully the experience of staff taking part (See Section 5.10).

There was little within the EBCD process that appeared to be redundant, however, the importance of face-to-face interactions to build a collaborative multi-disciplinary partnership with patients was seen to be an essential feature of the EBCD process.

The following features appeared to be important when trying to bring about change using the EBCD process:

- ‘Designerly’ principles – Using the skills, knowledge and tools of the design sciences and being led by a designer for optimal effect
- Face-to-face interactions
- Triangulating data from multiple stakeholder perspectives
- Recognising the therapeutic benefit of EBCD
- Empowering the patient: formal recognition of a legitimate role

In an attempt to summarise existing evidence for EBCD and the key finding from this thesis are presented in Figure 7.1.

This thesis reflects a more circumspect evaluation of the effectiveness of the approach, compared to previous evaluation findings within the systematic review in Chapter 2 and the survey by Donetto and colleagues (2014). EBCD is a novel approach to improve the experience of care by patients and staff. However, within the specific setting of this EBCD project, the viability of the specific approach was compromised. This was owing to the lack of resources that were required to implement the approach as intended, with staff unable to dedicate the time to fully engage and take ownership, despite the initial interest and support from the organisation. The implications for practice in the future are therefore, presented in the next section, and followed by future research directions.

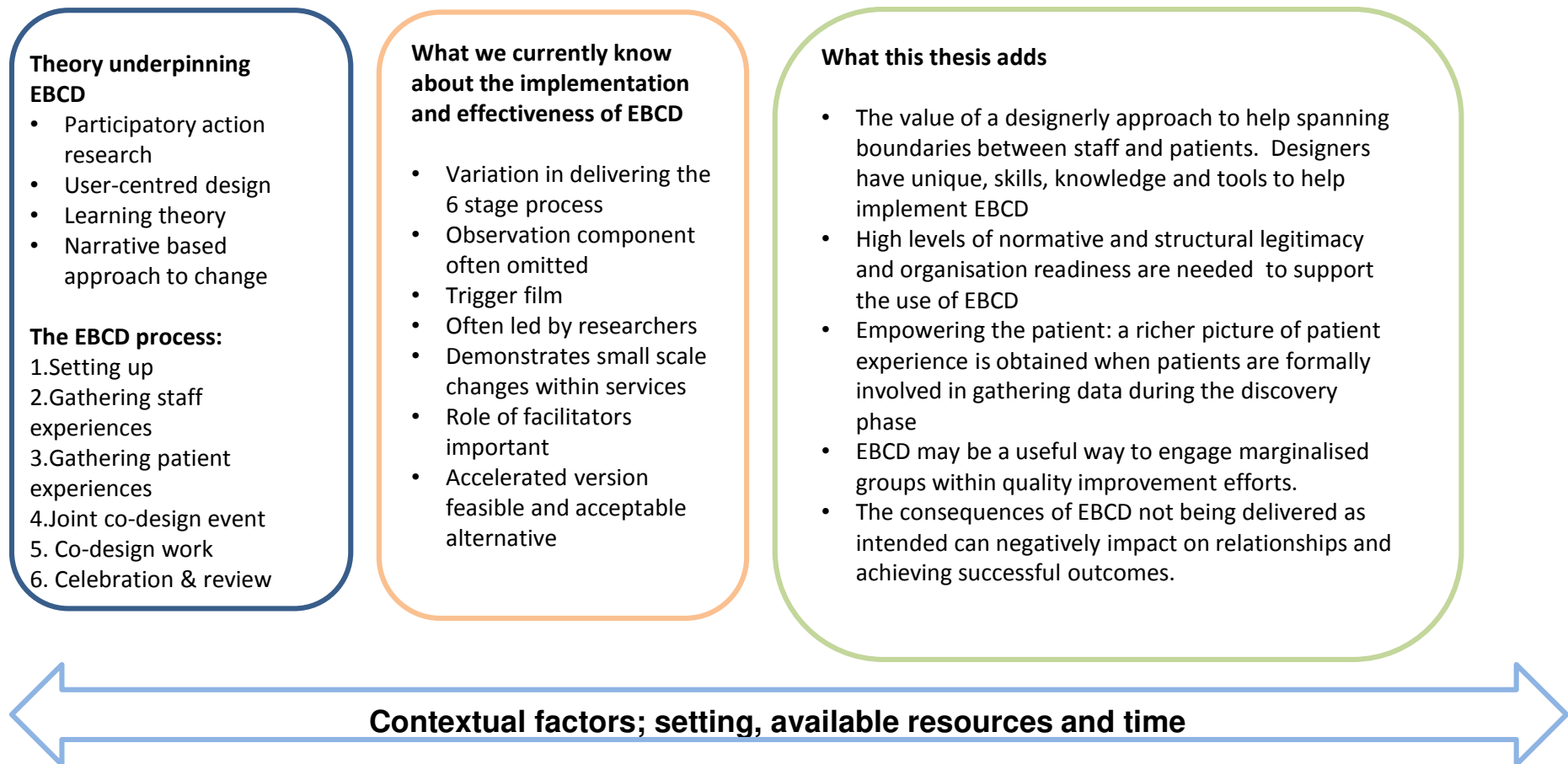


Figure 7.1 Thesis findings: contribution to the theory and practice of EBCD

7.5 Quality Assessment of IPA studies within the thesis

The quality of all three IPA studies was assessed using the guidelines proposed by Smith (2011) (See Section 3.5). Each point has been discussed and presented in Table 7.1.

