East Sussex Healthcare **NHS**
NHS Trust

Patient Experience Strategy

What matters to you, matters to us...






Patient Experience Strategy

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1. Foreword

East Sussex Healthcare Trust wants to put improving patient experience at the heart of our agenda so that we can really make sure that patients get the right care. The strategy that follows sets a clear and ambitious programme that will enhance the experience of patients and service users as they receive integrated care from our services.

The strategy is built around eight commitments, all of which have been made to ensure the services we provide are of the highest standard possible. Throughout the strategy you will see that we have emphasised that patient experience is everybody's business without exception. It is the aim of East Sussex Healthcare Trust that all patients, families and carers are treated with respect, dignity, compassion, courtesy and honesty.

Our excellent staff will be the vital component in delivering this exciting and innovative strategy. To recognise this, we have a commitment to improve staff experience. Within this commitment, we will develop a staff experience strategy with the aim of improving workplace cultures and improving staff well-being within the whole organisation.

Over the coming months we will introduce new ways of measuring the way patients, families and carers feel about the services we provide. We will use this information to learn about what we can do better and develop pathways of care that are excellent from start to finish.

Charles Ellis
Non-Executive Director

The experiences of patients and their families are extremely important to staff at East Sussex Healthcare. Everything we undertake at is aimed at improving the experience our service users have of our care and services. The ‘patient or service user’ is the reason for the existence of our organisation, without them we have no purpose or value. We need to make sure that we continue to see the person in the service user.

Patients and their families hold unique vantage points as expert witnesses to care. We know that their judgements are informed as much by the care they witness others receiving as the care they receive themselves. For most, experiences of care are mixed. Few are wholly good or wholly bad. Patient stories typically describe variability in the experience of care, hour by hour, shift by shift, day by day and from department to department.

Our staff are rightly proud of the high quality of services we provide, our patients and their families frequently tell us how much they appreciate the care they received. But we also know we can always do better.

As a Board, we are committed to fulfil our responsibilities to hold our organisation to account for improving the quality and responsiveness of services, and to be able to demonstrate this accountability to our local communities. More importantly improving services for our service users and their supporters is the right thing to do and the reason most NHS staff do their job so passionately.

Alice Webster
Director of Nursing

2. Acknowledgements

We would like to thank all those who have given their time and support to the development of this strategy (appendix 1), but particularly those members of the public who attended the Patient Experience Strategy focus groups in October 2012. Without your contribution, this strategy might have looked very different. Thank you for telling us what matters to you.

> *"I found it very useful to have the opportunity to comment and be listened to. Also I consider the idea of having patients directly involved in such open discussions a welcome initiative".*
>
> (Focus Group Participant, October 2012)

3. Equality Impact Assessment statement

3.1 As part of this strategy development, an Equality Impact Assessment has been completed (appendix 6). The purpose of this assessment is to minimise and, if possible, remove any disproportionate impact on employees of the Trust and/or on the patient population served by East Sussex Healthcare NHS Trust. The assessment covers criteria on the grounds of race, gender reassignment, pregnancy and maternity, disability, age, sexual orientation and/or religion and belief.

4. Introduction

4.1 This strategy sets out the priorities with regards to Patient Experience for East Sussex Healthcare NHS Trust (ESHT) over the next 3 years and maps out how we intend to deliver this. It is implicit that whenever “patient experience” is described within this strategy, it also includes the experience of family members, significant others and carers.

4.2 This is an ambitious strategy and we do not hide from that fact, or that it will be a challenge to deliver. Such change is fundamental to the care we want to deliver, to the services that local people want and to where we want to be as an NHS Trust. Although, we hear a tremendous amount about what a good job we are doing, this is not consistent enough and there is always room for improvement and for innovation.

4.3 This strategy has been developed in collaboration with service users, the public and ESHT staff and is centred on 8 commitments. It integrates and builds on existing monitoring and patient experience activities undertaken throughout the Trust and sets out some challenges for the future.

4.4 It describes a methodology or broad based approach to provide increased assurance that every service provided by the Trust engages in regular and consistent consultation with patients and other service users including seeking out meaningful feedback, in order to enable all Trust staff to learn from and improve patient experience. This strategy is dynamic and will need to continue to evolve in line with published national / regional evidence, local patient experience and better local practice. The strategy applies to all clinical, commercial and corporate services delivered by ESHT, and to all staff delivering, directly or non-directly, those services to patients, their families and carers because *we are all* responsible for patient experience.

4.5 This document is available in alternative formats such as large print, easy to read, children’s and community languages. Please contact the Equality, Diversity and human rights Team:

equality@esht.nhs.uk
Tel: (01323) 417400 ext. 3085

5. Aims of Strategy

5.1 At East Sussex Healthcare NHS Trust (ESHT) our vision is to be the healthcare provider of *first choice* for the people of East Sussex and our mission is to continuously improve outcomes for patients.

5.2 The experiences of patients, their families and our local population are extremely important to ESHT and it is a key factor when patients choose a provider (DoH,2010d). It is part of our core business and all staff working within the Trust have a duty to ensure that all those who use our services receive an experience that meets or exceeds their physical and emotional needs and expectations. ESHT is also looking to achieve Foundation Trust (FT) status in 2014. This will require an intensive focus on demonstrating and evidencing the improvement of experiences of patients, service users and the local population.

5.3 **In order to deliver this the following aims have been set for the Patient Experience Strategy:**

- To develop a shared vision and coordinated approach to continuously moving towards better* experience for patients, service users, family, carers, the local population and ESHT staff.

- To develop and enhance the culture of placing quality improvement and innovation of patient experience at the heart of what we do and how we work.

- To set out ESHT commitments to ensure that all our patients' and service users experiences are based on what matters to them and are of a high clinical standard.

- To work with our executive sponsors to heighten the profile and value of patient and service user experience within ESHT from "ward to board", and our partners with whom we work locally and regionally.

- To influence leadership, learning and development and individual responsibility with regards to patient experience.

* We have decided to use the term 'better' rather than 'best' as the vision is for continuous improvement and innovation which suggests that the 'best practice' end point is never reached.

6. How has the Patient Experience Strategy been informed?

6.1 This strategy has been informed and shaped by many different forms of evidence (Kitson et al, 2008; Rycroft-Malone et al 2004). Consultation with service users took the form of:

- Six focus groups with purpose of shaping this strategy (appendix 3).
- Secondary use of findings from a recent engagement project with people living with Learning Disability (Chapman and Lane 2010).
- Secondary use of findings from East Sussex LINk reports (Dignity and Nutrition, 2012; and Leaving Hospital, 2011).
- Analysis of compliments, comments, concerns and complaints received to the Trust 2011-12.
- Analysis of web based feedback on patient experience in the Trust 2012 from NHS Choices and Patient Opinion.

6.2 In addition other forms of local evidence helped shape the strategy including:

- Analysis of trends in Serious Incidents and key safety Indicators (e.g. falls, pressure sores, hospital acquired infections).
- Staff responses to an ongoing Staff Engagement Initiative “ Listening In Action”
- Engagement, through critical conversations, with a range of leaders within the Trust.

6.3 In addition to the above, the strategy has been informed (and in many instances mapped against (see appendix 2)), East Sussex Healthcare NHS Trusts Strategic aims and objectives and key national policy / guidelines including amongst others:

- NHS Constitution (2012)
- NHS Operating framework 2012-2013 (DH, 2011)
- NHS Patient Experience Framework (2012)
- NICE Guidelines (CG138) 2012
- Picker Principles of Good Patient Experience (2009)
- Kings Fund Point of Care Programme (Coulter et al,2009)
- Compassion in Practice (NHS Commissioning Board, 2012a)
- Everyone Counts (NHS commissioning Board 2012b)
- Care Quality Commission Essential Standards of Care (2010)
- National Pensioners Convention (NPC) Dignity Code (2012)
- Feeling Better? (NHS Confederation, 2010)
- “What Matters to Patients”(Robert & Cornwell et al, 2011; Robert & Cornwell,2011)
- Francis Enquiry Report (2013)

6.4 We considered specific pieces of work that had been done around Patient Experience and Health Inequalities with regard to groups with protected characteristics (age, sex, disability and carers. Gender identity, Religion / Belief, Race, Sexual Orientation, pregnancy / maternity) These are referenced in the Equality Impact Statement (Appendix 6).

6.5 We looked at what other NHS Trusts have been doing regarding Patient Experience Strategy as well as looking at some of the empirical research that has been done nationally and internationally. It is recognised that, at this stage, the methods employed are in no way comprehensive enough and this strategy is very much a live document that will be reviewed and consulted on regularly throughout its lifespan (3 years).

6.6 Analysis of all the above evidence and data sets took place and resulted in the creation of eight statements which we have termed commitments. We chose commitments rather than verbal ‘pledges’ because we take it to mean “the state of being bound *emotionally* and *intellectually* to a course of *action”* (www.freedictionary.com) and we (and local service users) want this strategy to result in positive action.

7. ESHT Patient Experience Commitments

We at East Sussex Healthcare NHS Trust commit:

1. To promote the concept that everyone, in any role, helps shape patient experience.

2. To continue developing compassionate, caring, person centred cultures within the Trust where *all* patients/families and staff are valued and treated with, dignity and respect.

3. To continue to get better at delivering the fundamentals of a good patient experience based on what local service users have told us is important, as well as using local and national guidance on best practice.

4. To improve how we find out what matters to you.

5. To learn from listening to you and then share with you, everyone in the organisation and others, the lessons of what is going well and what we need to do to improve and innovate.

6. To improve staff experience.

7. To reduce bureaucracy, increase efficiency in order to increase the amount of time we have to provide and improve your care experience.

8. To work more effectively with our partners locally and nationally to improve the way your care is planned and delivered.

These eight commitments form the central pillars of ESHT’s Patient Experience Strategy.

8. Background

8.1 The Department of Health (2012c) define patient experience as meeting not only our physical needs but our emotional needs too. This means:

- getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way.
- having information to make choices, to feel confident and to feel in control
- being talked to and listened to as an equal; being treated with honesty, respect and dignity.

8.2 Patient experience is a factor of the sub-culture or individual workplace cultures across the Trust. It is:

> **"the sum total of all *interactions*, shaped by an organisations *culture,* that influences patient perceptions across the *continuum of care*"**

The Beryl Institute (2013)

8.3 Within this definition, *interactions* are described as the "orchestrated touch-points of people processes, policies, communications, actions and environment". *Culture* is explained as the vision, values, people (at all levels of the organisation) and community. *Perceptions* might be described as what is recognised, understood and remembered (cognitively or emotionally) by patients and other service users. Perceptions vary based on individual experiences such as beliefs, values, and cultural background. *Continuum of care* means, before, during and after the delivery of care

The Beryl Institute (2013)

National Context

8.4 Section 242(1B) of the National Health Service Act 2006 ("2006 Act"), as amended by the Local Government and Public Involvement in Health Act 2007 ("2007 Act"), states:

> "*Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways)".*

8.5.1 The involvement must be clear, accessible and transparent, open, inclusive, responsive, sustainable, proactive and focused on improvement.Professionally, all registered health and social care practitioners must work within the law regarding practice and their professional standards. However there have been recent examples of poor patient and service user experience that have raised a number of concerns and also contributed to a policy drive to enhance the patient and service user voice (DH 2012b).

8.6 In order to deliver a fair, equitable and quality patient experience, national drivers, white papers and acts set out standards which providers of services should aim to work towards to enable them to provide a better patient experience. Some of these standards are described below. The 8 commitments which form the central pillars of this strategy have been mapped against these standards (appendix 2) to demonstrate how our 8 commitments fit strategically with them.

8.7

The Mid Staffordshire NHS Foundation Trust Inquiry, (Francis, 2013), has recently been published and the report makes over 290 recommendations that are far reaching across health, social care and from regulatory bodies, to management to frontline service delivery. The report emphasises real change in culture, including a refocusing and recommitment from all who work in NHS to putting the patient first and a common patient centred culture which promotes fundamental standards of care. Key themes to the reports that have relevance to this piece of work are

- Emphasis on and commitment to common values throughout the system by all within it;
- Readily accessible fundamental standards and means of compliance;
- No tolerance of non compliance and the rigorous policing of fundamental standards;
- Openness, transparency and candour in all the system's business;
- Strong leadership in nursing and other professional values;
- Strong support for leadership roles;
- A level playing field for accountability;
- Information accessible and useable by all allowing effective comparison of performance by individuals, services and organisation.

8.8 **The NHS Plan (2000)** launched the concept of patients being at the centre of NHS planning and development. This duty was strengthened in the introduction of the **Local Government and Public Involvement Health Act 2007.** Since then Darzi's next stage review (2008) and the White Paper **"Equity and Excellence" (2010)** and the **NHS Constitution (2009, 2010, 2012)** clearly indicate a government policy drive for engaging patients, service users and the public in their own treatment and also in the development of local services in England and Wales. This drive has been aided by patient and service user groups such as Patient's Association (www.patients-association.org.uk/).

8.9 The revised **NHS Constitution (2012)** articulates the principles and values that underpin the NHS in England as well as setting out the rights that public, patients and staff are entitled to (see box 1). It includes a set of pledges to which the NHS is committed to. All of these have been central to the development of this strategy and incorporated within its fabric.

Box 1

The 7 Principles that guide the NHS:

1. Access based on clinical need not ability to pay
2. Aspires to highest standard of excellence and professionalism
3. Reflects needs and preferences of patients, their families and carers
4. Works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population
5. Providing best value for taxpayers' money and the most effective, fair and sustainable use of finite resources
6. Providing accountability to the public, communities and patients that it serves

These are underpinned by the following values

Respect and dignity
Commitment to quality of care
Compassion
Improving lives
Working together for patients
Everyone counts

8.10 Several specific commitments within the NHS Constitution have a bearing on patients' experience of NHS services. For example:

- You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality.
- You have the right to expect NHS organisations to monitor, and make efforts to improve, the quality of health care they commission or provide.
- You have the right to make choices about your NHS care and to information to support these choices.
- The NHS commits to continuous improvement in the quality of services you receive, identifying and sharing best practice in quality of care and treatments.

8.11 In his introduction to **the Next Stage Review (DH 2008),** Lord Darzi said:

> *'High quality care should be as safe and effective as possible, with patients treated with compassion, dignity and respect. As well as clinical quality and safety, quality means care that is personal to each individual'*

The review defined quality as consisting of the following components:

- Patient safety
- Clinical effectiveness
- Patient's experience.

8.12 The NHS **Operating Framework 2012/13** (2011) sets out the planning, performance and financial requirements for NHS organisations. It has four key themes the first being "putting patients at the centre of decision making". Although this theme resonates throughout all five domains within the operating framework, domain four: "Ensuring that people have a positive experience of care" is a key measurable element of ESHT's quality plan. This is also a central issue for the NHS Commissioning Board and Clinical Commissioning Groups, who will hold providers to account for their performance. The NHS operating framework for 2012/2013 states that:

"NHS organisations must actively seek out, respond positively and improve services in line with patient feedback, This includes acting on complaints, patients' comments, local and national surveys and "real time" data techniques" Pg 17.

8.13 In October 2011, the NHS National Quality Board (NQB) agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. The **NHS Patient Experience Framework** (DH,2012), which was launched in 2012, is based on a similar principles from the Picker Institute (2009). This NHS framework outlines those elements that are critical to the patients' experience of NHS Services. (See Box 2)

Box 2 : NHS Patient Experience Framework

- ***Respect for patient-centred values, preferences, and expressed needs***, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making
- ***Coordination and integration of care*** across the health and social care system
- ***Information, communication, and education*** on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion
- ***Physical comfort*** including pain management, help with activities of daily living, and clean and comfortable surroundings
- ***Emotional support*** and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances
- ***Welcoming the involvement of family and friends***, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers

- ***Transition and continuity*** as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions
- ***Access to care*** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_132788.pdf
last accessed on 27 Dec 20/12

8.14 The Chief Nursing Officer for England, Jane Cummings has recently released the vision and strategy for Nursing, Midwifery and care Staff **"Compassion in Practice"**(NHS Commissioning Board, 2012a)**.** This strategy was driven by what users of services and staff said was important to them in receiving and delivering quality care. From these consultations 6C's have been developed which describe the values and behaviours people can expect when receiving care and what staff are expected to demonstrate when delivering quality care. These 6Cs naturally focus on putting the person being cared for at the heart of the care they are given (see box 3).

Box 3: "The 6C's" Compassion in Practice (NHS Commissioning Board,2012)

1. **Care** – Our core business, improving the health of the whole community, appropriate, consistent and throughout life
2. **Compassion** – How care is given, empathy, respect and dignity
3. **Competence –** Understanding individuals needs, expert clinical knowledge, evidence based
4. **Communication**- Listening, "no decision about me without me", key to effective relationships and team working
5. **Courage**- Doing the right thing for the people we care for, personal strength, vision and innovation to embrace new ways of working
6. **Commitment**- To improve the care and experiences of people who use our services

8.15 In order to deliver these values and behaviours the guidance highlights 6 key areas that will have the biggest impact of all, one of these is working with people to provide a positive experience of care. This will focus on providing rapid feedback, listening to the seldom heard populations, understanding and improving from what we are being told and supporting the Friends and Family Test (FFT).

8.16 These 6Cs have been fully considered in developing our 8 commitments and have been mapped against them (appendix 2).

8.17 The **National Institute for Health and Clinical Excellence (NICE)** released quality guidelines for patient experience in adult NHS services (2012a) which provide the NHS with clear, evidence based, commissioning guidance on the components of a good patient experience.