Table 7.1 Assessment of the quality of IPA studies within the thesis

Features of a good IPA study	Evidence
The paper should have a clear focus	All three research questions had a clear focus and addressed specific issues that been informed from extant literature and related EBCD theory.
Have strong data	Extracts used within the results have attempted to provide strong data to support interpretative claims.
The paper should be rigorous	The three studies have attempted to be a rigorous as possible, having used multiple data sources, worked with supervisors to during the development of the analysis, and drawn upon the expertise of experienced qualitative researchers (AM and LS). Constant reflection during the entire process has helped to provide a researcher's narrative with relevant extracts included in this thesis.
Sufficient space given to the elaboration of each theme	Space was given to explore themes, but it is also acknowledged the studies have been written up for the purposes of a thesis and thus, have had the luxury of reporting in full and complete fashion.
The analysis should be interpretative not just descriptive	The use of themes and meta-themes attempted to capture the conceptual essence of the themes and sub themes. The analysis has attempted to lift the description into a more interpretative world, using language to help identify conceptual meanings.
The analysis should be pointing to both convergence and divergence	There is evidence throughout the studies where convergent and divergent accounts were highlighted.
The paper needs to be carefully written	The studies were reviewed by my supervision team helping to improve and refine the final write up of the empirical studies. This was a time-consuming and highly iterative process, which as a novice IPA researcher, was very demanding and required a lot of time thinking and reflecting during the analytical and writing up process.

Reflexivity point:**Final reflections of IPA as methodology : ‘the deep bowl of spaghetti’**

IPA is a qualitative approach that has grown in its popularity and widely applied beyond the original home of health psychology. For the purposes of this thesis the approach has been adapted to answer questions about people’s experiences of a QI initiative using EBCD. Reflecting on the challenges of conducting this research, the sub title above is borrowed from a discussion paper by Wagstaff et al. (2014) in which one IPA researcher’s experience resonated when they described the process of identifying main themes felt they were drowning ‘*in a deep bowl of spaghetti*’ (Nolan, 2011). Owing to the numbers of participants it was difficult at time to keep an idiographic focus, with the fear that when moving away from the individual to the group and then to think about the effects of temporality, that something may get lost. This was an iterative process with writing becoming an important part of the process of analysis.

Using IPA as a methodology for evaluating QI effort has its merits. It has allowed a detail examination of experiences to explore in depth the lived experience. Taking a more descriptive approach may have uncovered more nuanced aspects from individuals’ accounts but it is time consuming and requires a certain level of skill and competence.

7.6 Recommendations for practice

The following recommendations are suggested for the implementation and evaluation of future EBCD projects:

- Consider the involvement of designers in the process.
- To make explicit the type of tools and techniques used in the process with regard to explaining how they help build relationships across stakeholder groups and address issues of professional hierarchy.
- Designers to share tools and techniques with healthcare professionals so that these become embedded within the EBCD process and facilitate the sustainability and spread of the approach.

- To have a strong sense of organisational readiness – this requires support from senior managers during the co-discovery, co-design, and implementation of changes to the service.
- To legitimise and the value the outsider perspective – this means that service users/patients are empowered to actively contribute to the process.
- To support staff by providing dedicated time and space to be able to carry out co-design.
- To disseminate findings from local EBCD projects more widely and improve the reporting of QI efforts. This requires publishing work within peer reviewed journals.
- To evaluate EBCD projects in order to distinguish between the effects of context, methods and outcomes.

7.7 Recommendations for further research

The following recommendations are suggested in terms of future directions for research:

- How can patients be involved with implementing changes to the service?
- What methods could be used to ensure the focus of change remains on improving patient experience rather than the process of care?
- What would be impact of staff creating a trigger film for patients about their experiences? Would this help to engage staff further with the process?
- How can we harness the principles of a 'designerly' approach to EBCD in order for staff to feel equipped with the right tools and techniques to implement the process for maximum benefit?

Reflexivity point: patient experience and EBCD at the end of the thesis

At the start of this thesis I provided my personal perspective about the importance of patient experience as a dimension of high quality healthcare and the belief that EBCD could be a novel approach to enhancing care.

Reflecting upon my research findings and extant literature I believe that EBCD is founded upon sound principles and theories but in order to ensure that EBCD is successfully implemented it requires careful and skilful facilitation, dedicated time and a commitment by all taking part. The focus of care delivery should be patient-centred. This means that healthcare professionals have to think and act differently to improve the experience of care *and* allow patients, carers and families into the world of quality improvement to ensure meaningful changes happen and potentially benefit staff and patients.

My views have changed in terms of the potential fragility of relationships between patients and staff with the impact of negative interactions being harmful to both individuals and jeopardizing the whole project. The importance of organisational culture appears to be increasingly relevant to support 'bottom up' quality improvement efforts.