8.18 These standards are similar in content to the patient experience elements of the **Care Quality Commission (CQC) Essential Standards of Quality and Safety**

(2010). The CQC is the independent regulator of health and adult social care services in England. These standards set out what NHS organisations should do to comply with Section 20 regulations of the Health and Social Care Act 2008 (Regulations 2010) and the Care Quality Commission (Registration), Regulations 2009.

8.19 From April 2013, the Department of Health have mandated that every acute Trust and A&E provider will ensure that every adult patient being discharged from a hospital bed or who has been seen in A&E (but not admitted) will be asked the Friends and Family Test (FFT). This will form part of the NHS contract and become a CQUIN Indicator, with financial implications. This mandate further emphasises the increasing importance of engaging with patients and service users.

8.20 A recent King's Fund report (Robert & Cornwell et al, 2011) highlighted that providing a good patient experience is multi-dimensional and is about both the *what* (functions or transactions) and the *how* (relational) of interactions with patients. One important and consistent finding across the different strands of work was the relative emphasis on the 'relational aspects' of patient experience in comparison to 'functional' (or 'transactional') aspects. The most commonly reported generic themes were:

- feeling informed and being given options
- staff who listen and spend time with patient
- being treated as a person, not a number
- patient involvement in care and being able to ask questions
- the value of support services
- efficient processes

(Robert & Cornwell, 2011)

8.21 What are the benefits of improving the Patient Experience?

There is a growing body of research demonstrating that an explicit focus on improving the patient experience can reap rewards for patients, carers, staff and the organisation.

- Enhanced Patient Recovery and health outcomes (e.g. reduced length of stay)
- Enhanced quality of life and reductions in pain, anxiety and depression
- Improved patient confidence, involvement and coping ability
- Enhanced individualisation of care and more dignity respect and understanding
- Enhanced quality of care including turnaround of problem areas
- Improved productivity, efficiency and reduced costs
- More streamlined care pathways that are less resource-intensive
- Lower staff turnover and absenteeism, better job satisfaction
- Enhanced team dynamics
- Better culture of care.

(The Kings Fund (2011a, 2012) NHS Confederation (2010) DiGioia et al, 2007; Charmel and Frampton, 2008).

8.22 Naturally one needs to consider resource implications when considering improving the Patient Experience but there is growing consensus in the literature that this is not likely to be “significant” (NICE,2012b) and is more often related to challenging and improving the *Values* and *Culture* of an organisation (CQC,2009, NHS Confederation 2010; Davies et al,2011).

8.23 The NHS Confederation (2010) state investing in patient experience is a win-win situation not only reaping the rewards such as decreased mortality and improved safety, but by having a sharp focus on Patient Experience can give early indications of poor practice. “With hindsight, data clearly showed poor patient experience at Maidstone and Tunbridge wells and Mid staffs long before it was acknowledged. Evidence that the trust boards did not act”(NHS Confederation,2010, pg5).

8.24 Focusing on a Trust wide approach to improving the Patient Experience can pay dividends; a case in point is Whipps Cross University NHS Trust which following a CQC inpatient survey in 2008 showed it in the bottom 20 per cent of trusts for two thirds of the questions asked, raising particular issues around the attitudes and behaviour staff. In 2009 the trust began working on a ‘patient experience revolution’, developed by 500 staff and 100 patients across the hospital. They identified key staff behaviours important to patients and started embedding these across the whole organisation via a manifesto, which included a set of shared values and ten core behavioural standards expected of all staff. Every member of staff was asked to sign up to this promise to patients and this was seen to empower staff to work in accordance with the values. This and other initiatives they introduced resulted in improvements within one year over 43 of 63 key indicators, making them one of the better performing trusts in London.(NHS Confederation, 2010).

Local Context

8.25 Whilst we naturally considered national policy, guidelines and empirical research as above, the starting point for developing this strategy was what our local service users were saying about East Sussex Healthcare NHS Trust.

Patient, Service user and staff Experience Evidence:

8.26 In October 2012, six focus groups were held locally with service users, with the purpose of shaping the strategy (This report is included in appendix 3). In addition, findings from a similar project “Treat me fair, treat me equal, treat me right” conducted 2 years ago within the Trust (Chapman and Lane,2010) with people with learning disabilities has been included as secondary evidence.

8.27 Findings from a sample of 2012 compliments, concerns and complaints have been included, as has feedback from the Patient Opinion and NHS choices websites.

8.28 Listening in Action (LiA) data (2012) has been included as it provides evidence of staff perspectives on patient and user experiences.

Patient Strategy Focus Groups (October 2012)

8.29 These groups were central to the shaping of this strategy and are reported in detail elsewhere (appendix 3). The major themes from this project and what matters to patients and service users are:

1. Communication
2. Attitude and Approach of staff
3. Standards of Care
4. Empowerment & Engagement
5. Learning & Sharing
6. Transition and Continuity

8.30 In addition, some minor themes emerged which were also seen as important; for example the importance of the environment, the role of volunteers, administration and food / nutrition.

8.31 Those service users/members of the public who took part in the focus groups were consulted on the draft strategy and their feedback taken into account.

8.32 **Communication*:*** The importance of good communication skills at a personal level was one of the things that was most commented on throughout all of the conversations we had. Participants stated how important it was to be listened to so that so that care can be individualised. Related to this was the importance of comprehensive and timely information to facilitate informed choices and shared decision making. The importance of having someone to talk to was also of great importance and cannot be underestimated. There was a recognition that we need to get better at communicating between departments, particularly the sharing of information as patients move through the continuum of care.

8.33 Finally, we discussed how we might communicate better with our local partners and in particular groups within the community from whom we seldom. There was an appreciation that this is challenging but all recognised how important this is and how we need to be creative and flexible in our approach to link in to the many existing forums that are already out there.

8.34 **Attitude and Approach of Staff*:*** The importance of a caring and compassionate approach as well as the need to treat patients with dignity and respect were paramount, particularly at a time when people were feeling very vulnerable. It was really important that care was personalised and that individuals were understood in terms of their needs and preferences.

8.35 **Standards of Care*:*** There were many instances where participants talked of experiences where the standard of care had been really good and met their expectations. This was often about the services within the main general hospitals, A&E, MAU, ITU however this may reflect the make up of the groups. Unfortunately there were also instances where the levels of care did not meet their expectations. There were few wholly negative or positive experiences but most were a mixture, indicating that we need to work at being more consistent in the care we deliver.

8.36 Good clinical skills were (as would be expected) one of the most highly regarded elements in terms of their experience of care. There was recognition of the importance of strong leadership (e.g. ward matron) in delivering the essential standards of care that people require.

8.37 Worryingly, there was a perception from a couple of participants that some of most vulnerable patients were not having their needs met and that when they tried to express this they did not feel they were listened to.

8.38 Having visible staff was something that was important. One participant stated that having access to particular services such as therapy should be based on need and that they should not have to ask for it.

8.39 **Empowerment and Engagement*:*** Being empowered to be involved in their own care was seen as essential and often this was related to simply being asked and being listened to. There was a sense that many people fear giving “honest” feedback for fear of repercussions, particularly when an inpatient.

8.40 Participants whilst happy to contribute highlighted that it was really important to know (with specific engagement activities) the purpose, how the information would be used and in what timeframe. Also how important it was to receive feedback on what had happened as a result. Specifically in regard to the strategy, participants felt that they did not want it to be just a tick box exercise or to be blocked because of resources. We talked a lot about the strategy being aspirational but realistic. With regards to engaging the community, the potential of technology was mentioned across the groups and the general trend was that “one size does not fit all” and we need to be flexible in our approach and timing to engagement, gaining feedback and general communication.

8.41 The question of patient representation at meetings and at board level was discussed. We were able to reassure on this point but perhaps we need to consider making this even more explicit and robust.

8.42 **Learning and Sharing*:*** There was much discussion about that feedback should lead to change and a realisation that we should also be learning from the things that we do well (and there were many examples within the groups). Peer review was mentioned as one way of allowing staff to actually see and experience high performing areas for themselves rather than just hearing about it. We need to encourage this and formalise this throughout the organisation. Some participants talked of positive experiences at other local providers and the need to be looking out as well as in, to find out why it is they are high performers.

8.43 Transparency was a theme that promoted some discussion with the feeling that we need to be honest about when things don’t go to plan and how an apology can go a long way. Participants recognised that there are pressures on resources but would appreciate knowing how long they would have to wait.

8.44 **Transition and Continuity*:*** Participants want transitions between shifts, teams & services (particularly into the community) to be smooth and efficient, often signified by timely and appropriate information exchange. People want to be involved in their discharge process.

8.45 Continuity of care was important and the use of agency staff did not help this. Finally there was a feeling that we need to be moving towards a full seven day service to improve the continuity of care.

8.46 Some of the **minor themes** still gave interesting perspectives, such as the need to be mindful of the physical environment and the importance of this on the care experience. We met with a volunteer who reminded us of the valuable contribution volunteers make to the patient experience. There was a feeling that they could do so much more but there were perceived barriers such as health and safety, team culture and learning and development s needs which prevented this happening.

8.47 There was much frustration with administrative elements of the NHS, and that often when you finally got access to our services they were very good, but to get there was a challenge. The use of technology was discussed and the recognition that there may be potential for reducing waste and inefficiency which would not only make things better from a service user perspective but save money (something people felt very passionate about).

8.48 Finally the importance of food and nutrition was mentioned by some participants. There were mixed comments, so clearly we need to look to reducing inconsistency to ensure patients get the nutrition they need.

Treat me Fair, Treat me Equal, Treat me Right (Chapman and Lane,2010)

8.49 Along with the focus groups we also included secondary data collected through a user engagement project for people with learning disabilities (Chapman and Lane, 2010). This project had four focus style groups across East Sussex with 53 people (including family /carers of people with learning disabilities). We included this data because it was an opportunity to make further use of existing local evidence and because the project method was contextually relevant and had similar aims to our work; one of which to understand what the local community thought was important in terms of patient experience. The experiences of Winterbourne View (DH 2012b) have highlighted the need to ensure people with learning disabilities and other vulnerable adults voices are heard and needs are truly met.

8.50 “Treat me fair, treat me equal, treat me right” highlights the challenges engaging groups from whom we seldom hear and this was cited as being due to lack of support in attending and lack of transport. Instead it was necessary to go to where the people were, Adult Social Care Directly Provided Services. Skilled facilitation and creative methods were required to ensure all participants view points were gained.

8.51 The main themes from this study resonated with the more recent Patient Experience Strategy Focus groups stated above and the messages from all the above guidelines. The main themes were communication, information, support, accessibility and training.

8.52 **Communication**: The importance of staff demonstrating and having a good awareness of how to communicate with people with learning disabilities was important. Mannerisms and body language can (in many instances) be more effectively interpreted than verbal communication, so a pleasant and friendly approach is essential. A sense of humour was much valued. The use of sign language and appropriate pictures can help communication too. Using appropriate language was highlighted as ambiguous language can lead to anxiety. Finally, appointment times should be longer so that staff can explain things better.

8.53 Participants wanted to be communicated with and not “talked over” or spoken to like children. “It’s ok to ask me what I can do for myself. It’s important for me to feel useful”.

8.54 **Information:** NHS services have got to get better at providing and using information for people with a learning disability. There needs to be consistency with easy read materials and more information on health promotion is needed. In addition, it was frustrating to hear of incidences where Health Action plans were not actively used , “put in drawer and not looked at again” or “told by ambulance staff, don’t bring it, the staff at the hospital will find out everything they need”.

8.55 **Support :** This means that support was needed for appointments from someone who is trusted and that when carers are present / involved that they should be listened to. Privacy is just as important for people with learning disabilities, however it was reported that there is the feeling some people think this is not important because the person lacks the understanding. Participants wanted to make their own decisions and explaining things clearly can help with this. Finally there was a request for ongoing support as even when a long term condition is under control, it can remain a source of worry to the person with learning disability.

8.66 **Accessibility:** People with learning disabilities find it difficult to sit for long periods in waiting rooms and there was a request for alternative ways to do things so they don’t have to wait too long, highlighting the need to firstly be aware of their needs but also to them make reasonable adjustments. Adjustments might also be offered to allow more flexible visiting arrangements. Signage and information can often be inaccessible due to medical jargon used, and there was a suggestion that different colours and pictures could be used.

8.67 **Training:** There was a call for more training for staff in terms of communication, relationship building and learning disability awareness. People with learning disability wanted their needs understood with dignity and respect “Treat my illness not my disability”.

8.68 The report suggests developing meaningful ongoing involvement structures and making strong links with existing groups to compliment involvement efforts. In addition they feel that key areas for development within the Trust are communication and the production of easier to read information.

Analysis of Friends and Family Test (FFT)

8.69 David Cameron (Prime Minister) announced the Friends and Family Test (FFT) in May 2012. ESHT have been offering the question to inpatients across the trust from July 2012. The FFT will be an increasingly important indicator of Patient Experience in the future and linked to quality targets. It will be mandatory from April 2013.

8.70 The FFT is a simple, comparable test which, when combined with follow up questions, provides a mechanism to identify poor performance and encourage staff to make improvements where services do not live up to the expectations of our patients. The FFT asks the question " How likely are you to recommend our ward (e.g. A&E department) to friends and family if they needed similar care or treatment?"

8.71 For the months August to November (inc) 2012 on average 82.5 % of people surveyed would be happy to recommend the service that they had got. This is very encouraging but of course there is always room for improvement. ESHT are looking to roll this programme out to more areas in 2013 and by 2015 be using it for all services across the continuum of care.

Analysis of Compliments, Comments, Concerns and Complaints received to the TRUST in 2012

8.72 Analysis of complaints, concerns, and comments within ESHT since the beginning of 2012 shows some trends that are fairly consistent, with standards of care, communication, attitude of staff, delays and diagnosis being consistently in the top 5. Standards of care are consistently the biggest reason that patients complain or raise concerns. This data is not at odds with National data on complaints, with the highest percentage for formal complaint being; *All aspects of clinical treatment* (45.8%), *Attitude of staff* (11.6%), *Written and oral communication of information to patients* (10.1%) (NHS Information Centre, 2012)

8.73 It is encouraging to see that we have got much better at recording compliments, with numbers of compliments far exceeding those of complaints, however ESHT needs to get better at learning from and sharing what we are doing well, both internally and externally to the organisation.

Analysis of Web based feedback systems (July –December 2012)

8.74 Web based systems have potential to obtain rapid feedback from patients who want to comment on their care outside of formal or internal feedback mechanisms. A number of websites offer this facility, including NHS Choices (www.nhs.uk), Patient Opinion (www.patientopinion.org.uk), and iWantGreatCare (www.iwantgreatcare.org). This form of feedback can be a useful source of intelligence, and responses can be provided via the websites too, so users can see what the trust is doing to address any problems. However, there is no way of knowing how representative the comments are, so this web-based feedback cannot be used for benchmarking or monitoring trends. Whilst this is understood, examining the comments over the last six months postings showed congruence with the feedback we were getting through our other feedback systems including the focus groups above and the compliments, comments, concerns and complaints.

8.75 The use of technology is something that the strategy needs to embrace and take account of, as this one posting from Patient Opinion website highlights.

“I am under the excellent care of Dr Sam and the rheumatology department. However, like many aging people, I have multiple problems, one of which is profound deafness. I would dearly love an email address to communicate with the clinics I attend. The telephone is utterly hopeless for me, and it cannot be beyond the capabilities of the IT staff to provide departmental patient contact email addresses, surely? Come on Eastbourne DGH! You get unfair press a lot of the time (especially about the outrageous car parking charges) but this is something you can do at almost

no cost, very quickly and it would be gratefully appreciated by deaf old fogies like me!".

"Deaf Fella" talking about EDGH.

Listening in Action (LiA)

8.76 ESHT is part of a network of 10 NHS organisations participating in a change programme called Listening into Action (LiA), which places staff at the centre of positive change. The LiA programme is based around an engagement framework developed nationally by Optimise (a consultancy organisation). The LiA process supports the organisation's development of staff engagement initiatives, and enables staff to influence and directly involve them in change. These initiatives enable ESHT to address key areas of poor staff engagement and communication identified through the staff survey.

8.77 As part of LiA 900 staff at ESHT undertook an online survey(the pulse check), 60% staff were proud to work in their teams and departments, 80% felt that communication could be improved across the organisation and sadly only 15% felt that their work was valued.

8.78 A series of staff engagement events "the Big Conversation" were held and as a result 8 themes were identified:

1. A better place to work
2. The best Patient Experience
3. Sharing knowledge and learning
4. Realising our potential
5. Environment and Infrastructure fit for purpose
6. Purposeful processes
7. Utilising resources wisely
8. Time to care.

8.79 As well as certain enabling projects centred on teams / areas, each of the above themes has a working group with executive sponsorship. Theme 2, "The best patient experience" has decided to focus on the creation Patient Experience Champions.

8.80 The LiA themes, enabling projects and supporting groups, have again helped to inform the strategy and sit well with the 8 commitments around improving Patient Experience. Within LiA staff have been consulted and engaged with and they have said that first impressions are not always great as the patient enters the hospital; there is a lack of smiles and welcomes. Some staff have a negative mindset, old fashioned attitudes and a lack of friendliness and openness. They have also stated that we do not always put patients first in service and role developments. Our staff are telling us they want to improve on these areas are have committed themselves to this programme which is very positive. This feedback is congruent with what was found in the focus groups, complaints analysis and web based feedback, demonstrating that staff actually have a good understanding of areas we need to focus on.

8.81 It must also be mentioned that there are other improvement initiatives within the trust such as the productive series. Similarly, the strategy will help to coordinate all these valuable initiatives which have direct impact on the patient experience.