The value of including patients during the discovery phase may also be of real benefit. It is difficult to at times reflect on what that is *doe* rather work that is imagined. The idea of co-discovery thus may be a further refinement of the EBCD approach in the future, with patients participating actively at the earlier stages to identify key issues. The PPI movement within research and improvement continues to grow with the introduction of new national standards for public involvement (NIHR, 2018). This includes, working together, being inclusive, support and learning and capturing and learning from the difference PPI makes to research ad QI efforts.

7.8 General limitations of studies within the thesis

Using IPA as a methodology to examine of how people make sense of life experiences it is suggested claims at a broader population level can be made through the notion of theoretical generalisability. This allows the reader to assess the analysis in relation to existing literature and evidence, as well as, their own professional and/or personal experiences, which, in turn, enables a wider generalisation to their patient populations (Smith et al, 2009). In addition, it is argued that generalisations from qualitative research can be made through 'theoretical inference' by exploring deviant or divergent cases in order to refute theories (Silverman, 2011).

7.9 Concluding remarks

EBCD as an approach to improve the patient experience undoubtedly has its merits: it is a highly theoretical approach which is envisaged in practical terms as a six stage cyclical process. However, it requires certain resources and a supportive environment to ensure it can be applied as intended. Time is a key issue. Without being able to engage in face-to-face meetings staff are unable to develop the relationships and the empathy associated with the success of the approach and to become reflective practitioners. Patients need to feel empowered in the process which means addressing issues associated with professional hierarchy. Taking a '*designerly*' approach for novice users of EBCD may be seen as a key mechanism to ensure that meaningful changes happen. Support from the organisation is invaluable when thinking about implementing changes. The risks of EBCD not being delivered as intended may have negative consequences when thinking about fostering new relationships and creating a way of collaborative working with patients. Therefore, careful and thoughtful facilitation is required to ensure stakeholders understand what is needed to ensure successful partnership working to improve the experience of care.

Finally, EBCD possibly heralds a better and more creative way of improving the patient experience and in turn improving the overall quality of care. It addresses the wider movement of increasing participation and involvement of patients, carers and the public within health service improvement and research efforts. It has been a worthy endeavour to have been part of a real life EBCD project in the scientific pursuit of improving the quality of care.

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List of abbreviations

AEBCD	Accelerated Experience Based Co-Design
CCU	Coronary Care Unit
CDSR	Cochrane Database for Systematic Reviews
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
CLBP	Chronic Low Back Pain
CNS	Clinical Nurse Specialist
CQC	Care Quality Commission
CRD	Centre for Reviews and Dissemination
DARE	Database of Abstracts for Reviews of Effect
EBCD	Experience Based Co-Design
EBD	Experience Based Design
EBM	Experience Based Medicine
ED	Emergency Department
FFT	The Friends and Family Test
FoNS	Foundation of Nursing Studies
GP	General Practitioner
IOM	Institute of Medicine
IPA	Interpretative Phenomenological Analysis
LQR	Longitudinal Qualitative Research
MRC	Medical Research Council
NHS	National Health Service
NIHR	National Institute for Health Research
NL	Normative Legitimacy
PDSA	Plan Do Study Act
PE	Psychological Empowerment
PPI	Patient and Public Involvement

QATSDD	Quality Assessment Tool for Studies with Diverse Designs
QI	Quality Improvement
OR	Organisational Readiness
RCT	Randomised Controlled Trials
SL	Structural Legitimacy
TIDierR	Template for Intervention Description and Replication
PFRF	The Patient Feedback Response Framework
RN	Registered Nurse
TPS	Toyota Production System
TQM	Total Quality Management
UK	United Kingdom
US	United States of America

Appendices

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Appendix 1: A systematic review of literature to assess the use of evidence-based co-design as a quality improvement approach within healthcare: a protocol

Introduction

High quality healthcare encompasses patient safety, clinical effectiveness and the patient experience. Improving these measures of quality are a fundamental requisite for healthcare organisations, in light of the acknowledgement of current socioeconomic climate, the scale and cost of medical errors and public investigations into poor patient experience (Department of Health 2013a; Department of Health 2013b; Kohn et al, 2000). Patient safety has made significant steps forward with measuring and monitoring care. However, the best method to capture, understand and measure patient experience in a meaningful way continues to be debated (Locock et al, 2013). Improving experiences of healthcare require rich data from qualitative enquiry which purely objective measures miss (Roberts, 2013).

Experience-based co-design is a theoretically informed quality improvement approach, developed by and for the National Health Service (NHS) (Bate and Robert, 2007). It was piloted in 2005-6 within the NHS in England and to date it is estimated that there are over 60 projects that have implemented EBCD across six countries (Donetto et al 2014). However, empirical evidence surrounding quality improvement methodology is scant. Therefore, the purpose of this systematic review is to synthesise existing empirical evidence surrounding the use of experience-based co-design (EBCD) within the healthcare setting. This will contribute to the growing knowledge base of improvement science with required empirical evidence to support EBCD as a reliable and valid method of quality improvement (The Health Foundation, 2013).