East Sussex LINk Dignity and Nutrition report (April 2012)

8.82 The East Sussex HOSC (Health Overview and Scrutiny Committee) Review of nutrition, hydration and feeding in hospitals (September 2010) formed the basis for East Sussex LINks' (Local Involvement Network) survey and report completed in April 2012. They visited 7 wards across our organisation speaking to patients and staff. LINk concluded that ESHT had made progress against the HOSC recommendations but that we still had work to do. The findings have been discussed within the attached paper (appendix 3) but the main themes were:

8.83 **Protected meal times**: generally recognised as important by staff and being implemented. It was recognised the role that family members might play in supporting nutrition and so they were allowed to be present at support times.

8.84 **Care and compassion:** The majority of identifiable patient responses and observations reflected a caring attitude on the part of staff towards patients.

> *"the whole atmosphere of the ward was friendly and all care was patient centred and friendly. Giving food was always accompanied by pleasant and relaxed conversation".*
>
> *"all staff are very caring and considerate. They treat patients with warmth and respect. Their tone in communication is friendly and warm".*

8.85 There were inconsistencies though with some with some concerns regarding the quality of the interactions with patients with special needs. For example, standing over patients whilst assisting them with their nutrition. This gave the impression that the staff were rushed.

8.86 **Hand Cleanliness:** There was little evidence of patients being encouraged to wash their hands prior to their meals.

> *"I did not see any patients using wipes to clean their hands prior to eating nor did I hear any staff suggest that they should"*

8.87 HOSC recommendation 6 on good practice states that Trusts should adapt pre-mealtime routines, including encouraging patients to make use of hand gels or wipes prior to consuming meals and snacks, as part of infection control strategy.

8.88 **Quality of food:** Generally good for non-specialist diets but there did not appear to be a formal way of gaining feedback. There appeared to be some inconsistency in quality and the appearance of fresh fruit on food trolleys was not general practice. There was no evidence of patients being aware of the availability of snack boxes on any of the wards.

8.89 **Specialist diets, cutlery and patient assistance:** Most reporting indicated that specialist diets are available according to the needs of the patient. Specialist staff were generally available to support In relation to volunteer assistance during mealtimes, this was observed to be limited as they were not allowed to feed patients due to a number of reasons. This issue was picked up during a conversation with a volunteer during our Patient Experience Strategy focus groups. Red trays**:** There was lack of systematic approach to use of red trays with them in some instances being used inappropriately and indiscriminately.

8.90 **Day rooms** were not seen to be used during meal times. These could be used for those patients who are able to. This will make meal times more sociable and potentially easier to manage for the staff.

8.91 **Pictorial menus** were suggested as well as the routine use of menu books

East Sussex LINk Leaving Hospital report (November 2011)

8.92 Another report by LINk looked at experiences of discharge from our local hospitals (including the community hospitals). Unfortunately there was minimal follow up at home after discharge, but there were still some interesting recommendations including reviewing the discharge policy and reinforcing this to staff. There was a lot of variety in the ways things happen across East Sussex including using different documentation.

8.93 Patient Involvement in discharge planning needed to be evidenced and a suggestion was made to provide more information to patients on their discharge. Effective working relationships in some wards were required with Adult Social Care to minimise delayed discharges and similarly access to out of hour’s pharmacy and transport could be investigated.

ESHT Key Indicators Analysis

8.94 Within ESHT there is a lot of data collected and reported with regards to safety from falls to pressure sores to hand hygiene to hospital acquired infections. It is a key belief that a crucial part of a good patient experience is having a safer and more (clinically) effective patient experience.

8.95 In addition there are staff surveys (e.g., staff responses to whether they would recommend their own services to others, reports of errors, near misses or incidents (that could have harmed patients or service users); surveys of cleanliness undertaken by the Patient Environment Action Team (PEAT); and routine data (e.g., the proportion of patients seeing a relevant specialist nurse). In addition to the above ESHT currently collates patient feedback from a variety of sources including

- National Inpatient / outpatient surveys
- National A&E surveys
- Extended inpatient surveys on quarterly basis
- Regional pilots for heart failure and hips and knees Enhancing Quality programme
- Service / ward level surveys
- Local outpatient surveys
- Community nursing surveys
- Patient stories

8.96 Collecting information in itself has limited value; it is how this information is used which adds the value. ESHT needs to move to a position where there is more emphasis on using this information to better effect. Often the results of surveys are not shared with staff, in a timely fashion. Additionally there is limited sharing between directorates or departments. ESHT needs to focus efforts towards the analysis and use of information to make real evidence based changes and improvements. The Data Rich/Information Poor (DRIP), a concept borrowed from Waterman (1987) refers to “the problem of an abundance of data that does nothing to inform practice because it is not presented in context through the use of relevant comparisons” (Dufour et al 2006 p 215).

8.97 We are not alone in struggling to ensure we have adequate systems for co-ordinating data collection and assessing its quality, or for learning from and acting on the results in a systematic way (Davies et al,2011;Kings Fund, 2010;Bate and Robert, 2006; Coulter et al, 2009). This may be due to the amount and complexity of the data and lack of systems to aggregate it. A central commitment within the strategy is to get better at using the information we already go to great lengths to collect.

8.98 The same quality criteria should be applied to measuring and improving patient experience as are brought to bear in the other domains of quality: (i) clinical effectiveness and (ii) patient safety. As we stand, improving patient experience does not have the same status or value as improving these other two domains (Kings Fund, 2011a).

9. East Sussex Healthcare NHS Trusts Patient Experience Commitments

East Sussex Healthcare NHS Trust commits:

1. **To promote that everyone, in any role, helps shape patient experience.**

We will:

Promote the notions of Care, Compassion, Competence, Commitment, Communication and Courage within everything we do as a Trust.

Ensure patient experience is written into all job descriptions (not just clinical staff).

Ensure patient experience is a necessary learning requirement for all staff working in the organisation.

Ensure all induction programmes will reflect strongly the Trusts culture, values and expectations for patient experience.

Continue to work with executive and non-executive sponsors to raise awareness and profile of patient experience within the organisation and with partners.

How has local evidence shaped this commitment?

Feedback from focus groups, staff, complaints, concerns, comments and local reports that a cultural shift is required so patient experience needs to become everyone's business in order for this to happen.

Communication was the biggest theme (and was evident throughout many of the others) in the focus groups.

Focus groups have fed back that a compassionate caring approach is central to a good experience

We need to develop those staff that we have and ensure new staff buy into our values and compassionate culture.

Most people we spoke to had mixed experiences. We need to ensure that good care is more consistent.

How has local evidence shaped this commitment?

The approach and attitude of staff is one of the biggest things that affects the patient experience.

Being treated with dignity and respect can make a huge impact on the patient experience.

Personalised care, the personal touch and understanding me as a person were fundamental to a good experience.

A compassionate approach can make all the difference when you are not well

Families play an important role and patients want them to be involved. This is even more important with more vulnerable members of the community.

2.To continue developing compassionate, caring, person centred cultures within the Trust where *all* patients / families and staff are valued and treated with, dignity and respect

We will:

Treat all patients, families and carers with respect, dignity, compassion, courtesy and honesty. Ensure and promote equality and diversity in all that we do.

.

Respect values, preferences and choices and work with you to make shared decisions about your care.

Deliver individualised care based on understanding who you are as a person* and what your needs are (including physical, mental, emotional and spiritual needs).

Communicate better with patients, families and carers and local communities.

Provide a work environment where everyone can feel valued, is respected and have access to support, understanding, personal and professional development.

Establish a culture of compassionate care, where staff feel enabled and empowered to foster Improvements and innovations in order to enhance patient experience.

Improve access to and the quality of patient experience, professional customer service and communication training and learning programmes.

Develop, promote and support innovative Patient Experience Champion programmes which will recognise good performance, celebrate success and publicise it throughout Trust and local communities.

Develop / review Patient experience steering group and related forums ensuring a coordinated approach to improving the patient experience and representation from all interested parties including service users.

Recruit staff for their values and attributes such as compassion and communication as well as clinical / technical skills.

To ensure that care environments are clean and as safe as possible.

* person includes infants, children and neonates.

How has <u>local evidence</u> shaped this commitment?

Communication seen as fundamental to good experiences, at an individual level (good communication & English language skills) and across teams, the whole organisation and with external partners.

An awareness of different methods of communication would be useful e.g. Basic sign language, pictures

Having someone to talk to is important

A central part of having a good patient experience is having a *safe* patient experience.

It's *really* important to be listened to.

Individualised care is so important, as is focusing on the person not the illness or disability.

Healthcare passports were not always seen as important.

Good experiences of care could be affected by poor discharge processes and lack of communication / appropriate information exchange.

Focus group participants recognised the benefits of learning from high performing organisations, locally and nationally.

Good clinical skills viewed as essential.

3. To continue to get better at delivering good patient experience based on what local service users have told us is important, as well as using local and national guidance on best practice.

We will:

Improve the way we communicate with patients and with each other

Keep improving the standards of care we provide to ensure an individualised, safer and more comfortable care experience (e.g. reducing number of inpatient falls, attending to nutritional needs, ensuring adequate pain management)

Promote and embed the use of healthcare passports for the most vulnerable members of the community.

Keep working on improving the continuity of care – where you receive care and treatment from the same people/teams as far as is possible.

Keep working to improve the consistency of care so that we aim to get it right first time, every time.

Develop clearer more comprehensive information at all stages of your care.

Promote your independence and when this is not possible work with you to establish alternative ways to manage.

Improve your access to rehabilitation whilst within our care

Improve our discharge planning and aftercare where appropriate.

Work with you and your family to enable you have care at the end of your life in the way you would want and where you want.

Continue to explore best practice with regards to patient experience both within and outside of ESHT

How has <u>local evidence</u> shaped this commitment?

We need to be flexible and creative in our approach to engaging and building meaningful partnerships with groups from whom we seldom hear.

In some instances there were concerns over the standards of care that vulnerable patients receive.

Engaging with us about strategy and service improvement was seen in a positive light.

Some participants were happy to get involved in more specific projects based on their skills or simply what interested them e.g. IT.

Some focus group participants felt that there was not always an obvious mechanism for feedback about their experiences.

There were concerns / fears about repercussions when giving feedback.

Focus group participants felt that it was really important to know why their feedback was needed, what happened to any feedback they gave and any changes that happened as a result.

We heard about the positive role that patient groups and forums can offer to our service users.

4. To improve how we find out what matters to you.

We will:

Have a Trust wide approach to understanding the patient experience, capturing it, improving it and measuring the outcome.

Build links with, listen to, consult with, involve and ultimately collaborate with people we seldom hear from within local communities so that we can better understand health care needs and how to provide for them.

Make special efforts to ensure that vulnerable people and their carers' experiences and opinions are heard and acted upon.

Continue to engage with and consult you as patients, service users, staff, outside groups and organisations about service development and redesign.

Establish and improve a database of patients/families and community members willing to contribute to patient experience work and their preferences for how they do this.

Ensure that every patient who wants to has the opportunity to tell us about their experience of care, and share comments, compliments, concerns and complaints without fear of sanctions.

Be clearer about why we need feedback, what we will use it for and what has happened as a result.

Have a patient experience team knowledgeable and skilled in methodologies / methods for patient experience research and development and strengthen the visibility and role of the patient experience steering group (or equivalent) in the Trust.

Establish, support and pilot effective patient forums / councils within the Trust.

5. To learn from listening to you and then share the lessons of what is going well and what we need to do to improve and innovate.

We will:
Enhance the efficiency and effectiveness of processes within the divisions to gather data/evidence on learning from and action on improving patient experience.

To invest in a solution to improve the way we aggregate and triangulate all the existing data that we are collecting.

Drill down into the evidence/data to better understand key moments* or "touch points"* where we might need to concentrate efforts to listen and learn more.

Become more effective at using patient experience indicators and feedback for evidencing against national standards such as those set by the NICE and Care Quality Commission.

Reduce the amount of time that themes and trends from feedback (complaints, compliments, safety reports, and key patient experience indicators) take to reach clinical staff for action.

Be more transparent about areas for improvement, what is going well in addition to what changes have happened as a result of any feedback.

Ensure that positive feedback is shared and celebrated both within and outside the organisation.

Ensure 'productive series' and other improvements projects contribute to the patient experience strategy.
Ensure that we evaluate the effectiveness of any patient experience improvement or innovation activities and that this learning is shared.

Develop a robust peer review system.

* terminology form Experience Based Design (Bate and Robert, 2006)

How has local evidence shaped this commitment?

The local community / patients and service users are happy to get involved and give feedback on their experiences but there is a feeling that this does not always lead to positive change.

The importance of learning from positive experiences of care and high performing areas.

Participants in the groups felt that engagement should be a transparent two way process, "you said this...we did this".

Peer review was seen as a way to support change and allow others to actually experience it, rather than just hear about it.

Being open and honest was seen as really important, when things are going well and when things are not going so well. The importance of just saying sorry..

We already collect a lot of data on many different aspect of care and patient experience, but don't always make the best use of it.

There are lots of improvement initiatives going on, we need to share the learning.

How has local evidence shaped this commitment?

There was recognition within the focus groups that happy, engaged staff deliver good care and communicate better.

The physical environment affects the patient experience and this needs some attention, e.g. outside spaces and maybe moving the nurses' station "back into the bays".

A discussion with a volunteer highlighted their valuable contribution to a positive patient experience and potential for doing more within the role.

There was a recognition that working in the health service / caring can be demanding so there is a need for supportive mechanisms.

The role of leadership was seen as being important to the overall standard of care

6. To improve staff experience

We will:

Develop a staff experience strategy with the aim of improving and innovating workplace cultures and improving staff wellbeing within ESHT.

Develop better approaches and methods to engagement across the organisation, including learning from current initiatives e.g. Listening in Action work and productive series.

Capitalise on the expertise within learning and development, clinical governance and practice development to ensure each member of staff has an individualised personal development plan which reflects their own needs as well as the vision of local services and the organisation.

Continue to look at ways to enable staff to empower themselves to spend more time with patients and families

Work at improving the physical and environmental workplace to better enable staff to deliver better patient experience

Work with / alongside Volunteers within the organisation, to fully support them and their own learning and development as well as embracing their contribution to the patient experience.

Develop more creative learning spaces including reflective spaces for individuals and teams to learn from their own experiences and that of others

Embed clinical supervision and other forms of mentoring and coaching within clinical leadership roles

Ensure a process for reward and recognition including the patient experience champion programme.

7. To reduce bureaucracy, increase efficiency in order to increase the amount of time we have to provide and improve your care experience.

We will:

Work with staff, patients and our partners to improve efficiency and reduce bureaucracy from “community to ward to board”.

Improve the visibility of staff and enable them to spend more time with patients

Establish ‘best practice” patient experience wards and teams to role model and pilot innovations in enhancing patient experience

Look into using technology to improve the way that we communicate with each other, including patients and families

Scope the use of technology to help us gather real time data regarding patient experience

Continue to expand 7-day working and evaluate the outcomes of this on patient experience

How has local evidence shaped this commitment?

Focus group participants recognised that there are finite resources and these are challenging times, but that from their perspective there is a lot of bureaucracy and waste that leads to inefficiency.

Visibility of staff is important.

Focus group participants and other feedback have highlighted the potential role that technology might play (from text message reminders, to email communication to electronic discharge letters).

Focus group participants felt that things wind down at weekends and this affects their care and recovery. 7 day working was also seen as a way to reduce waiting times and potentially increase revenue.

8. To work more effectively with our partners locally and nationally to improve the way your care is planned and delivered

We will:

Ensure that patients experience coordinated care with clear and accurate information exchange, particularly during transitions of care and the discharge process.

Work to improve the continuity of care across services and organisations

Continue to develop evidence and contextually based integrated care pathways

Promote the role of patient representation within steering groups and boards.

Strengthen partnerships with Local Authority Organisations, LINk / Healthwatch as well as develop links with existing voluntary and community organisations, support groups and patient forums.

Communicate with commissioners and other interested parties about what we are doing to improve the patient experience.

Establish and develop links with Patient Experience networks regionally, nationally and internationally.

How has local evidence shaped this commitment?

Focus Group participants felt coordination of care and communication are particularly important during handovers, transitions of care and especially discharge.

Ensuring we have continued and robust patient representation at Trust Boards and meetings / groups was a concern.

There are many existing groups and forums which would be good to engage with.

The community wants us to look “out as well as in” to establish best practice

10. Summary

10.1 We have seen very recently on television and in the press, the consequences of when the culture of an organisation, team or values of staff are not right. Given that the largest percentage of all complaints that we receive, relate to direct patient interaction with healthcare professionals (standards of care, communication and attitude of staff) and from what we have learnt from the focus groups, local reports and talking to staff, we can see that this would support the notion that improving patient experience within ESHT requires a culture shift. This resonates with central policy and guidelines. We at ESHT believe that by engaging our two most prized resources our patients (and families) and our staff, we can help to make this happen through the implementation of this strategy.

10.2 ESHT spends an enormous amount time and effort in collecting evidence /data and on improvement projects. The purpose of this strategy is not necessarily collecting more or even doing a lot more. It’s about doing things a bit differently. Not in all areas though as there is much to celebrate here at ESHT.

10.3 We need to be more effective in pulling together all that we do, because *everything* we do shapes the patient experience. It will be desirable to combine measures of experience with measures of outcome to obtain a rounded view of the quality of care. Amongst this must be an attention on the relational dimensions of care not just the technical.

10.4 We need to get better at learning and sharing that learning. To drill down not just into problem areas, but also into those areas that are doing a fantastic job (and there are many). Unfortunately there are inconsistencies and we need to focus our attention on these too.