1.0 Background

Systematic reviews are undertaken for numerous reasons e.g. in response to commissioned calls for review of evidence or led by investigators without formal funding to answer clinical questions (Centre for Research and Dissemination (CRD), 2009). The aim of a systematic review is to answer a research question by identifying all available empirical evidence using pre-specified eligibility criteria. The selected studies are assessed for validity, the findings synthesised and presented methodically (Green et al, 2011; CRD, 2009). What sets systematic reviews apart from other types of review e.g. scoping reviews are the methods used to reduce the effects of bias and therefore, provides reliable results from which the reader can draw conclusions. (Green et al, 2011). Systematic reviews are also an important step to help inform new primary research, as they may identify knowledge gaps and prevent the duplication of work. This prevents conducting unnecessary research which has cost and ethical implications for the researcher and participant (CRD, 2009; Dixon-Woods, 2001).

2.1 Quality improvement

Quality within healthcare is a multidimensional concept which considers patient safety, person centred care, timely delivery, equity, efficiency and effectiveness (Health Foundation, 2013). Quality improvement seeks to enhance these dimensions. There is no single definition of 'quality improvement' within QI literature but, a central tenet is a consistent and systematic approach to improve quality using specific QI tools. One definition offered describes quality improvement as: 'better patient experience and outcomes achieved through changing provider behaviour and organisation through using a systematic change method and strategies.' (Øvretveit, 2009: p8).

The underlying principles of quality improvement are about understanding and improving the reliability of the process while addressing demand, capacity and flow. This requires engaging and involving staff and patients throughout the process (Health Foundation, 2013). The need to improve the quality of healthcare is a challenge faced by most organisations worldwide. The publication of 'To Err is Human: Building a Safer Health System' and 'An organisation with a memory' highlighted the alarming number of avoidable patients deaths attributed to medical errors within the United states and England. Both reports provided recommendations how to improve safety and set the path for organisational change which continues to influence policy and practice (Kohn et al, 2000; Department of Health, 2000).

Healthcare reforms in England have addressed improving the quality and safety of healthcare over the last 15 years, with a firm re-emphasis of placing the patient at the heart of the NHS i.e. Lord Darzi's review with the introduction of indicators e.g. mortality rates, complication rates for patients, a register of reportable 'never events' and financial incentives for hospital Trusts (Department for Health, 2008).

The need to improve the quality, effectiveness and efficiency of healthcare is also driven by the pressure of an ageing population, medical advances and the current socioeconomic climate to ensure the NHS can meet the demands of healthcare with finite resources (Department for Health, 2010). In addition, more recent national policies have been influenced by investigations into the catastrophic failures of healthcare within NHS England with the legacy of the Francis report requiring the government to address the systematic organisational failures of the NHS (Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013; Department of Health 2013b). Within NHS England, high quality health care is now measured in terms of patient safety, clinical effectiveness and patient experience and enshrined within the Health and Social Care Act 2012 (Vincent, 2013; Department for Health, 2012). Quality improvement methodology within healthcare has been largely informed by approaches from industry i.e. The LEAN approach. In April 2013, NHS Improving Quality (NHS IQ) was launched as a vehicle to drive improvement across the NHS England, which has aligned improvement programmes to meet the five domains of The NHS Outcome Framework (Department for Health, 2013). The NHS change model is currently being rolled across the NHS and comprises of eight

components, one of which underpins the model: improvement methodologies e.g. Total Quality Management (TQM) and Plan-Do-Study-Act (PDSA) cycles. However, literature suggests that many QI tools and techniques used within the clinical setting are based on little proof and are poorly reported and evaluated (Taylor et al, 2013; The Health Foundation, 2013). The growing discipline of improvement science aims to bridge this gap by scientifically expanding the knowledge around improvement methodologies (The Health Foundation, 2011).

While there has been significant work to create and test methods to measure, monitor and improve patient safety and clinical effectiveness, some argue that the tools to understand and measure patient 'experiences' of care have been far slower in development (Robert and Cornell, 2011). Recent evidence suggests that patient experience is consistently and positively associated with patient safety and clinical effectiveness across a wide range of disease areas, study designs, settings, population groups and self-rated/objectively measured health outcomes (Doyle et al, 2013). However, the debate continues in regard how best to capture, measure and improve the patient experience (Locock et al, 2013).

2.2 Improving the patient experience

Understanding and measuring patient experience has become increasingly more important to healthcare organisations to improve the quality of care (Locock et al, 2013). From the early 1990's methods to capture patient experience have been led by the Picker framework and have involved large scale surveys (Roberts, 2013). Currently, the main indicator within the NHS Outcome Framework to measure patients experience of care is the 'Friends and Family' test which mainly provides a quantitative measure. However, the appropriateness and meaningfulness of this measure has come under criticism, especially for particular disease specific populations (Appleby, 2013). There is also evidence that suggests that patient data gathered at a national level does not drive change or address service improvement needs as they are not recognised at a local level and information is not captured frequently enough (Robert and Cornwell, 2011). It is argued that improving experiences of healthcare require both quantitative and qualitative inquiry to measure experience; objective data to measure the impact and success of QI approaches and qualitative data to gather data rich contextual information at a local level (Roberts, 2013). However, one quality improvement tool has taken a fresh approach to improving the 'experience' of care: experience-based co-design.

2.3 Experienced-based co-design

Experience-based co-design (EBCD) is a theoretically informed quality improvement approach that was developed and tested within the English NHS and for the NHS. EBCD aims to systematically and scientifically 'capture, understand, and improve patient's experiences' where the patient is not seen as a passive recipient but integral to the process, a shared partnership (Robert, 2013; p138).

This approach uses patient narratives, via the medium of film, to engage health care professionals and patients to co-design improvements surrounding the 'experience' of care (Bate and Robert, 2007). This is a cyclical approach, as the process is rooted within participation action research (PAR), which takes the improvement team through various stages.

First piloted in head and neck cancer service, EBCD has been used worldwide across different healthcare settings and patient groups (Donetto et al, 2014). A survey conducted by the National Nursing Research Unit, King's College London, between Spring/Summer 2013, to map the current use of EBCD and establishing further directions, identified 59 projects that had been implemented over 6 countries with an additional 27 projects at the planning stage (Donetto et al, 2014). However, the limitations of the survey suggest that projects may have been omitted in the results owing to the methods of disseminating the survey (Donetto, 2014).

2.4 Rationale for the systematic review

Despite the recent survey mapping the use of EBCD in healthcare by Donetto and colleagues (2014) the methodology that underpins a survey fundamentally differs from a systematic review, as the later adopts a rigorous and scientific methodology to capture all available empirical evidence and reduce possible effects of bias (Green et al, 2011).

After an initial search of the Cochrane Database for Systematic reviews, the Database of Abstracts for Reviews of Effect (DARE) database and personal communication with the co-developer of the approach (Glenn Robert) no existing reviews were identified on the use of EBCD as a quality improvement approach in healthcare.

Therefore, as EBCD appears to be increasingly adopted by healthcare organisations worldwide, a systematic review to appraise the 'empirical' evidence base would be appropriate. This will add to the existing evidence for EBCD which was identified as a future direction in the survey by Donetto and colleagues (Donetto et al, 2014).

This review will also add to the empirical evidence base for quality improvement approaches and contribute to the wider discipline of improvement science. This review will also inform any further areas for research and support the development of my PhD project.

2.5 Aims and objectives

This systematic review aims to identify studies that have employed experience based co design as a quality or service improvement approach within the healthcare setting. The overarching research question for this review is:

'How has experienced-based co-design been used as a quality improvement approach within the healthcare setting?'

Owing to the breadth of this research question is advisable to narrow the focus using sub-questions (EPPI-Centre, 2010). Therefore the broader research aim will be investigated by addressing the following questions:

- Which health care settings and/or disease specific populations has EBCD been implemented in?
- What has been the rationale for using EBCD over traditional methods of quality improvement tools and techniques?
- How has the EBCD approach been implemented? i.e. have all six stages been adhered to?
- What are the results of EBCD project? E.g. improving patient satisfaction, improving staff well being
- How has the study been reported?
- How has the impact of EBCD been reported? E.g. length of hospital stay, medication errors.
- How has cost effectiveness been measured and reported?

3.0 Methods

The development of the protocol for this systematic review has been informed by The Cochrane Handbook for Systematic Reviews of Interventions, the Centre for Reviews and Dissemination (CRD) guidance for undertaking reviews in health care and UK Evidence for Policy and Practice Information and Coordinating Centre (EPPI-Centre) (Green et al, 2011; CRD, 2009; EPPI –Centre, 2010).

An advisory group has helped with methodological issues while developing the protocol and while conducting the review. Second reviewers are experienced Research Fellows from the Institute of Psychological Sciences at the University of Leeds and from the Yorkshire Quality and Safety Research (YQSR) team at the Bradford Institute for Health Research, England.

The reporting of this review will be guided by the Preferred Reporting Items for Systematic reviews and Meta Analyses (PRISMA) statement to ensure transparent and complete reporting of this systematic review (Moher et al, 2009).

For the purposes of this systematic review the term 'study' will be used to refer to studies or projects or initiatives that have published empirical evidence surrounding EBCD as a quality improvement approach. This is owing to the fact that EBCD was developed as a service and quality improvement approach for healthcare and therefore, may not be reported as a research study.

3.1 Study selection criteria

Inclusion criteria

- Any study that has used experienced-based co-design (EBCD) or accelerated experienced-based co-design (AEBCD) or experience-based design (EBD) as a quality or service improvement method.

EBCD has evolved since 2005, with the name changing from EBD to EBCD. There have also been recent developments with the development and testing of an accelerated version (accelerated experience based co-design, AEBCD) (Donetto et al,

2013). Therefore, all three terms have been included within the study inclusion criteria in order to capture all relevant studies.