10.5 It is imperative that this strategy recognises that in order to create good patient experiences and thus safe quality care, we need to look after our staff.

> *“Any organisation that wants to improve patient experience cannot ignore how its staff feel about their jobs”*
> NHS Confederation (2010)

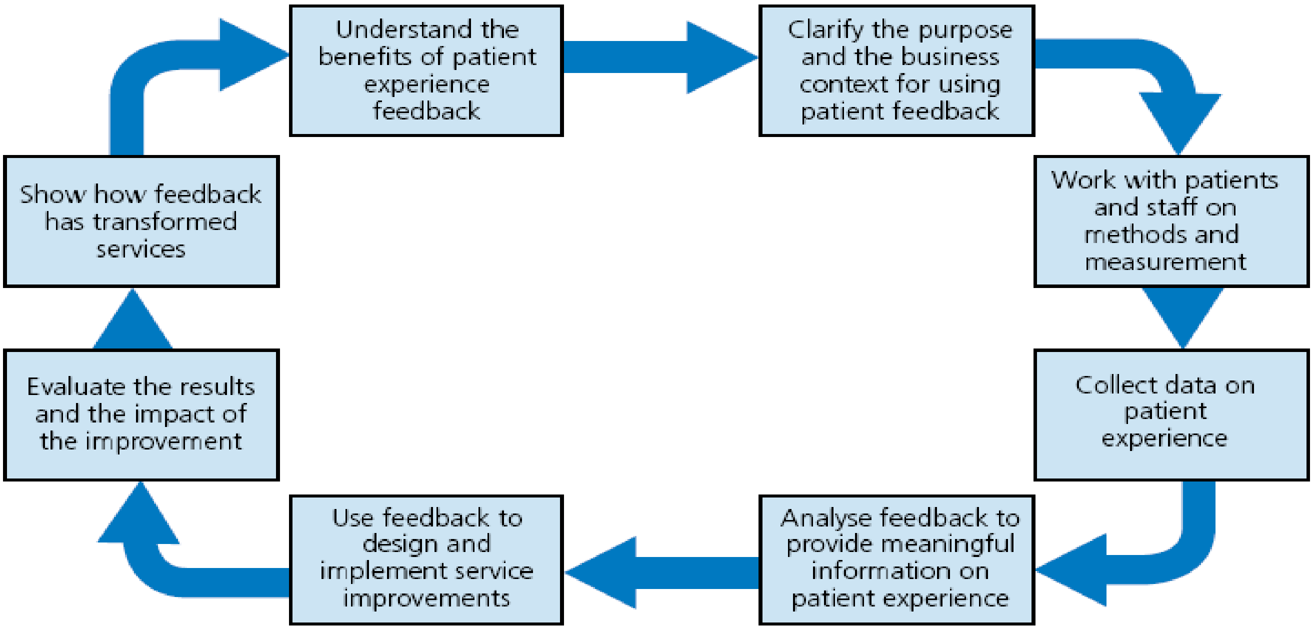
10.6 Improving Patient Experience is everyone’s business without exception, no matter in what role or at what level. The Patient Experience strategy is about ensuring everyone is pulling in the same direction.

11. Putting it all into Action

11.1 East Sussex Healthcare strives to develop and deliver services that have people at the centre. The range of objectives or priorities within this strategy reflects the scale of our ambition to deliver safe, effective, quality patient experiences and be the Healthcare Provider of first choice for the local community.

11.2 We need to do the following

- Capture the experience
- Understand the experience
- Improve the experience
- Measure the improvement



(Diagram 1: Patient Experience Improvement Cycle. National Institute of Innovation and Improvement)

How will we capture the experience?

11.3 We need to develop a set of Patient Experience measures and indicators that

- simultaneously serve the 3 purposes of accountability, quality improvement and transparency.
- are aligned with clinical outcomes (both relational and transactional)
- are evidence based
- are simple
- are embedded in quality standards (e.g. NICE CG138, CQC essential standards)
- are contextually relevant

(Adapted from Robert & Cornwell, 2011)

How will we understand and improve the experience and measure the improvements?

11.4 There is a growing consensus within the literature both nationally and internationally (Fitzsimons & Wright,2012; NHS Conderation,2010) on what elements are important to ensure successful implementation of Patient Experience Improvement Initiatives and this strategy (in particular the commitments) take these into account. They are:

- Leaders that give a clear vision of what is needed and expected.
- Set out the desired values and behaviours and embed these across the whole organisation.
- Make sure there is a consistent and joined up approach patient experience activity across the whole organisation rather than a series of small random projects.
- Ensure staff are enabled to deliver excellent patient experience and empowered to make changes themselves.
- Promote greater multi-professional clinical engagement and professional empowerment.
- Engage patients and families more in care and ensure that the experience of care is considered from the users' perspective.
- Emphasise continual feedback from patients, families, significant others and carers and constantly aim for improvement and innovation.

11.5 This strategy takes into account these elements and our commitments set out what the Trust will do to deliver this strategy. The following plan identifies the priority areas identified via analysis undertaken to establish the current position of the Trust in relation to the patient experience strategy. This included the use of a value chain analysis, SWOT (Strengths, weaknesses, opportunities &Threats), PESTEL (Political, Economic, Social, Technological, Environmental & Legal) and stakeholder analysis.

11.6 The priority areas have been linked to the appropriate commitment. It is anticipated that the priority areas will be the focus for year 1 of the strategy. It is intentional that no future years have been planned at this stage to enable the strategy to evolve through further consultation and development opportunities.

Action Plan

Action Year 1	year 2	year 3	RAG	Lead Accountability	Outcome	Evaluation
Consult thoroughly on draft strategy inc groups from whom we seldom hear.				Patient Experience Team, Equality and Diversity Manager	Strategy developed. Ratified by CME/Trust Board	Audit trail
Launch & promote Patient Experience Strategy across ESHT, local partners and commissioning groups.				Executive Board, Non-Exec Directors. Dir of Nursing. Patient Experience Steering Group PESG,Dir of Nursing, Non Exec Director	Patient Experience Strategy embedded from “community to ward to board”	Evidence within minutes of notes and local action plans.
Comprehensive Action Plan based on 8 commitments established through engagement and consultation with all relevant stakeholders				PEXP steering Group	Action Plan established , resources identified	Evidence of plan
Appropriate Key performance indicators (KPI) which reflect patient experience and are evidence based agreed with relevant stakeholders.				PEXP Lead, PSCIG	KPI agreed with commissioners and embedded across continuum of care	
Establish shared values with ? set of behavioural standards				Practice Development Team, L&D, HR, JSC, LiA group	Values reflected through system part of all PDR	Audit

12. Communication of strategy

12.1 The strategy will be communicated via the following methods

- A thorough consultation (with particular attention to groups we seldom hear from).
- Celebration and Launch event followed by 3 month intensive awareness raising
- Published on Trust Intranet and External Website
- Trust wide action plan developed by a coordination group.
- Directorate and individual services will have own action plan (see template – appendix 4)
- Circulation to all key external stakeholder groups.
- Strategy should be part of PDR, Recruitment, Trust Induction, team or area meetings, forums (including patient groups).
- Patient Experience Champions will lead implementation alongside ward / team leads
- Public engagement will continue including Media coverage
- Publication of supporting paper

13. Monitoring and Evaluation

13.1 The aim of this strategy is to have one overarching plan that is coordinated and implemented through the Patient Experience Steering Group but has sign up at the highest levels within the organisation and with all our stakeholders locally. Updates on the progress of the action plan for this strategy will be monitored, evaluated and discussed monthly at the Patient Experience Steering Group (PESG) and reported onto staff, Quality and Safety Committee, Therapy Nursing and Midwifery Group (TNMAG) and Clinical Management Executive. There will be a formal annual report.

13.2 At the mid-point in the time line we will subject the delivery progress and any exceptions to an external peer review in collaboration with the England Centre for Practice Development.
www.canterbury.ac.uk/health/EnglandCentreforPracticeDevelopment/Home.aspx

13.3 Commitment no 1 emphasises that everyone within the organisation shapes patient experience in some way. With this in mind Personal Development Reviews / appraisals will take into account Patient Experience and so will monitor this at an individual level.

13.4 This is a live document and will be updated in light of national guidance and local need. The Patient experience steering group will be responsible for this and for liaising with stakeholders to continually seek additional perspectives.

14. References

Bate P, Robert G (2006). ‘Experience-based design: from redesigning the system around the patient to co-designing services with the patient’. *Quality and Safety in Health Care*, vol 15, pp 307–10.

The Beryl Institute (http://www.theberylinstitute.org/) last accessed 10th January 2013

Care Quality Commission Essential Standards of Care (2010) London: Care Quality Commission.

Care Quality Commission (2009) Investigation into mid Staffordshire NHS Foundation Trust. London: Care Quality Commission

Charmel PA, Frampton SB (2008) ‘Building the business case for patient-centred care’ *Healthcare Financial Management* March, vol 62(3), pp 80-5

Chapman and Lane (2010) Treat Me Fair, Treat Me Equal, Treat Me Right. East Sussex Hospitals NHS Trust.

Coulter, A, Fitzpatrick, R and Cornwell, J (2009) The Point of Care Measures of patients’ experience in hospital: purpose, methods and uses. Kings Fund.

Davies, E.A, Meterko, M.M, Charns, M.P., Nealon Seibert, M.E and Cleary P.D (2011) Factors affecting the use of patient survey data for quality improvement in the Veterans Health Administration. *BMC Health Services Research*, 11:334

DiGioia A 3rd, Greenhouse PK, Levison, TJ (2007) ‘Patient and family-centred collaborative care: an orthopaedic model’ *Clinical orthopaedics and related research*. Oct; vol 463, pp 13-9.

Department of Health (2012) *The NHS Constitution for England. London.* Department of Health. Available from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961 (accessed 4/1/2013)

Department of Health (2012b). Transforming care: A national response to Winterbourne View Hospital – Department of Health Review: Final Report https://www.wp.dh.gov.uk/publications/files/2012/12/final-report.pdf Last accessed 9th January 2013

Department of Health (2012c) Patient Experience Framework. Available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132786 Last accessed 13th January 2013

Department of Health (2011) NHS Operating Framework (2011) The operating framework for the NHS in England 2012-13. London. Department of Health.

Department of Health (2010) The NHS Constitution for England. London: Department of Health. Available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113613

Department of Health (2010b) National Patient Choice Survey, England – February 2010. Available at: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_116958

Department of Health (2010c) Equity and Excellence: Liberating the NHS. London. Department of Health

Department of Health (2008) High Quality Care for all: NHS Next Stage Review Final Report. Department of Health, London. Available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

East Sussex LINk (April 2012) Dignity and Nutrition Report http://www.thecountylink.net/upload/ESHTNutrition&DignityReportApril2012FINAL.pdf

East Sussex LINK (December 2011) Leaving Hospital Report http://www.thecountylink.net/upload/LeavingHospitalReportFinalJan2012.pdf

Fitzsimons, B & Wright, K (2012) Hospitals Pathway Programme – Lessons Learned. London: The King's Fund, December 2012. Available at http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/hospital-pathways-programme-dec12.pdf Last accessed 10/1/2013

Francis R (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Executive Summary. London: The Stationery Office. http://cdn.midstaffspublicinquiry.com/sites/default/files/report/Executive%20summary.pdf Last accessed 18th February 2013.

Goodrich J, Cornwall J: Seeing the person in the patient. The Point of Care review paper London: The King's Fund; 2008 http://www.healthissuescentre.org.au/documents/items/2010/05/319001-upload-00001.pdf

HMSO (2009) The Health Act 2009. London. The Stationary Office.

HMSO (2009b) The Care Quality Commission (registration) Regulations 2009. London. http://www.legislation.gov.uk/uksi/2009/3112/contents/made

HMSO (2008)Health and Social Care Act 2008 available at http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/HealthandSocialCareBill/index.htm

HMSO (2007) Local Government and Public Involvement Health Act 2007. Available at http://www.legislation.gov.uk/ukpga/2007/28/pdfs/ukpga_20070028_en.pdf

HMSO (2006) National Health Service Act 2006 http://www.legislation.gov.uk/ukpga/2006/41/contents

Kings Fund (2012) Anticipating the Francis Enquiry: available at http://www.kingsfund.org.uk/projects/anticipating-francis-inquiry-report?gclid=CL2jyqPcurQCFcjKtAodXj8ANA last accessed 27 Dec 2012

Kings Fund and Kings College London (2011a) What matters to patients' Main report. http://www.institute.nhs.uk/images/Patient_Experience/Final%20Project%20Report%20pdf%20doc%20january%202012.pdf. Last Accessed 10th January 2013

Kings Fund (2011b) Transforming our health care system. London: Kings Fund

Kings Fund (2010) Improving patients' experiences: an analysis of the evidence to inform future policy development (March 2010).

Kitson, A.L, Rycroft-Malone, J, Harvey, G, McCormack, B, Seers, K and Titchen, A (2008) *Evaluating the successful implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges*. Implementation Science , **3**:1 http://www.implementationscience.com/content/3/1/1

National Institute for Health and Clinical Excellence (NICE) Patient experience in adult NHS services: improving the experience of care for people using adult NHS services (2012) Available at http://www.nice.org.uk/cg138 Last accessed 13th January 2013.

National Institute for Health and Clinical Excellence (NICE) Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: Costing Report (2012b). http://www.nice.org.uk/nicemedia/live/13668/58360/58360.pdf Last accessed 10th January 2013.

National Pensioners Convention (NPC) Dignity Code (2012) available at http://npcuk.org/wp-content/uploads/2011/11/NPC-Dignity-Code.doc Last accessed 13th January 2013

NHS Confederation (2010) *Feeling better? Improving Patient Experiences in Hospital*. London. http://www.nhsconfed.org/Publications/Documents/Feeling_better_Improving_patient_experience_in_hospital_Report.pdf (accessed 4/1/2013)

NHS Commissiong Board (2012) *Compassion in Practice: Nursing, Midwifery and Care Staff. Our Vision and Strategy (2012)*: London: NHS Commissioning Board.

NHS Commissioning Board (2012b*) Everyone Counts: Planning for Patients 2013/14.* London: NHS Commissioning Board.

NHS information Centre (2012) Data on written complaints 2011-2012 https://catalogue.ic.nhs.uk/publications/patient/complaints/data-writ-comp-nhs-2011-2012/data-writ-comp-nhs-2011-2012-rep.pdf (accessed 6/1/2012) Health & Social Care Information Centre, Workforce and Facilities Team.

Picker Institute (2009) what matters to patients http://www.pickereurope.org/

Robert, G, Cornwell, J, Brearley, S, Foot, C, Goodrich, J, Joule, N, Levenson, R, Maben, J, Murrells, T, Tsianakas, V and Dick Waite (2011) What matters to patients'? Developing the evidence base for measuring and improving patient experience. Project Report for the Department of Health and NHS Institute for Innovation & Improvement. Available at http://www.institute.nhs.uk/images/Patient_Experience/Final%20Project%20Report%20pdf%20doc%20january%202012.pdf Last accessed 10th January 2013

Robert, G & Cornwell, J (2011b) What matters to patients'? Policy Recommendations for the Department of Health and NHS Institute for Innovation & Improvement.

Rycroft-Malone J, Seers K, Titchen A, Harvey G, Kitson A, McCormack B. (2004) What counts as evidence in evidence-based practice? Journal of Advanced Nursing. 47:81–90

Appendices

1. Consultation Summary Table
2. Patient Experience Strategy Mapping Summary Table
3. Focus Group Supporting Paper
4. Team Planning Sheet
5. NICE Patient Experience Quality Standards
6. Equality Impact assessment (not yet completed 10/1/2013)

Appendix 1

Consultation Summary Table

This strategy has been developed in consultation with the groups and/or individuals in this table

Name of Individual / Group	Title	Date
Service User Focus Groups		October 2012
Alice Webster	Director of Nursing	Ongoing
Patient Experience Steering Group	Mixed group	24.1.13 21.1.13 cx electronic feedback requested
Practice Development Team	Professor Jan Dewing	Ongoing
Charles Ellis	Non-Executive Director	
TNMAG membership	ESHT TNMAG	18.12.12 & 22.2.13
Patient Safety and Clinical Improvement Group	ESHT PSCIG	11.1.2013
Compassion in Care Conference Attendees	Various members of public and staff	1.2.13
National Association of Educators in Practice Conference	Mixed Academic / Practice based delegates	2.3.13
Clinical Management Executive (CME)		25.2.13
Quality and Standards Committee		12.3.13
Staff BME Network	Sent “virtually” 1.3.13	
ESHT Age and Health Steering Group		25.2.13
Wheelchair Users Group		22.2.13
Improving the Patient Experience workshop (Learning and Development)		31.1.13 14.2.13
Respond Academy (St Leonards)		5.3.13
Staff LGBT staff network		26.2.13
Practice Development Team		Ongoing
Patient Experience Champions	40+ individuals within trust	Ongoing 27.3.13
Therapy Leads	Michelle Connell Abigail Turner	25.1.13 tbc
Workforce Development	Lorraine Mason	14.2.13
Learning & Development	Mike Bailey Jenny Lloyd- Lyons	14.2.13
Health Trainers	Claire Ledwith	18.3.12
Equality and Diversity Team	Jourdan Durairaj	2/1/13
Listening in Action	Jeanette Williams LiA Values Group	23.1.13
Exec Director	Dr Amanda Harrison	1.3.13
Exec Director	Dr David Hughes	4.3.13
	Dr Alesia Moulton- Perkins	4.3.13

Occupational Health	Christian Lippiatt / Paula Hunt	5.3.13
Health Visitors *Travellers	Melissa Kerr	26.3.13
Chairman	Stuart Welling	28.3.13
ESHT Website		Ongoing
Joint Staff Comittee		18.4.13
Maternity group	TBC	

Appendix 2

Patient Experience Strategy Mapping Summary Table

ESHT Patient Experience Commitment	The 6c's (Compassion in Practice)	ESHT aims	ESHT Objectives	NHS Constitution	NHS Values	CQC essential standards of care	NICE quality Standards (QS15)	NHS Patient Experience Framework	NHS Operating Framework (Domain 4)
1.To promote the concept that everyone, in any role, helps shape patient experience.	Care Compassion Communication Competence Courage Commitment	1,4,6	3,5,6	✓	1,2,3, 4,5,6	Outcomes 1,7,10,12,13, 14,17,21	2,3	1,7	✓
2. To continue developing compassionate, caring, person centred cultures within the Trust where *all* patients/families and staff are valued and treated with, dignity and respect.	Care Compassion Communication Competence Courage Commitment	1,2,3, 4,5,6	1,2,3,4,5 6,8	✓	1,2,3, 4,5,6	Outcomes 1,2,4,7,8,12, 13,14,16,17, 21	1,2,3,4,5,6,7, 9,10,11,12,1 3,14	1,2,3,4 5,6,7,8	✓

ESHT Patient Experience Commitment	The 6c's (Compassion in Practice)	ESHT aims	ESHT Objectives	NHS Constitution	NHS Values	CQC essential standards of care	NICE quality Standards (QS15)	NHS Patient Experience Framework	NHS Operating Framework (Domain 4)
3.To get better at delivering the fundamentals of a good patient experience	Care Compassion Communication Competence Courage Commitment	1,4,5,6	1,2,3,4,5,7	✓	1,2,3, 4,5,6	Outcomes 1,2,4,5,6,7,8, 9,10,11,12,14,21	1,2,3,4,5,6,7, 9,10,11,12,13,14	1,2,3,4 5,6,7,8	✓
4. To improve how we find out what matters to you.	Care Compassion Communication Competence Courage Commitment	1,4,6	3,4,5,6,7,8	✓	1,2,3 4	Outcomes 1,2,4,5,6,8, 16,17,21	5,6,7,8,13	1,2,5,6	✓
5. To learn from listening to you and then share with you,	Communication					Outcomes	6,7,9,13,14	3.	