- Any study design i.e. prospective Randomised Controlled Trials (RCTs), qualitative, quantitative or mixed design methodology. Where only abstracts are available, if sufficient information is provided with regard to methods, participants, intervention, primary and/or secondary outcome measures and results, these studies will be eligible for inclusion. Protocols for current studies will also be eligible for inclusion. A wide inclusion criterion for study design will ensure all eligible studies will be included in the review.
- Any study that has been published in a peer reviewed journal. Studies that have been peer reviewed have undergone a rigorous process before publication to detect issues such as; errors, fraud and to ensure clear reporting (Smith, 2006).
- Any study in any health care setting i.e. either primary, secondary or community health care setting. The rationale for looking at a range of health care settings, from the hospital environment to the community is to capture any service improvement project or intervention that may bridge care settings, as care pathways for acute admissions or long term conditions should consider the movement between hospital, home or community setting (Shepperd et al, 2013).
- Any type of disease specific population, any types of participants i.e. adults, children and health care professionals. A wide inclusion criterion for types of participants will ensure all eligible studies will be included in the review.
- Any study published from 2005. EBCD was developed from 2005 therefore, there will be no identifiable studies before this period within healthcare.

Exclusion Criteria

- Studies/projects that did not use experienced-based co-design, experience based design or accelerated experience-based co-design as a service or quality improvement approach.
- Studies not in English language.
- Studies that are not a review or do not report empirical data.

3.2 Search Methods

EBCD was developed in 2005 and therefore, there will be no pre-existing studies using this approach before this date. Therefore, for the purposes of this review the following electronic databases will be searched from 2005 to 2014 in terms of date of entry of records to databases:

- Web of Science
- Ovid MEDLINE(R) - In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present
- Ovid EMBASE
- Ovid PsychINFO
- Ovid CINAHL

- The Cochrane Central Register of Controlled Trials

Search terms

A review question can be framed by looking at the population, intervention, comparators, outcomes and study design (PICOS) which helps to determine relevant search terms (CRD, 2009). For the purpose of this systematic review the population and intervention i.e. EBCD were used to develop the search strings to identify relevant studies owing to the research question, which is not comparing other QI approaches and the broad study design inclusion criteria (See Appendix I). A combination of keywords and MeSH terms were used to identify all available evidence.

For the purpose of this systematic review 'grey literature' has been defined as literature that has not been formally published e.g. in books or journals (CDR, 2009). Therefore, owing to inclusion criteria i.e. only peer reviewed articles to be considered, additional literature identified through a pre-specified grey literature search strategy will not be required. To identify any further studies eligible for inclusion healthcare experts on experience-based co-design will be contacted for bibliographies and/or reference lists. The final list of full text studies that are considered eligible to be included in the systematic review will also be reviewed by the expert to check for any omissions of known studies. Scanning reference lists of eligible studies references will be conducted to identify any further studies eligible for inclusion. Reference management software Endnote v6 will be used in order to collate and manage the results, which will also allow the removal of duplicate studies before screening full text studies

3.3 Data collection and analysis

Selection process : First stage

The main reviewer (LT) will search the pre-specified databases to identify relevant citations with title and abstract will be assessed for relevance against the pre-specified inclusion and exclusion criteria. If the article does not meet the inclusion criteria it will be rejected but if it is unclear the article will be included for further assessment from full papers. It is considered to be best practice to over include at this stage of selection to avoid missing relevant studies (CRD, 2009).

In order to add rigour to the selection process, second reviewers will screen 100% of studies identified from the database search to check for agreement. Any differences will be discussed in order to reach a consensus and any discussion will be documented to provide a transparent audit of decisions reached.

Second stage

Studies that appear to meet the inclusion criteria will have full papers retrieved for a detailed assessment against the inclusion criteria by the main reviewer (LT). Decisions whether to exclude studies at this stage will be documented with explicit justifications. Second reviewers will also screen 100% of these studies to check for agreement. Any differences will be discussed in order to reach a consensus and any discussion will be documented to provide a transparent audit of decisions reached. If full text version of the

studies are not available and if there is sufficient information contained within the abstract, studies will be eligible for inclusion.

Data extraction

Data will be extracted using a data extraction sheet. The main reviewer (LT) will extract data from all included studies and the second reviewer will check for accuracy from a proportion of included studies. Any disagreements will be addressed via discussion between the two reviewers to reach a consensus of opinion and documented as needed. If there are missing data required to complete the data extraction an attempt will be made to contact authors for more information.

3.4 Methodological quality

Owing the broad study inclusion criteria it is anticipated that will be diverse types and levels of papers and publications. Therefore, to assess the quality papers the Quality Assessment Tool (QATSDD) will be applied to included papers (Sirriyeh et al, 2011). This tool was developed to address the issues surrounding different levels and types of evidence that may be included within a systematic review in healthcare. This tool was developed in response to recognised difficulties and methodological and epistemologically that mixed-methods review can present. It has been shown to have good reliability and validity and a pragmatic approach to providing a robust, transparent and standardized method for assessment of quality across different research methodologies (Sirriyeh et al, 2011).