ESHT Patient Experience Commitment	The 6c's (Compassion in Practice)	ESHT aims	ESHT Objectives	NHS Constitution	NHS Values	CQC essential standards of care	NICE quality Standards (QS15)	NHS Patient Experience Framework	NHS Operating Framework (Domain 4)
everyone in the organisation and others, the lessons of what is going well and what we need to do to improve and innovate.	Competence Courage Commitment	1,4,6	3,5,6,7,8	✓	2,4,5	1,4,16,17,21			✓
6. To improve staff experience	Care Compassion Communication Competence Courage Commitment	1,2,4,6	1,2,3,5,6	✓	1,2,3, 4,5,6	Outcomes	1,2,3	1.	✓
7. To reduce bureaucracy, increase efficiency in order to increase the amount of time we have to provide and	Care Communication	1,2,3,4	1,2,3,5,7,8	✓	2,4,5	Outcomes	12	3, 8.	✓

ESHT Patient Experience Commitment	The 6c's (Compassion in Practice)	ESHT aims	ESHT Objectives	NHS Constitution	NHS Values	CQC essential standards of care	NICE quality Standards (QS15)	NHS Patient Experience Framework	NHS Operating Framework (Domain 4)
improve your care experience.	Competence Commitment								
8. To work more effectively with our partners locally and nationally to improve the way your care is planned and delivered	Care Communication Competence Courage Commitment	1,4,5	1,2,3,4,5,7,8	✓	1,2,4,5,6	Outcomes	9,11,12,14	2,5,6,7	✓

Key to Mapping Summary Table

✓= that the commitment supports the guideline / policy in a general sense (access actual document for further details)

ESHT Aims are to deliver patient centred care by:

1: Making safe patient care our highest priority.
2: Using our resources efficiently and effectively for the benefit of our patients and their care.
3: Ensuring our services are clinically and financially sustainable.
4: Improving and enhancing patients' experiences and clinical outcomes.
5: Working in partnership to meet the needs of our local population.
6 :Continuously developing our services and our staff.

ESHT Objectives are to:
1. Provide high quality, innovative and accessible emergency care.
2. Provide high quality, innovative and accessible elective care.
3. Revolutionise services for older people and those with long term and complex conditions through the provision of integrated services.
4. Deliver the right care in the right place at the right time by working in clinical networks and other partnerships.
5. Communicate effectively with our patients, our staff, our community and our partners.
6. Maintain and develop a skilled and motivated workforce.
7. Realise the benefits from our estate and IT infrastructure.
8. Drive productivity and efficiency and, where appropriate, maximise our market share.

NHS Values

1. Respect and Dignity
2. Commitment to quality of care
3. Compassion
4. Improving Lives
5. Working together for patients
6. Everyone counts

NICE Quality Standards (see appendix 6)

NHS Patient Experience Framework

1. Respect for patient-centred values, preferences, and expressed needs
2. Coordination and integration of care
3. Information, communication, and education
4. Physical comfort
5. Emotional support
6. Welcoming the involvement of family and friends
7. Transition and continuity
8. Access to care

Care Quality Commission Essential Standards of Quality and Safety

CQC essential standards of quality and safety
www.cqc.org.uk/content/essential-standards-quality-and-safety

Involvement and Information

Outcome 1: Respecting and involving people who use services
Outcome 2: Consent to care and treatment
Outcome 3: Fees

Personalised care, treatment and support

Outcome 4: Care and welfare of people who use services
Outcome 5: Meeting nutritional needs
Outcome 6: Cooperating with other providers

Safeguarding and safety

Outcome 7: Safeguarding people who use services from abuse
Outcome 8: Cleanliness and infection control
Outcome 9: Management of medicines
Outcome 10: Safety and suitability of premises
Outcome 11: Safety, availability and suitability of equipment

Suitability of staffing

Outcome 12: Requirements relating to workers
Outcome 13: Staffing
Outcome 14: Supporting workers

Quality and management

Outcome 15: Statement of purpose
Outcome 16: Assessing and monitoring the quality of service provision
Outcome 17: Complaints
Outcome 18: Notification of death of a person who uses services
Outcome 19: Notification of death or unauthorised absence of a person who is detained or liable to be detained under Mental Health Act 1983
Outcome 20: Notification of other incidents
Outcome 21: Records

Suitability of management

Outcome 22: Requirements where the service provider is an individual or partnership
Outcome 23: Requirement where the service provider is a body other than a partnership
Outcome 24: Requirements relating to registered managers
Outcome 25: Registered person: training
Outcome 26: Financial position
Outcome 27: Notifications – notice of absence
Outcome 28: Notifications – notice of changes

Appendix 3

Supporting Paper 1: Patient Experience Strategy Focus Groups

"What Matters To You, Matters to Us"
Engaging Service Users to Inform our Patient Experience Strategy.

Background Paper

Professor Jan Dewing

Head of Person-centred Research & Practice Development

East Sussex Healthcare NHS Trust/Canterbury Christchurch University Kent

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Simon Wilson

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Abstract

Focus groups were used as one way in achieving more meaningful consultation with patients and service users. The groups formed one part of a multi-method approach to collate evidence to shape a new Trust wide patient experience strategy. Six groups were held and alongside this, data analysis from recently held groups with people who have learning disabilities was also included. Participants were asked about “what patient experience meant to them, what good experiences they had had of Trust services as well as how things could have been better”. Participants had plenty of experiences about using services, some very positive however many fell short of their expectations and what the organisation aims to deliver. Following analysis, the major and minor themes were identified. The themes are discussed and their implications for the patient experience strategy explored. The process of engagement through focus group methodology is also reflected on. Finally, recommendations are made for undertaking similar work in the future.

Keywords: Patient Experience, Experience Based Design, Focus Group, Facilitation, strategy, Service User Engagement.

Note: This background paper has been written in the form of an academic publication as it is our intention to demonstrate rigour in regards to how local patient experience data has been used to shape the formation of the Patient Experience Strategy and because we aim to publish this work.

Introduction

There has been an increasing recognition of the rights of patients and other service users to participate in how health and social care services are designed, developed and evaluated. New responsibilities emerging from key government legislative and policy initiatives have placed a requirement on organisations to consult with service users (National Institute for Health and Clinical Effectiveness, 2010). As a result, service users are being asked more and more to take part in the planning, provision, and evaluation of services. This has created increased greater interest in what works in participation and why. In preparation for developing a patient experience strategy in one NHS Trust in the south coast region of England, a number of initiatives were undertaken that would ensure patient and service user experience was central to the strategy focus and content. This paper presents one of these initiatives; participation of patients and services users through focus groups.

Background

Up until the last 20 years, according to Beresford (2001), health and social care provision was largely shaped by politicians, managers, academics, planners and occasionally practitioners, with service users and citizens generally having little or no say. Now there is a mass of policy that aims to shape patient and service user involvement. Explicit requirement for service user participation includes, amongst others, the White Paper Our Health, Our Care, Our Say (DH, 2006); the Valuing People White Paper for people with a learning disability (Secretary of State for Health, 2001); the National Service Frameworks (NSFs) for older people (DH, 2001); for people with mental health problems (DH, 1999) and users, including older people, in care long term conditions (DH, 2005), and up to the revised NHS Constitution (DH 2012) and the Nursing and midwifery strategy for England (NHS Commissioning Board,2012).

Methodology/Approach

Involving patients in service improvements through listening and responding to what they say has, in theory, played a part in the evaluation and redesign of healthcare in recent years. Over the last five years, patients and other service users have seen increased attention put on user experience and specifically on their experience of care and service use. However, as Bate and Robert (2006) argue this attention has not necessarily resulted in meaningful dialogue or outcomes. Bate and Robert also propose that the exploration of user experience has not been systematic enough, nor has the information or data obtained been used as effectively as it needs to be. Partly, as a response to this lack of rigour, design science is becoming an emergent discipline within healthcare. Within this science, experience based design is, in particular, growing in prominence. Experience Based Design (EBD) as a methodology, originates from work by Bates and Robert (2007) and has been used in global industry for many years. EBD has taken principles and methods from other paradigms such as phenomenology and ethnography. In healthcare, EBD can be regarded as an extension of current participatory approaches and has more recently been used by The Kings Fund and also by the NHS Institute of Improvement and Innovation in their experience-based design (EBD) programme which aims to bring patients and staff together to improve care and redesign services.

Features of EBD

EBD is a user-focused design process with the goal of making user experience accessible to the designers, to allow them to conceive of designing experiences rather than designing places or services. This means that the traditional view of service improvement is challenged in several ways. Managers and Executives in healthcare need to conceive themselves as designers and ensure that they have designer knowledge and skill set; then the designers must place user experience at the centre of the (re)design process and the service user as a passive recipient of a service needs to give way to a position that places users as central to improvement and innovation processes. Knowledge held by patients and other users is unique and is of at least equal value of other forms of knowledge and data (Barnes 2005; Bate and Robert 2006). This implies that user knowledge gained through experience becomes a form of evidence or data that must be used to the maximum in the (re)design work (Rycroft-Malone et al 2004).

Experience is defined as ‘‘how well people understand it, how they feel about it while they are using it, how well it serves its purpose, and how well it fits into the context in which they are using it’’ (Bate and Robert, 2007 p24). This is qualitatively different from attitudes or satisfaction which traditionally has been the way in which patient care was evaluated. The aim of EBD is to identify the key moments and places (moments of truth or touch points) where people come into contact with the service and where the patient’s subjective experience is shaped (Gage and Kolari 2004). This is done in order to establish where the desired emotional and sensory connection with service providers needs to be established. Once this is known the EBD approach requires working with the people who deliver and manage the key moments and touch points in the journey to focus more on designing experiences rather than processes. There is generally four phases in approach: capturing experience through stories; understanding experience; improving experience and measuring improvement. In this approach the use of patient stories and therefore skills in collecting and analysing stories is vital.

Focus groups

In the organisation, there was a good understanding of the work that has been done nationally on patient experience and what matters to patients (NICE, 2012; NPC 2012). However, locally, there was a lack of qualitative patient experience evidence; most data collected was in the form of quantitative metrics and complaints. After some discussion, it was agreed that patient experience data was needed and that focus groups were one way of achieving this. Focus groups are an approved research method to understand current experiences in care delivery, to inform continuous improvement and redesign of services and help professionals reflect on their practice (Coulter et al,2009).

Focus groups are guided discussions that require skilled facilitation to ensure discussions remain focused and all participants can contribute as they wish. They vary in size but frequently involve between six to ten participants. Prompts and questions are used to guide the discussion which is recorded, transcribed and systematically analysed. Participants often ‘spark off’ one another to produce in depth and less predictable data.

This type of evidence can be useful for exploring experiences and also “for identifying the cultural norms of specific groups” that are seldom heard, such as people from minority ethnic groups (Kitzinger,1995). This method can also be suitable for people with limited literacy (Coulter et al, 2009), however there are limitations which need to be considered. Focus Groups are less sensitive to variations in opinion (particularly if incongruent with the general feel of the group) than one to one interviews. Participants may be influenced by more dominant members of the group. The moderators or facilitators need to be skilled in this method and therefore in group processes and it can often take a number of supporting people to make a focus group work well. Finally, focus groups tend to generate a lot of data and the transcription and analysis requires resourcing and can be time consuming.

Methods

We decided on the use of focus group to shape our EBD enquiry, as this collective approach to gathering views and perceptions fitted well with the overarching paradigm of Patient Experience, i.e. listening, respecting people’s views, shared decision making as well as central policy “putting the patient at the centre of everything we do”. Although not part of this paper, the findings from the groups were also mapped against other local qualitative and qualitative patient and service user data such as compliments and complaints. In addition we used data collected through a recent user engagement project for people with learning disabilities in the county (Chapman and Lane, 2010). This project had four focus style groups across East Sussex with 53 people (including family /carers of people with learning disabilities). We included this data because it was an opportunity to frame the findings of our work with another similar piece of work which was contextually relevant and had similar aims; one of which was to understand what people from a ‘seldom heard’ group in our local community thought was important in terms of patient experience. The experiences of Winterbourne View have highlighted the need to ensure people with learning disabilities and other vulnerable adults’ voices are heard (DH,2012b). In addition by utilising this previous study, it enabled the findings (which were congruent with our focus group findings) to be incorporated within the patient experience strategy

The planning, facilitation, analysis and follow up of the groups were a joint piece of work between the Practice Development Team and the Patient Experience Team in the organisation. The patient experience team promoted the focus groups, recruited the participants, organised venues and provided administrative support. In addition they provided a budget for refreshments and the reimbursement of travel expenses which was seen as important. The practice development team provided the methodological planning, actual facilitation of the focus groups, having done similar work with patients within the Trust before. The systematic analysis of data was done together.

A total of eight focus groups were offered, including a couple of evening sessions. It was important that we should offer some evening sessions in order for people who work, are busy in the day, or who would just prefer to attend in the evening. Recruitment of participants was done through posters and flyers and also by contacting those who had stated on return of a recent inpatient survey that they would be happy to be contacted to work on service development issues. The focus groups were also publicised with the public at the Trust's annual general meeting. Potential participants were contacted via email and a few who had offered contact telephone numbers were contacted by phone. At this point an invitation was offered and information was provided about the project, what was involved and that the project was the basis of the developing an organisation wide patient experience strategy. Due to low uptake for a couple of the offered sessions, 6 focus groups and 1 "one-to-one" interview took place over a period of 1 week on two separate days, in four locations across the Trust. There were 23 participants in total with 15 women and 8 men taking part. Participants were predominantly white British, and with a wide age range from early 20's - 80's. Clearly, there is need to reach out to more ethnically diverse service users.

Ethics

Formal ethics approval was not required for this work, however attention was given to establish ethical procedures at every stage of the focus group work; e.g. explaining about right to withdraw, anonymity, confidentiality and respect for each others' perspectives. A process was set up to enable individual follow up conversations if they were needed. We also ensured that details of Patient Advice and Liaison Services were available. Prior to each focus group, the voluntary nature of the group was explained, Issues of confidentiality and respect of others' viewpoints were discussed as well as framing the engagement event in terms of its purpose. Much reassurance was required in a couple of the groups that this was not just a tick box exercise and that their views would help to shape strategy locally.

The focus group session was planned around four questions with the aim of understanding the unique perspective of our local population with regards to patient experience.

1. What does the term "good patient experience" mean to you?
2. How could the Trust achieve good experiences for our patients?
3. What helps to achieve this?
4. What do you value the most about a good experience within the Trust?

The duration of focus groups was on average between 60-75 minutes. We built in time for review to learn how participants felt about taking part in this engagement processes. It was central to our principles to do this, given that we were working with EBD approach and were new to this type of work ourselves. We wanted to learn how to make our engagement processes and facilitation skills better in the future. In addition to the formal field notes taken in the group, notes were additionally taken by the moderator, which were useful in summing up, and were also used to frame the debrief after each focus group. Photo elicitation or trigger imagery was used in two of the groups at discretion of the moderator/facilitator. Use of photos helped to gain further perspectives and exploration of meaning where the conversation was slow or where participants needed more time and support to respond. The photo elicitation was positively received and would be a good addition in future groups.

Thematic analysis from typed notes and original field notes was undertaken using a thematic network diagram (Attride–Stirling, 2001) to assist with repeated inductive analysis. Claims, concerns and issues were then used to generate some questions that the strategy would need to answer. Briefly, Claims Concerns and Issues (Guba and Lincoln 1989; Koch 1994) is a method commonly used by Practice Developers whereby stakeholders provide input into an evaluation process in a systematic way (i.e. claims or positive assertions and concerns) with the intent of developing questions (i.e. the issues) that will then be answered through taking action.

Findings

There was a lot of similarity between the different groups in terms of experiences and what they valued with regards to good patient experiences. However, each group did contribute unique perspectives and although they could not be said to be major themes, they were still felt to be important contributions and so were included in the overall findings from the data analysis. The themes emerging from the focus groups were:

1. Communication
2. Attitude and Approach of staff
3. Standards of Care
4. Empowerment & Engagement
5. Learning & Sharing
6. Transition and Continuity
7. Environment
8. Volunteers
9. Administration
10. Food

The themes are listed in order of how prevalent the theme was across the entire 6 meetings. Communication for example, came up regularly throughout the 6 groups and elements of communication were evident within most of the other themes. Attitude and approach of staff, closely related to communication was also frequently discussed. The final four themes listed above, were not so prevalent, but still felt to be important in helping to shape the patient experience strategy.

The themes from “Treat Me Fair, Treat Me Equal, Treat Me Right” (Chapman and Lane 2010), whilst not identical were found to sit well with the themes identified in our groups. (See Table 1 below)

Table 1; comparison of the two sets of focus groups themes

"Strategy" Focus Groups	Treat Me Fair, Treat Me Equal, Treat Me Right" (Chapman and Lane,2010)
Communication	Awareness and skills in communication Support (appropriate) Information
Attitude and Approach of Staff	Happy staff Dignity and respect of them as an person Perceptions of ability Support
Standards of Care	Dignity and respect of them as an person
Engagement & Empowerment	family/carers Involvement (of & themselves)
Learning & Sharing (inc transparency)	Perceptions of ability Involvement (of family/carers & themselves)
Transition and Continuity	Support , information
Administration	(reasonable adjustments)
Volunteers	
Environment	Accessibility, Support, Information
Food	

We will now expand on each of the above themes, illustrate them with extracts from the groups.

1. Communication:

Much discussion was centred on communication. Communication between patients and staff; between staff members; between departments and also between organisations. In addition, many of the other themes in the data analysis also had elements of communication within them. For example, the notion of two way communication was seen as important in the theme on Empowerment and Engagement. When communication was happening well, it was highly valued, however there were many examples within the focus groups of when good communication was not evident and this impacted on the care that our service users described.

There was a feeling that people in departments do not talk to each other and that there was a general lack of joined up working both across the organisation, but also with other agencies.

"communication is at the heart of everything, but as far as I can see its non-existent...... your departments need to talk to one another"

(Strategy Focus Group Participant October 2012)

Good communication skills were highly valued on an individual basis; yet there was a feeling that we could listen to patients (and carers) more effectively.

"I recently was an inpatient myself, and I specifically said that I did not want to be treated by a colleague. This did not happen, and I felt very uncomfortable, not listened to".

(Strategy Focus Group Participant October 2012)

"As a carer I need to be listened to about my daughters care"

(Treat me right, Treat me equal, Treat me fair, Carer 2010)

One participant remarked on the need to be sensitive when breaking bad news.

Having someone to talk to was seen as really important and was reflected across many of the conversations.

There were many instances where communication skills were evident but also where staff of all levels could do better. Ensuring that all staff can speak good English was seen as important. The learning disability groups also picked up on the fact that understanding strong accents can be difficult and posed the question

"was it ok to ask to see someone else with not such a strong accent if you don't understand them?".

Also the importance of good non-verbal skills such as smiling and body language. People with learning disabilities may pick up on these better than verbal cues and help to build a sense of trust.

Furthermore there needed to be more awareness and skills in different methods of communication such as basic sign language e.g. drink, toilet, help, please and thank you. Pain and worry might be also useful additions. The use of appropriate language was also seen as essential when dealing with people with learning disabilities e.g. abstract terms or flippant remarks could lead to anxiety and misunderstanding. Doctors were mentioned as needing to explain procedures in simple terms.

Information needed to be clearer. The learning disability groups felt that we were still not getting information for people with learning disabilities right and that there should be more information on health promotion. Aids such as pictures and models could be put to better effect for people with learning disabilities.

Allowing enough time for good communication was discussed as well as the actual timing of the communication, especially on the need to receive information prior to healthcare intervention and around discharge planning came up. One participant wondered why the hospital discharge information booklet couldn't be sent out with the admission booklet. It was also felt that bus and train time tables should be sent out with appointment letters

More broadly, some participants felt the Trust could do better in terms of how it promoted itself in the community. Specifically mentioned was that information could be better and media releases / news and other information needs to be sent via multiple sources to multiple destinations in the community.

For people with learning disabilities, enabling their supporters to attend appointments and having someone with them at all times (that they trust) was instrumental in facilitating good communication.

2. Attitude and Approach of Staff

The majority of participants articulated the importance of the attitude and approach of staff to a positive experience of care and there were many experiences where staff had demonstrated a compassionate and caring approach.

"being well looked after, visible staff, cared for.. and there is a strong social element to this".

"*staff who listen, love....and there is a friendliness from staff"*

"A friendly welcome and just the way you are spoken to goes a long way".

(Strategy Focus Group Participants October 2012)

The importance of a "*personal touch*" was discussed a few times and there was a recognition that named nurses [or other key workers] was a positive thing and to be encouraged. There was recognition by participants of the importance between patient experience and staff wellbeing / happiness. This was also picked up on in the learning disabilities study. Participants commented on the importance of staff being happy and satisfied with the level of care they are able to provide.

Attitudes of medical practitioners, especially consultants were seen as important and it was mentioned that they also need to be more mindful of their communication skills.

The appearance of professionalism was seen as important and consisted of promoting professional attitudes and practices:

"there is a calmness, it's peaceful and unhurried. Not too many instructions".

(Strategy Focus Group Participant October 2012)

The Dignity and Nutrition LINk report (2012) found much evidence of positive interactions with terms such as" caring attitude, talking softly, friendly, considerate, relaxed and peaceful" being used, however there was some practice that did not appear person centred such as standing over patients whilst assisting them with their food.

Poor experiences were often associated with staff that did not appear to show compassion or were seemingly unhappy and unhelpful:

“the general attitude is poor”

“it’s really important to have someone who is interested in you and your care and not look at you as a number”

“sometimes I think you are just judged on your appearance....”

“I had concerns about a patient and I went and tried to talk to the staff, but they didn’t appear interested”.

(Strategy Focus Group Participants October 2012)

Some general views were expressed about varying levels of professionalism such as the discussion of non-professional topics within earshot (particularly at night) and more specific concerns such as some staff displaying ageist attitudes or talking to people with learning disabilities “like children”. It was important that people with learning disabilities should be “treated for their illness, not their disability”. Patients said they wanted staff to be approachable and to be interested in them as a person. Participants said, *“it is the personal touch that is often missing”.*

The appropriate involvement of family members / carers was highlighted within the learning disability focus groups but this should not be at the expense of involving the person themselves

“talk to me not just my carers”.

. (Treat me right, Treat me equal, Treat me fair, Participant 2010)

3. Standards of Care

Good clinical skills were deemed to be an essential part of a positive experience of care. There were many examples of “*excellent care”* for example, A&E, MAU, ITU and other ward areas. However, there were clear inconsistencies in the standards of care that people receive at different times or at different places and with different staff members across our Trust.

For example, not cleaning essential equipment before or after use was noted. Many participants equated standards of care with nursing:

“nursing standards on some wards need to improved”

(Strategy Focus Group Participant October 2012)

The recent Dignity and Nutrition report by East Sussex LINk (2012) highlighted that all patients should encouraged and supported to wash their hands prior to meal times.

The role of strong leadership was clearly recognised by these participants as is the need to get the essentials of care right.

"need to go back to basics, reintroduce the matron and ensure that her presence is felt".

"I think that the sister has a really important role in the hospital and the named nurse system can work well".

(Strategy Focus Group Participants October 2012)

There was an impression from some participants that some vulnerable clients were not having their needs met. Concerns regarding the quality of Interactions with patients with special needs have been reported elsewhere (East Sussex LINk, 2012). There was a feeling that some staff were not well enough equipped to deal with some patients such as those living with dementia.

"I feel that there needs to be specialist nurses who are skilled and able to deal with patients with dementia for example. I notice how different these patients are treated".

(Strategy Focus Group Participant October 2012)

Feedback from the learning disabilities group supports this in that some people felt that their levels of privacy were not always respected and upheld as there was possibly an assumption that they would not mind a lack of privacy because of their level of understanding.

There was a feeling that staff should be visible and not *"hidden behind the nurses' station",* On the subject of "hourly rounds" there was some positive feedback, but one participant felt that they were a "*tick box exercise"*. This may of course be related to the manner in which rounds were explained and/or carried out and of course the patient's perception of their importance.

While participants recognised the need for agency staff, there was a general feeling that this should be minimised as it felt that they did not know the patients. Again, this highlights the importance of individualised and continuity with care.

Having sufficient access to services was a common theme – with access to rehabilitation mentioned on a couple of occasions. One participant stated that if you need it, it should be available, "you shouldn't have to ask for it".

4. Engagement and Empowerment:

On the level of engagement with their own care, one lady in the learning disability groups stated that she was often forgotten because she was quiet and did not make a fuss. Also there was a request that

"*It's ok to ask me what I can do for myself. It's important for me to be useful".*

(Treat me right, Treat me equal, Treat me fair, Participant 2010)

Making one's own decisions were important, and building on the theme of communication explaining things clearly was helpful in achieving this.

The role of supporters was a major theme in the learning disability focus groups with people stating how important these relationships are. Allowing flexible visiting and support arrangements and respecting these relationships were seen as essential.

"don't undermine trust between carer and LD person, it is crucial to good healthcare being accessible".

(Treat me right, Treat me equal, Treat me fair, Participant 2010)

Regarding the actual focus groups themselves some participants were sceptical that such engagement activities would lead to changed due to it being just a tick box exercise or because of financial restrictions. Scepticism has been reported in other studies (Cross, 2007). However the general feeling was that they were happy to be involved if it led to positive change.

Meeting other service users appeared to create a sense of safety to explore and share experiences of care. This was viewed positively and a number of participants in our focus groups highlighted the importance of being listened to.

"Really good to provide a space for people to feely air their views – being able to speak and be heard is such a valuable thing and therapeutic in itself"

(Strategy Focus Group Participant October 2012)

There was some confusion as to what the purpose of our focus group activity was, some thought that the primary aim was to express their views about personal issues. A number of participants commented on the importance of clarifying purpose of any engagement activities.

"Quite interesting, but it was not what I thought it would be. A lot of the matters put forward were very true, so let's hope something useful comes from the meeting. I would have liked to have had another meeting to tackle the subject of the way things work from being an outpatient to an inpatient and what help is available after. Look forward to reading the report sometime".

(Strategy Focus Group Participant October 2012)

There was an understanding across the groups of the need to importance of engaging with seldom heard groups. Ways that this could be done were suggested and one of the major points was the need to think creatively and utilise all media to do this. It was mentioned that there are already a lot of forums in the community and it is making the links that is important. One of the main conclusion from "Treat me fair, Treat me equal, Treat me right" was to make "meaningful involvement structures and sustainable links with existing groups to compliment their [the trusts] involvement efforts" as well as developing better communication skills awareness and appropriate information.

The challenge of accessing people who live at home was discussed but did not reach any practical solutions, although the potential role of technology was mentioned. Clearly though, various methods applied in a systematic way need to be adopted if all groups are to be heard and given opportunity to comment on care received and service development issues.

Patient representation within the Trust was discussed with the question of whether there was patient representation at board level. We were able to reassure that there was indeed and explained about our relationship with LINks. We were fortunate to hear from a service user who was currently taking part in an expert patient group. This was a group of service users from a discrete service, who had formed to share experiences, support each other and help develop the service from the patient's perspective. Whilst they were in their early days, they had already formed a stable group and had started on some shared goals such as fund raising and setting up further support networks.

Utilising the interests and skills of participants was discussed and a couple of participants offered to be involved in areas that particularly interested them such as IT or patient literature. Many commented that they would like to read and comment on the strategy during its consultation period. Participants did not want the strategy to be blocked due to financial constraints. There was a view that a patient experience strategy might be 'blocked' rather than welcomed by senior managers.

Various methods for seeking feedback were explored and what was clear was the need to develop a variety of different methods to capture patients' experiences. One participant mentioned an open feedback book on one ward, where you could add your feedback and read what other people had written. This patient felt empowered through being able to do this. The same patient described other positive experiences of care but where there has not been any apparent mechanism for feeding this back.

5. Learning & Sharing (including transparency)

The participants were asked about learning from positive experiences. One woman, a teacher, talked about her experience of frequent peer review. She expressed how allowing staff the chance to not just hear about other services but experience it was important:

> *"There needs to be opportunities to not just hear about successes within the trust, but for those relevant people, an opportunity to see and if possible experience it for themselves"*
>
> (Strategy Focus Group Participant October 2012)

Many participants had experienced healthcare elsewhere that they used as comparators to current services locally. There was a suggestion that we could learn by looking out as well as in and get ideas about providing better patient experiences. Many participants liked the idea of the friends and family test, and felt that it could be used to identify consistently high performing services and then going and looking and finding out why; a form of appreciative inquiry.

“I really hope you can find a way to learn from positive experiences”

(Strategy Focus Group Participant October 2012)

Participants had strong views about how the patient experience strategy needed to be developed; once written in a draft version it needed to be shared in true consultation with stakeholders including service users. Thus patients were suggesting that consultation needs to be a process rather than a one off event. More broadly, patients said that the organisation needed to get better at the feedback process. Patients said they wanted to be told what the information they volunteer is to be used for, how it will be used, and where they can see the outcomes. Participants commented that events such as the focus groups helped reduce fear in giving feedback. Although a note of caution was expressed:

“people who are awaiting a procedure or who are receiving care won’t complain due to fear of repercussions”

(Strategy Focus Group Participant October 2012)

Finally, for this theme, patients wanted staff to get better at apologising when things don’t go so well.

“I think there is a fear of just saying sorry, apologising, but it goes a long way”

(Strategy Focus Group Participant October 2012)

The Trust does have a “being open” policy but The Government in its response to the NHS Future Forum in June 2011, stated that it will introduce a “Duty of Candour”, a new contractual requirement on providers of NHS funded care to be open and transparent with patients and service users in admitting mistakes(NHS Operating Framework (DH 2011b),p.18).

6. Transition and Continuity

Whilst the NHS Constitution pledges that we will make the transition as smooth as possible when patients are referred between services, and to include patients in relevant discussions, patients said their reality was different.

Our service users perceived the use of lots of agency staff as not helping with regards continuity of care which was seen as a very important part to their experience. Poor handovers were also seen as affecting the patient experience, particularly when agency staff were involved as “they did not know me”.

Participants discussed inconsistencies in care between different shifts, teams or consultants and how this could cause them problems. One woman described how she had become anxious about mixed messages she had got from different consultants with regards to some medications she should be taking post operatively. Communication around discharge planning, was described as rushed with a lack of sharing of information and poor organisation of follow up care mentioned:

"I had a really good experience whilst undergoing my procedure, however there were issues around the whole discharge process. Nobody told me that I was going to be going home, then I was suddenly told you're going. I just felt that I was the person nearest to discharge and they just needed the bed. Once I got home, I felt isolated and felt that I had just been left to drift".

(Strategy Focus Group Participant October 2012)

The Leaving Hospital report from East Sussex LINk (2011) tended to support these findings that people did not feel actively involved in their discharge planning and were given little information. The study stated that there was little written documentation to dispute this fact. Hesselink et al (2012) in a large study (but not conducted in UK) identified that:

1. Healthcare providers do not sufficiently prioritise discharge consultations with patients and family members due to time restraints and competing care obligations
2. Discharge communication varied from instructing patients and family members to shared decision-making
3. Patients often feel unprepared for discharge, and post discharge care is not tailored to individual patient needs and preferences;
4. Pressure on available hospital beds and community resources affect the discharge process.

Our participants felt that things just wound down at weekends and that this affected the continuity of care and their general experience. The participants suggested that a 7 day working week ethos in the Trust might help continuity of care and discharge planning. They also felt it might present opportunities for further business, as well as helping with waiting lists.

"the era of Monday to Friday working has to be left behind, hospitals seem to still work Monday to Friday 9-5. This needs to change. Everyone else is doing this".

(Strategy Focus Group Participant October 2012)

A comment from Treat me fair, Treat me equal, Treat me right" supports this

"it may be we would have been better not to go in on a Friday. So holidays and weekends tend to make for a less resilient service! Again, individual acts of kindness and support make a difference, but after 5pm on a Friday, you do seem to enter the twighlight zone. Everything was resolved the following Monday, when everyone came back, but those two days and three nights were very tough".

(Treat me fair, Treat me equal, Treat me right, Carer 2010)

The use of healthcare passports / health action planning has been developed as a way to facilitate a better understanding of vulnerable people's health needs in order to be able to improve quality of care and patient experience. A couple of participants in the learning disability focus groups stated that the importance of these did not seem to be appreciated.

One "put in drawer, not looked at again" and , in another instance told by ambulance staff "not to bring it, the hospital will find out everything they need to know".

Finally people with long term conditions need ongoing support even if their condition is under control it can still remain a source of worry to them.

7. Administration

There was within the groups a frustration at what was perceived as wastefulness and inefficiency in the Trust, particularly around appointments, waiting lists and looking for medical notes

"Two letters are sent out for each appointment, then you get a phone call. That's three methods of contact and I think, what a waste of money".