3.5 Data Synthesis

Owing to the research aim and objectives and wide eligibility of studies to be included in this review a meta-analysis will be inappropriate to synthesise the findings. The UK Evidence for Policy and Practice Information and Coordinating Centre EPPI-centre suggests an empirical narrative synthesis as an appropriate method. Therefore, data synthesis will be informed by the 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews' by Popay et al (2006) having gained necessary permission.

3.6 Dissemination

The results of the systematic review will be shared locally with health care professionals and fellow students and researchers at the University of Leeds and Bradford Institute for health research, through mechanisms such as post-graduate conferences and show case events. Results will also be shared with the wider research community and the co-developer and their colleagues of EBCD. Social media will use such as the LinkedIn EBCD group to share findings. This review will also be considered for publishing in relevant health journals.

Appendix 2 Search strategy Ovid Medline

The following search string was used to retrieve studies from Ovid Medline with a similar

approach to other databases:

Database(s): Ovid MEDLINE(R) 1996 to May Week 2 2014

Search Strategy:

1 patient*.mp.

2 inpatient*.mp.

3 outpatient*.mp.

4 in-patient*.mp.

5 out-patient*

6 (Accident and Emergency patient*).mp.

7 (((accident and emergency) or A&E) adj3 patient*).mp.

8 hospital inpatient*.mp.

9 (hospital adj3 patient*).mp.

10 hospital outpatient*.mp.

11 (hospital adj3 outpatient).mp.

12 exp Patients

13 exp Inpatients

14 exp Outpatients

15 (patient* adj3 community).mp.

16 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15

17 adult*.mp.

18 (child\$ or kid\$ or toddler\$ or bab\$ or school age or schoolage or school-age or pre\$school\$ or schoolchild\$).mp.

19 (young adult or adolescen*).mp.

20 p?ediatric\$.mp.

21 exp Transition to Adult Care/ or exp Adult Children/ or exp Adult/ or exp Young Adult/

22 exp Child, Preschool/ or exp Pediatrics/ or exp Child/ or exp Infant/ or exp Adolescent/

23 17 or 18 or 19 or 20 or 21 or 22

24 16 and 23

25 16 or 23

26 experience-based co-design.mp.

27 EBCD.mp.

28 experience based design.mp.

29 EBD.mp.

30 accelerated experience based co design.mp.

31 AEBCD.mp.

32 26 or 27 or 28 or 29 or 30 or 31

33 (2005* or 2006* or 2007* or 2008* or 2009* or 2010* or 2011* or 2012* or 2013* or 2014*).ed.

34 25 and 32

35 33 and 34

Appendix 3 Guidelines - recording observations in the clinical area

Patients as partners in co-design: Improving the experience of discharge care within the cardiology service

Experience based co-design - Observation Guidelines

Introduction

The cardiology service at Bradford Teaching Hospitals NHS Foundation Trust has identified discharge care as an area that requires improvement. This has been informed in part by the ward's own patient satisfaction survey findings and experiences from staff within the service.

This service improvement project is using experience based co –design (EBCD) in order to address staff and patients concerns and re-design the experience of discharge care together. As part of the 'discovery' phase observations are conducted in the clinical area (see Diagram 1).

The role of observation within the experience based co-design process is to provide 'valuable' insights into the day to day running of the service. Observation work helps to provide an understanding what the patient and staff perspectives might be. Observation is considered an important way to build trust with the ward team to show commitment and interest in the service.

The purpose of this guideline is to set out the procedure for the observation stage of the EBCD project. This is a service improvement project and therefore does not traditionally require formal ethical approval. However, ethical, patient safety and the Trust's governance policies have been addressed for observers, staff and patients within the procedural guidelines below.

Observation – Set up

Observers will have met Bradford Teaching Hospitals NHS Foundation Trust's governance requirements in order to safely conduct observations as part of the service improvement project with the cardiology service.

Observers will have been briefed on the observation guidelines and have the opportunity to discuss any issues identified that may occur while conducting observations.

Observations sessions will be arranged with the nurse in charge on Ward 22 prior to being conducted.

Ward staff on the day of observations will be informed and verbal consent gained to observation work being conducted. Written information will be displayed on the ward for staff.

Written patient information will be displayed on the ward and provided on the day of observation. For patients that do not speak or read English, efforts will be made to verbally explain the nature of observation work being conducted on the day, by using staff resources and via family and friends with the patients.

Conducting Observations

The project facilitator will accompany all observers to and from the clinical area for observation sessions.

Identification badges will be displayed by observers while in the clinical/ward area. Observers will use the antiseptic hand wash on entrance and exit to the clinical/ward area.

Observers will be introduced to ward staff by the project facilitator to ensure staff are aware who the observers are and why they are there.

The project facilitator will ensure that observers have the materials required to conduct observations and deal with practical issues as they arise, in order to minimise burden on ward staff.

Observations will be conducted between 30-60 minutes periods. If the observers witness a patient 'safety concern', this will be reported to the project facilitator and the nurse in charge at the time or on the day of observation. A 'safety concern' for the purpose of the EBCD project is defined as 'anything that has either caused actual harm or potentially may lead to harm for a patient or the participant e.g. witnessing a patient fall.'