(Strategy Focus Group Participant October 2012)

There were suggestions of sending reminders by text (which other healthcare providers do) or possibly email. One person did feel that the appointment system was better than it used to be, but generally people felt that waiting times were too long. There was some discussion that it would help to know what the expected waiting list was or "where you were on the list", and that there should be some honesty and transparency around this. One woman stated that

"Once I got into the system, my consultant, the care was excellent – but to get there... bad communication"

(Strategy Focus Group Participant October 2012)

The subject of making reasonable adjustments for people with learning disability appeared regularly. Time given to people with learning disabilities needs to be reflective of their special needs, such as perhaps allowing them to be first on lists. They talked of struggling waiting for long periods of time for appointments and how there was nothing to do. The only thing to do seemed to be magazines that they could not read.

8. Volunteers

This was not a major theme, however there was a call to ensure that the patient experience strategy reflected the importance of the volunteer role to creating a good patient experience such as welcoming patients and their carers /families, answering phones, administration, supporting teams and even settling fractious children whilst their parents get treatment.

"*above all else... volunteers want to be useful"*

(Strategy Focus Group Participant October 2012)

There was discussion around the potential barriers to developing the potential of volunteers and these were perceived to be issues around access to learning and development, health and safety and often the culture of the area in which they work. Questions were posed by the volunteer as to how the Patient experience strategy might accommodate these issues. The volunteer did talk about assisting patients with their nutrition. This is something that was picked up in the Dignity and Nutrition Report (East Sussex LINk, 2012).

9. Environment

The need to consider the environment as a factor in influencing patient experience was captured in one group. One element was mentioned was the value of outside spaces. However, participants did not expand on this theme greatly.

In the learning disability focus groups "environment" was a more prominent theme. Hospital and outpatient signs could be confusing with too many long words and there was a suggestion that less medical jargon, different colours and even pictures could be used especially for signs such as toilets and exit.

10. Food

The subject of food came up in a couple of the groups, with some apparent inconsistency, and not just in terms of different hospital sites. Food was described as both being "good, you get a couple of choices and "inedible". One participant described losing a considerable amount of weight in hospital and wondered if the Trust was meeting MUST standards. One participant felt that the "red tray" system was a waste of time. She had experienced a fellow patient being given a red tray which she felt was inappropriate

> *I think that people are judged on their appearances, I saw a patient given a red tray for 3 days in a row... and she was able to feed herself".*

(Strategy Focus Group Participant October 2012)

These findings were supported by the East Sussex LINk report on Dignity and Nutrition (2012) that found we need to weight patients more consistently and use the red tray system more appropriately within our organisation. Additional findings of note in this report were that whilst standard diets were well catered for, there needed to be more availability for specialist diets, fruit and snack boxes needed to be more widely advertised. Day rooms could also be utilised more, enabling more social interaction whilst eating if patients wanted.

In summary, the findings from the focus groups show a number of major themes with commonality and a number of minor themes with some variances. Clearly, a limitation of this project is the small number of focus groups that were held and that not all services or groups of service users were represented. However this project has shown that focus group methodology can be a useful way to engage with patients and service users.

Discussion

Positively, there are things about the patient experience that the Trust gets right and does well, this can be seen in other local reports such as those conducted by East Sussex LINk (2012;2011). However, it may be that we do not understand enough about this and therefore are not learning or exploiting their potential. The positive aspects of what we do are in danger of being watered down or negated by inconsistencies in care experiences and on occasion by unacceptable attitudes and communication. Inconsistencies were featured in the LINk report about leaving hospital (East Sussex LINk, 2011).

A recent King's Fund report "What Matters to patients" highlighted that providing a good patient experience is multi-dimensional and is about both the *what* (functions or transactions) and the *how* (relational) of interactions with patients. In 'What Matters to Patients' (Robert, Cornwell et al,2011) one important and consistent finding across the different strands of work was the relative emphasis on the 'relational aspects' of patient experience in comparison to 'functional' (or 'transactional') aspects. The most commonly reported generic themes were:

- feeling informed and being given options
- staff who listen and spend time with patient
- being treated as a person, not a number
- patient involvement in care and being able to ask questions
- the value of support services
- efficient processes

The findings of our local study are congruent with this.

On the issue of communication, patients experienced that the skills of staff were closely aligned with their attitude and the approach. The Trust needs to work harder at embedding the values and practices needed to grow a person-centred culture. It is unacceptable that patients do not feel listened to and this needs to be eliminated. This applies to all professions within the organisation including medical practitioners and engaging *all* in this work in order to develop more caring, compassionate behaviours and increased competency in communication skills will present some challenges. Because of the size of the theme, communication clearly needs to be explicit within the strategy and probably has a number of dimensions to it. The Trust needs to promote this fundamental element of care to all staff and ensure that we help people to do this better more often. Ensuring staff can speak good English is important and whilst this might be easier to do, where staff are employed directly, it might be more difficult to do where agency staff are arranged at short notice. This ability to speak the language competently is important. However, it also prompts questions about how effectively we provide for patients whose first language is not English and how well we enable those who need additional support to communicate. Furthermore related to language we need to Increase individual and organisational capacity for the use of Basic Sign Language and appropriate pictorial information.

It became clear that the patient experience strategy needs to not only be about collecting, analysing and learning from patients experiences but needs to be equally about promoting good patient experiences and central to this are standards of care. One of the significant findings in this project is quite simply the need to be treated with dignity and respect and consequently, the patient experience strategy must at its heart have the aspiration to promote this as central. After all, patients have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff (NHS Constitution 2012).

Patients were also mindful of staff experience. Therefore, any patient experience strategy needs to be complimented and work alongside a staff experience strategy.

"All staff should have rewarding and worthwhile jobs, with the freedom and confidence to act in the interest of patients. To do this, they need to be trusted and actively listened to. They must be treated with respect at work, have the tools, training and support to deliver care, and opportunities to develop and progress".

(NHS constitution 2012 p. 10)

A variety of methods will be needed to ensure every patient has an opportunity to feedback on their experience of care at various or different stages of their journey. It could be argued that not all "data" collection methods should be formal and post intervention, but we should also be able to encompass methods as simply asking mid-intervention "how are we doing so far? ".

The Compassion in Care report (NHS Commissioning Board 2012) requires that measurement should focus on the experience of the person using the service, the outcomes of care, and should be transparent. From our analysis it became clear that for meaningful participation and for user experience to be taken seriously a whole systems approach is needed. Groene et al (2009) asserts that even with organisational commitment, policies may not always be evident at the front line. The nature of the links means organisational change at every level, from senior management to direct and indirect care givers is needed (Wright et al 2006). Kirby et al (2003 p144) set out two further core requirements in a whole systems approach: participation should become part of daily practice, not a one-off event or activity; participation operates at different levels and a wide range of ways is needed through which patients and service users can participate in different types of decision making.

Although it was not our purpose to demonstrate this, it is clear that participant's experiences in our Trust are powerful drivers for patients and users to get involved in service improvement activities. Participants contextualised notions of what is needed regarding wider strategy and service improvement in terms of their own experience.

Bate and Robert (2007, pg 11) talk of the need to discover ways of "*seeing deeper into experience"* and in this regard we did not want to focus too much on a strategy if people needed to explore their own experiences within the focus groups. Indeed it proved a good way of helping people to share and ultimately explore their experiences. To focus purely on the strategy at the expense of peoples personal and emotional "touch points" with our service would have been missing the point of having a Patient Experience Strategy which places importance on *people* and their *experiences* and not just systems and processes.

Participation is more than developing a policy and implementing it. It is about ensuring that all members of an organisation are committed to participation and recognising that it will involve sharing power with service users.

Cultural changes needs to occur throughout the organisation. A massive learning, development and leadership agenda arises to ensure support in developing a more participatory culture. Attention needs to be paid to formal and informal ways of supporting service users to participate. For example, participation can be hindered by structural barriers, such as formal meetings or a lack of technological support. We need to consider how we can avoid practices that may make people feel excluded, and how they can build up capacity among service users and service user organisations. Many barriers can be removed by good planning. Making changes to the system, not simply looking at how to support an individual is generally a better way of removing barriers. Specific strategies may be needed to ensure that the voices of people who are ‘seldom heard’, such as service users from black and minority ethnic groups, and service users with communication difficulties are included.

We also need to know more about how participation is undertaken effectively for all service users, including those who are ‘seldom heard’. Certainly it is clear that traditional engagement techniques are not suitable for people with learning disabilities (Chapman and Lane, 2010). Wilkinson et al (2009) state that there is a need for further emphasis on research into ‘what matters most’ to currently under-represented and “hard to reach groups”. Locally, in one particular group “Learning Disabilities” we may have some degree of understanding, however we need to continue engaging in meaningful ways (Chapman & Lane,2010) and reach out to the many other groups from whom we seldom hear.

As a result of the data analysis from the two sets of focus groups and from the other sources of local patient experience evidence, eight commitments were developed. Once the eight commitments were drafted out they were populated with data from the focus groups and with aims and objectives from a wide range of national policy and other local evidence on patient experience. This mapping exercise was then shared with people in the Trust and refined over a number of rounds until agreement was reached on their content. These commitments and their subsequent objectives have formed the foundation of the patient experience strategy in the Trust. (See table 1 for eight commitments)

We acknowledge that there were a few limitations to the project. The primary one was that we only held a small number of focus groups, so the numbers of patients participating were a very small number compared to the overall numbers of service users across the Trust and not all services were represented. Participants tended to have been inpatients quite recently to the groups taking place. This may have offered a biased perspective or led to a sample of people who accessed services within a similar time period. In terms of the method, some of the richness of the data was lost as hand written notes were taken at the groups rather than audio recordings. In the future this needs to be addressed.

Box 1: Eight Patient Experience Commitments

To promote the concept that Patient Experience is everyone’s responsibility within East Sussex HealthCare NHS Trust, irrespective of role; “I am Patient Experience”.

To continue to work hard at developing compassionate, caring, person centred cultures within the Trust where patients/families and staff are valued and treated with dignity and respect.

To continue to get better at delivering the fundamentals of a good patient experience based on what local service users have told us is important, as well as using local and national guidance on best practice.

To improve and innovate how we find out about your experiences of care/services, making particular efforts to engage with people we seldom hear.

To improve and innovative the way we use what we have learned from listening to you; to share with you, and everyone in the organisation and others, the lessons of what is going well and what we need to do to improve.

To improve staff experience

To continually look for ways to reduce bureaucracy, increase efficiency to increase the amount of time we have to provide and improve your care experience.

To work more effectively with our partners locally and nationally to improve the way your care is planned and delivered

Recommendations for similar work in the future

Future focus groups need to be planned to ensure enhanced representation from the community including those seldom heard. This can be a challenge and creative methods are required to overcome the barriers such as transport, support and facilitation (Chapman and Lane, 2010).

We need to be clearer about the purpose of the engagement activity, possibly think about using more detailed information (written, verbal) prior to the event. We need to ensure that recruitment is fully inclusive and does not bias those who have recently been an inpatient. The geographical spread is important to ensure that we are equitable in our approach. While participants did not take up offer of reimbursement for travel expenses, we must continue to offer this resource. In addition mobile hosting, where we join existing community groups for shared focused discussions should be considered.

Conclusion

Participants contextualised notions of what is needed in terms of wider strategy and service improvement in terms of their own experience. Whilst this was expected, the strength of feeling expressed within the groups required at times quite significant facilitation to keep conversations moving forward to find solutions and enable aspirations to be positively articulated. A balance had to be struck in terms of allowing cathartic exploration of experience whilst finding what are important elements that could inform wider strategy. Service users had felt the process worthwhile and understood what we were trying to do. Service users had felt very positive about the way sessions were conducted. Findings from the two sets of focus groups were used alongside other data evidence in the development of 8 commitments which will form the foundation of the patient experience strategy. The patient strategy will have at its heart the feedback/ local evidence from the community which will be integrated with national policy and guidelines for delivering good patient experiences.

References:

Attride–Stirling, J. (2001) Thematic networks: an analytic tool for qualitative research. *Qualitative Research*. 1(3): 385-405

Barnes, M. (2005). The same old process? Older people, participation and deliberation. *Ageing and Society*, 25 (2): 245–259

Bate, P and Robert G (2007) Bringing User Experience to Healthcare Improvement: The Concepts, Methods and Practices of Experience-Based Design. Oxford: Radcliffe

Bate P and Robert G (2006) Experience-based design: from redesigning the system around the patient to co-designing services with the patient. Quality and Safety in Health Care 1(5) 307-310

Beresford, P. (2001). Service users, social policy and the future of welfare. *Critical Social Policy*, 21 (4): 494–512.

Chapman and Lane (2010) Treat Me Fair, Treat Me Equal, Treat Me Right. East Sussex Hospitals NHS Trust.

Coulter, A, Fitzpatrick, R and Cornwell, J (2009) The Point of Care Measures of patients' experience in hospital: purpose, methods and uses. Kings Fund.

Cross, P (2007) Exploring attitudes towards and experience of the NHS in the NorthWest: A report prepared for the NHS North West by PICKER INSTITUTE EUROPE as part of "Our NHS our Future" review. Available Online at http://pickereurope.org/assets/content/pdf/Project_Reports/NHS_NW_report_for_webmedia__with_covers_.pdf last accessed 9/1/2012

Department of Health (2012) NHS Constitution revised. London Department of Health http://www.dh.gov.uk/health/2012/03/nhs-constitution-updated/ last accessed 4th January 2013

Department of Health (2012b). Transforming care: A national response to Winterbourne View Hospital – Department of Health Review: Final Report. London. Department of Health. https://www.wp.dh.gov.uk/publications/files/2012/12/final-report.pdf Last accessed 9th January 2013

DH (2011a) A Framework for Patient Experience (2011) London, DH. http://www.dh.gov.uk/health/2012/02/patient-experience-framework/ Last accessed 4th January 2013

DH (2011b) NHS Operating Framework 2012/2013. London. DH.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131360
Last accessed 9th January 2013

DH (2006) Paper Our Health, Our Care, Our Say. London. DH
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127602
Last Accessed 9th January 2013

DH (2005) National Service Framework for people with long term conditions. London. DH
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4105361
Last Accessed 9th January 2013

DH (2001) National Service Framework (NSFs) for older people. London. DH
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002951
Last Accessed 9th January 2013

DH (1999) National Service Framework for people with mental health problems. London. DH
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009598
Last Accessed 9th January 2013

East Sussex LINk (April 2012) Dignity and Nutrition Report
http://www.thecountylink.net/upload/ESHTNutrition&DignityReportApril2012FINAL.pdf

East Sussex LINK (December 2011) Leaving Hospital Report
http://www.thecountylink.net/upload/LeavingHospitalReportFinalJan2012.pdf

Gage M, Kolari P. (2004) http://boxesandarrows.com/making-emotional-connections-through-participatory-design/ (accessed 19th December 2012).

Guba, E.G, & Lincoln, Y.S. (1989) Fourth generation evaluation Sage: California.

Hesselink,G., Flink, M., Olsson, M., Barach,P., Dudzik-Urbaniak,E, Orrego, E, Toccafondi, R., Kalkman, C., Johnson, J., Schoonhoven, L., Vernooij-Dassen, M. and Wollersheim, H. (2012) Are patients discharged with care? A qualitative study of perceptions and experiences of perceptions and experiences of patients, family members and care providers. *BMJ Quality & Safety*. Nov 1. 2012.

Groene O et al (2009) 'Is patient centredness in European hospitals related to existing quality improvement strategies?' *Quality and Safety in Health Care*, vol 18, pp i44-i50

Kirby, P., Lanyon, C., Cronin, K. and Sinclair, R. (2003). *Building a Culture of Participation: Involving Children and Young People in Policy, Service Planning, Delivery and Evaluation: Research Report*. London: Department for Education and Skills.
http://www.everychildmatters.gov.uk/_files/BFD4A0EB73C4A69EA0E6E717F0E9E745.pdf. Last accessed 22nd December 2012

Koch, T. (1994) Beyond measurement: fourth-generation evaluation in nursing. Journal of Advanced Nursing 20, 1148–1155

National Institute for Health and Clinical Effectiveness (2012) Patient Experience adults in Adult NHS Services. http://publications.nice.org.uk/quality-standard-for-patient-experience-in-adult-nhs-services-qs15
Last Accessed 9th January 2013

National Institute for Health and Clinical Effectiveness (2010) Patient and public involvement.
http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp last accessed 4th January 2013

NHS Commissioning Board (2012a) *Compassion in Practice. Nursing Midwifery and Care Staff. Our Vision and Strategy.* London: NHS Commissioning Board. http://www.commissioningboard.nhs.uk/files/2012/12/compassion-in-practice.pdf Last accessed 9th January 2013

NHS Commissioning Board (2012b*) Everyone Counts: Planning for Patients 2013/14.* London: NHS Commissioning Board. http://www.commissioningboard.nhs.uk/everyonecounts/ Last accessed 9th January 2013

National Pensioners Convention (NPC) (2012): Dignity Code http://npcuk.org/710 Last accessed 10/1/2013

Picker Principles available at http://www.pickereurope.org/ Last Accessed 9th January 2013

Rycroft-Malone J, Seers K, Titchen A, Harvey G, Kitson A, McCormack B. (2004) What counts as evidence in evidence-based practice? Journal of Advanced Nursing. 47:81–90

Secretary of State for Health (2001) Valuing People White Paper for people with a learning disability.

Wilkinson S, Stockl A et al. (2009) *Surveying hard to reach groups. Final report*. University of East Anglia.