Observers will respect the privacy and dignity of patients. If patients do not wish to be observed they will have the opportunity to let the nursing staff aware, who can inform the observation team and facilitator. Prior to observation the nurse in charge will be asked if there are any patients or areas that are not appropriate to observe e.g. adhering to any infection control procedures in place.

If, at any time, the observation causes difficulties for a patient or staff member, the observer will withdraw.

Observers will not interact or talk to ward staff while observing to prevent any unintended distractions. Observers may introduce themselves to patient to explain why they are there and the purpose of the observations work for the service improvement project.

There will be a de-brief session at the end of observation in a confidential area away from the ward. This meeting will be audio-recorded with the permission of the observers, in order to discuss and record their findings. This discussion may be transcribed and anonymised.

At the end of the observation period the nurse in charge will be informed and thanked for participation. Any issues that arise from conducting the observations from the observers, ward staff or patients will be dealt with by the project facilitator (Liz Tomlin).

After Observation

The project facilitator will collate the observation data and analyse the data for key themes.

Observers will meet after observations to review findings. The key points and best method to feedback to staff will be discussed and implemented with the core project team.

Appendix 4 Observation Proforma

Service Improvement Project
Patients as partners in co-design: Improving the experience
of discharge within the cardiology service

Observations Record

1 Complete the following information to record the specifics of the observation session.

Date of Observation	Area observed	Time started	Time stopped	Observer (Initials)

2 Use the table below to record your observations.

Try to imagine you are a patient, or are seeing the service through fresh eyes as a visitor to that area.

This stage involves noting 'what you see' and 'thinking about how you respond to it' by focusing on anything that seems impressive, unusual, surprising, confusing or worrying.

For example, in one clinic, observers noted that patients who arrived early in the morning had to sit in the dark until the receptionists arrived and turned the lights on. Patients will often not mention this sort of detail, even though it may have a major effect on their experience of care.'

(Taken from - EBCD toolkit <http://www.kingsfund.org.uk/projects/ebcd/carrying-out-observations>)

This will involve observing the 'processes' of care being delivered e.g. a patient being given medication and relational aspects e.g. interactions between staff and patients.

Type of activity observed	What I saw / heard...	What I thought ...

Appendix 5 Example of IPA analysis Key for coding: Yellow = descriptive, Green = linguistic, Pink = conceptual

personal experiences	24	support the project	Reason for taking part – direct experience of the ward with family members – direct relevance and meaning to take part- personal motivation	
	25	I: so you had a vested interest		
	26			
	27	P: yes	'Support' the project	
	28	I: because family had been through . . .	Reflecting on previous experiences on the ward as a close relative/carer. Emotive and traumatic experiences remembered	
Emotive and traumatic associations	29	P: yes, my mother had er, heart problems, and	The phrase 'an operation went wrong' – a perception that care did not go as they expected. The use of word 'many' and 'brought back a lot of memories' indicating lots of emotive/sad/traumatic experiences –emphasising intimate knowledge of the ward	Comment [p2]: This previous experience on the ward – sense of fear, was apparent throughout the interview and her perception of patients anxieties.
	30	problems where an operation went wrong um, they ruptured a vein when they were doing the angio plasma, or whatever it is, and many family		
sense of loss	31	members who have passed away in that ward as well	'– recall of emotions 'scary' 'it was difficult' '...very little support'	
	32			
	33	I: so you said that might have been difficult for you	Challenge of the activity in a setting that conjures negative feelings. What does it mean to be involved in this type of activity (observation) for the improvement project for the participant? How does prior experience affect the observation task? The physicality of being there? The task is a very subjective exercise? ?Negative associations on multiple occasions. Making a difference – motivational factors was strong despite conflict, Does taking part help to make sense of previous experiences? If the experiences had all been 'positive' would they have the same motivation to take part?(motivational factor outweighed conflict)	
	34			
self determination/ motivation (the 'hook')	35	P: it was, it was difficult . . .		
desire to improve experience for others	36	I: on the ward		
	37	P: . . . it brought back a lot of memories er, but er, um, what kept me going was that your project title of discharge and how, how patients um, feel the discharge is, was, was quite close to me because obviously when my mother was discharged from that ward we had no idea what to do. We had very little support and it was quite scary. Mm		Comment [p20]: Do we need to acknowledge why someone has taken part if they are a patient/carer?
	38	I: okay. So perhaps tell me a little bit about what it was like then doing the observations. So when you went onto the ward for the first time, before you started the observation, did you have any kind of expectations; what you were expecting to see or . . .		
	39	P: um	Importance of taking part	
	40	I: . . . hear or feel or . . .	The phrases 'what kept me going' -implies that even though this activity was a personal challenge the thought of improving the experience for other patients was a motivational factor. Uses the words 'very little support' and 'scary' to emphasise the vulnerability and anxiety associated with her mother being discharged.	
	41	P: I have expectations but I prob . . . anxiety really for whether the staff were going to welcome	Observation activity initially was anxiety provoking. Feelings of anxiety over legitimacy	Comment [p3]: Captures the anxiety of being on the ward, with a dip board – accepted by staff and patients, opposing hostility but relieved that the ward had been prepared
The legitimate self	42			
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