Wright, P., Turner, C., Clay, D. and Mills, H. (2006). The Participation of Children and Young People in Developing Social Care. London: Social Care Institute for Excellence. http://www.scie.org.uk/publications/practiceguides/practiceguide06/files/pg06.pdf. Last accessed 22nd December 2012

Appendix 4

Service / Area / Team / Planning Sheet

e.g. To continuing our work hard at developing compassionate, caring, person centred cultures within the organisation where both patients/families and staff are valued and treated with dignity and respect.

In our team this commitment means:

When we are successful you can expect to experience:

Across the Trust:

In our service you will experience:

The general evidence base we are drawing on includes:

1.

2.

3.

In our service we also draw on this evidence base:

1.

2.

3.

If you want to speak to anyone about this commitment please ask for:

Appendix 5

NICE Quality Standards for Patient Experience (QS15) (part of Clinical Guidelines 138)

Quality statements

These quality statements are from the NICE quality standard on patient experience in adult NHS services in England.

No.	Quality statements
1	Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.
2	Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.
3	Patients are introduced to all healthcare professionals involved in their care, and are made aware of the roles and responsibilities of the members of the healthcare team.
4	Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.
5	Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.
6	Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.
7	Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.
8	Patients are made aware that they can ask for a second opinion.
9	Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.
10	Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.
11	Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.
12	Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.
13	Patients' preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.
14	Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.

Appendix 6

Equality Impact Assessment Form

Equality and Human Rights Analysis (EHRA)

Guidance is appended to this form or click the 'Help' links… Help

Title(s): East Sussex Healthcare NHS Trust Patient Experience Strategy

Aims / Objectives:

- To develop a shared vision and coordinated approach to continuously moving towards better* experience for patients, service users, family, carers, the local population and ESHT staff.
- To develop and enhance the culture of placing quality improvement and innovation of patient experience at the heart of what we do and how we work.
- To set out ESHT commitments to ensure that all our patients' and service users' experiences are based on what matters to them and are of a high clinical standard.
- To work with our executive sponsors to heighten the profile and value of patient and service user experience within ESHT from 'ward to board', and our partners with whom we work locally and regionally.
- To influence leadership, learning and development and individual responsibility with regards to patient experience.

* We have decided to use the term 'better' rather than 'best' as the vision is for continuous improvement and innovation which suggests that the 'best practice' end point is never reached.

Evidence

Help

Describe any relevant evidence about people's characteristics (e.g. health inequalities) and how people's views have been included ➲ E.g. admission / incident data; NICE / clinical guidance / research; surveys ➲ Mark with an '**X**' in the columns the relevant characteristics	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
Findings from "Treat me fair, Treat me equal, Treat me right"(Chapman and Lane, 2010); a Trust study to find out views of local people with learning disabilities and adult carers were included in this strategy.		X						
There has been consideration of some research / guidelines around patient experience and health inequalities for people with protected characteristics; however this is in no way comprehensive, and is on-going. The studies considered so far have been summarised below. There is an acknowledgement that our engagement so far (February 2013) has not been comprehensive; however we are proposing engagement with these groups during the consultation period to ensure that the strategy reflects all the protected groups.	X	X	X	X	X	X	X	X
Older People 1) DH (2001) National Service Framework (NSFs) for older people. London. DH	X							

Describe any relevant evidence about people’s characteristics (e.g. health inequalities) and how people’s views have been included ➲ E.g. admission / incident data; NICE / clinical guidance / research; surveys ➲ Mark with an ‘**X**’ in the columns the relevant characteristics	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4002951 **Children & Younger People** 2) Children and Young Peoples Trust (2012) An update on the emotional health and wellbeing amongst children and young people in East Sussex.								
Physical Disability: 3) Satchidanand, N et al, (2012) Attitudes of Healthcare Students and Professionals Toward Patients with Physical Disability: A Systematic Review American Journal of Physical Medicine & Rehabilitation: 91(6) p 533–545 4) Department of Health (2012). Transforming care: A national response to Winterbourne View Hospital – Department of Health Review: Final Report. **Learning disability:** 5) GAIN (2010) Guidelines on Caring For People with a Learning Disability in General Hospital Settings.		X						
Gender reassignment 6) The Harry Benjamin International Gender Dysphoria Association's Standards Of Care For Gender Identity Disorders, Sixth Version February, 2001 7) Whittle et al (2008)Transgender EuroStudy: Legal Survey and Focus on the Transgender Experience of Healthcare. http://www.pfc.org.uk/pdf/eurostudy.pdf			X					
Pregnancy or Maternity 8) Hobart, E (2009) What women and their families need and want from a maternity service: overview of existing data (healthcare for London. http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/What-women-want-from-a-maternity-service1.pdf				X				
Race 9) Race for Health Report http://www.raceforhealth.org/storage/files/RFH__In_POWERFUL_HEALTH__FINAL_.pdf 10) Ethnicity and Health. Parliamentary office of science and technology. http://www.parliament.uk/documents/post/postpn276.pdf 11) Thalassis & Taha (2006) Minding the Gaps Are BME groups partners or substitutes in health provision? http://www.bmehf.org.uk/media/publications/research/MindingTheGaps					X			

Describe any relevant evidence about people's characteristics (e.g. health inequalities) and how people's views have been included ➲ E.g. admission / incident data; NICE / clinical guidance / research; surveys ➲ Mark with an '**X**' in the columns the relevant characteristics	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
.pdf								
Religion / Belief 12) Worth et al (2009) Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study http://www.bmj.com/highwire/filestream/356725/field_highwire_article_pdf/0/bmj.b183.full.pdf						**X**		
Sex Vaswani (2011) Encouraging Help-Seeking Behaviour among Young Men: A Literature Review. Report for the Child Protection Committee 13) Barriers to better health – why men's health is so poor *EMHF Background Information* http://www.emhf.org/resource_images/barriers.pdf 14) Engaging the women's Voluntary and community sector: A guideline for public bodies. Womens resource centre. July 2011. http://www.wrc.org.uk/includes/documents/cm_docs/2011/e/engaging_the_womens_vcs_july_2011.pdf							**X**	
Sexual Orientation 15) Stonewall Health Briefing http://www.healthylives.stonewall.org.uk/includes/documents/cm_docs/2012/e/experiences-of-healthcare.pdf 16) Musingarimi (2008) Health Issues affecting older gay, lesbian and bisexual people in the UK. http://www.ilcuk.org.uk/files/pdf_pdf_70.pdf								**X**

Equality Impacts

Help

Please evaluate how the work could impact people with protected characteristics to meet the three **aims (A-C)** of the Equality Duty below. If a particular aim is irrelevant please explain why.

Aim A. Eliminate discrimination – Please describe if and how the work could treat people negatively due to a protected characteristic ➲ Include who is impacted (e.g. carers with learning disabilities) ➲ Detail the argument if it can be objectively justified ➲ Explain if it is an exception or exclusion under the Equality Act 2010	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
The patient experience strategy will not discriminate against anybody by ensuring that equality of opportunity is advanced as described below.								
+ Insert more rows if necessary								

Aim B. Advance equality of opportunity – Please describe how the work includes or lacks provisions to: ➲ Address disadvantage linked to a characteristic (e.g. health outcomes) ➲ Meet different needs linked to a characteristic (e.g. within care or at work) ➲ Encourage participation where it is disproportionately low (e.g. therapies)	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
The Patient Experience Strategy will advance equality of opportunity for all protected characteristics e.g. it will promote reasonable adjustments and the individualisation of care, with respect for peoples' views / needs and preferences.		**X**						
The national guidance on Patient Experience in children and younger people is limited and it has been highlighted in a recent National Children's Bureau (NCB) report that there needs to be increased focus on this nationally (La Valle and Payne et al, 2012). It is our intention to set up on-going meaningful engagement processes to ascertain the needs and preferences of children and younger people, in regards to this strategy and beyond. This is detailed in the Improvement plan (section 7).This strategy is very much in draft form and we commit to a true and transparent consultation to include all protected groups.	**X**							
The strategy will help to promote equality by making a commitment to engage with, listen to and act on the feedback of groups from whom we seldom hear from (including those with – but not exclusive to those with protected characteristics). This needs to be in an ongoing meaningful way – not just a quick one off event. The Patient Experience strategy will include provisions to ensure: • Utilising existing forums and networks to minimise disruption, promote ability to contribute and avoid *'consultation fatigue'*. For example, the internal networks that already exist: race, sexual orientation and gender identity, age, disability and carers, religion and belief and gender (including sex and pregnancy and maternity). • Use of local expertise (e.g. trusted people within these local communities) / facilitators to help plan engagement activities. This might benefits people and communities from groups seldom-engaged by the Trust, such as Trans people, where building confidence is important. • Engagement will be planned to consider mixed and appropriate methodologies to facilitate full engagement e.g. specialist focus groups for seldom-engaged groups, the use of appropriate facilitators (e.g. Acute LD liaison Nurse), accessible communication methods (EasyRead) and interpreters and communication support (e.g. Speech-to-text Reporters used by some deaf and hard of hearing people). The strategy will also align itself with the ESHT's Equality Strategy, which includes objectives to improve patient access and experience.	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**

Aim B. Advance equality of opportunity – Please describe how the work includes or lacks provisions to: ➲ Address disadvantage linked to a characteristic (e.g. health outcomes) ➲ Meet different needs linked to a characteristic (e.g. within care or at work) ➲ Encourage participation where it is disproportionately low (e.g. therapies)	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
The Patient Experience strategy will include provisions to ensure that engagement will be planned in consideration of cultural awareness, such as being flexible in timing (e.g. to avoid prayer times), this will help people of faith as well as people with caring responsibilities.		**X**				**X**		
The Patient Experience strategy will include provisions to ensure that engagement will be planned in consideration locations that are accessible, include adequate facilities to enable the participation of disabled people or new parents and culturally sensitive, for example running an engagement event in a function room attached to a bar serving alcohol in a hotel which may exclude certain potential participants on religious grounds or in function rooms without accessible toilets or baby-changing facilities would exclude some disabled people and new mothers and fathers. All externally booked facilities will be asked to supply a copy of their equal opportunities policy.	**X**	**X**		**X**		**X**		
The Patient Experience strategy will include provisions to ensure that engagement will be considerate of transportation and parking issues, which will particularly benefit disabled people with mobility impairments, as well as some older people. Consideration will be given to locations to ensure they are accessible to children and young people when relevant.	**X**	**X**						

\+ Insert more rows if necessary

Aim C. Foster good relations – Describe how the work includes or lacks provisions to: ➲ Tackle prejudice (i.e. reduce negative bias by changing attitudes) ➲ Promote understanding (e.g. staff guidance on diverse patients' needs)	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
Establishment of a behavioural code (through consultation with staff, patients, service users, their supporters including those with protected characteristics) and the promotion of person centred care and emphasising relational elements of care may help to promote understanding of diverse needs. Listening and treating patients, families / supporters and staff with dignity and respect is one of the central commitments of the strategy. Learning and development to deliver training / work based learning on communication skills / customer relations. Learning packages that align well with this strategy and the values and beliefs of the Trust. Tackling prejudice by promoting positive patient experience is one of the big levers to improving the health of many people with minority identities	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**

Aim C. Foster good relations – Describe how the work includes or lacks provisions to: ➲ Tackle prejudice (i.e. reduce negative bias by changing attitudes) ➲ Promote understanding (e.g. staff guidance on diverse patients' needs)	Protected characteristics (Mark **X**)							
	Age	Disability and Carers	Gender Reassignment	Pregnancy or Maternity	Race	Religion or Belief	Sex	Sexual Orientation
and who suffer a penalty on their health because of having to cope with prejudice, discrimination and hatred (whether physical, emotional or mental). This challenge will need a coordinated and consistent approach across the organisation. The action plan of the Patient Experience strategy will reflect this issue and a collaborative plan of action, taking into account views (of protected groups) sought in the consultation phase will be used to inform this.								

\+ Insert more rows if necessary

Monitoring Arrangements

Help

Describe how and when any equality impacts will be monitored: (e.g. annual policy / incident data review)

- Standards for patient experience will set out the mechanisms by which equality impacts will be monitored, this includes as a minimum the monitoring of participants protected characteristics
- Patient experience indicators relating to protected characteristics, prejudice and discrimination will also be reported as part of the Trust's statutory annual reporting process
- Monthly Patient Experience Steering Group meetings will monitor implementation of this strategy and will be mindful of equality impacts within this.
- Formal annual review and report will take account of equality impacts.
- Peer review at approx 18 months with specific attention to equality impacts.
- Liaison with Healthwatch and other relevant external stakeholders to ensure ongoing consultation is meaningful.
- Regular analysis of comments, compliments, concerns and complaints as well as other Key indicators and local evidence will highlight progress & exceptions with regards to implementation of strategy.
- Equality impacts within all strategy methodologies will be reported (e.g. certain patients from protected groups did not access xxx survey / focus groups.
- Equality outcomes (improving awareness, promoting involvement/ removing barriers to engagement for protected groups will be monitored, reported on and shared.
- Concerns regarding the impacts of prejudice and discrimination will be reported to the appropriate person within the senior leadership for a response and improvement plan.
- Relevant reports and findings will be shared with internal networks (race, age, sexual orientation, religion / beliefs) which will provide additional scrutiny and promote involvement in decision making.

Human Rights

Help

Describe how the work promotes human rights values of: Fairness, Respect, Equality, Dignity and Autonomy:

Fairness: A consultation period has been sought to better understand the needs and preferences of the protected groups within the local community.

Respect: The strategy promotes the concept of respect through its central commitments and it will promote (alongside the equality strategy) the notion of acknowledging and respecting protected characteristics, which can sometimes overshadow the presenting condition and may delay the investigation, diagnosis and treatment of their medical condition. Safe and person centred care is underpinned by effective and sensitive communication, and there is much within the strategy to promote understanding people's

Describe how the work promotes human rights values of: Fairness, Respect, Equality, Dignity and Autonomy:

individual needs and preferences.

Equality: Equality for patients with protected characteristics may not mean necessarily treating them in the same way. This may mean providing additional and alternative methods of support, communication and information with the patient and/or their families/carer. Reasonable adjustments will be promoted for disabled people

Dignity: the strategy promotes compassion in care through its central commitments. The strategy promotes communication as a central theme and states that all care and work with colleagues should be person-centred.

Autonomy: the strategy promotes that all healthcare staff (even those in non-clinical roles) should respect the choices and preferences of all patients, carers and supporters by encouraging them to be actively involved in decisions regarding their care. It commits to providing accurate, appropriate and timely information and there is an emphasis on improving communication with partner organisations.

The following values are set out in the revised NHS Constitution (2012): Respect and Dignity, Commitment to quality of care, Compassion, Improving Lives, Working together for patients, and Everyone counts

These values are embedded throughout the strategy and are mapped against the eight Patient Experience Commitments. They will be considered within any action planning that emerges from the strategy and help to support the human rights above.

Mark **‘X’** in the column where the work safeguards people’s rights positively or infringes negatively		+	−
Article.2	Right to life (e.g. Pain relief, DNAR notices, staff competency, suicide prevention)		
Article.3	Prohibition of torture, inhuman or degrading treatment (e.g. Informed consent)		
Article.4	Prohibition of slavery and forced labour (e.g. Safeguarding trafficked people)		
Article.5	Right to liberty and security (e.g. Deprivation of liberty protocols, security policy)		
Articles.6-7	Rights to a fair trial; and no punishment without law (e.g. Legal services policy)		
Article.8	Right to respect for private and family life, home and correspondence (e.g. Confidentiality, records, patient letters, patient visitors or staff leave)	X	
Article.9	Freedom of thought, conscience and religion (e.g. Last offices, prescribing, uniform)	X	
Article.10	Freedom of expression (e.g. Patient information or whistle-blowing policies)	X	
Article.11	Freedom of assembly and association (e.g. Trade union recognition)		
Article.12	Right to marry and found a family (e.g. Fertility, maternity services)		
Article.14	Prohibition of discrimination with respect to human rights (e.g. Illiteracy)		
Protocol.1.A1	Protection of property (e.g. Patient property, last offices policies)		
Protocol.1.A2	Right to education (e.g. Staff crèche or student nurse agreement policies)		
Protocol.1.A3	Right to free elections (e.g. Foundation Trust elections)		

Outcome

Help

X	Mark 'X' next to the final outcome(s) a-d of the analysis and note the reasons why in the space below:	
	(a) Continue the work	Continue to engage with all relevant stakeholders and in particular groups from whom we seldom hear (including those with protected characteristics). The patient experience strategy will be amended / consulted on continually through its 3 yr lifespan to reflect changes to national policy / guidelines and in particular the better understanding of the local community (including protected characteristics) and its needs / preferences.
X	(b) Change the work	
	(c) Justify and continue the work	
	(d) Stop the work	

If you selected outcome **(d)** please score any equality or human rights risks below:

Consequence score:		x	Likelihood score:		=	**Equality and Human Rights Risk Score**:	

Assurance Statement: I have reviewed the evidence with rigour and an open-mind and am satisfied there has been due regard to the need to eliminate discrimination; advance equality of opportunity and foster good relations, and there is compliance with Section 149 of the Equality Act 2010.		
Analysis Lead(s) Sign-off:	Simon Wilson	Date: 7 February 2013
Quality Assessor (Office Use):	Jourdan Durairaj	Date: 14 February 2013

Equality and Human Rights Improvement Plan

Help

- Plan below to eliminate any identified unlawful discrimination or human rights interferences
- Improve positive actions to advance equality of opportunity:
  - Remove or minimise disadvantage; meet different people's needs or encourage participation
  - Take account of disabled people's disabilities where their needs are different
- Foster good relations to tackle prejudice and promote understanding
- If the analysis evidence is unclear, take proportionate action to improve this, e.g. run a focus group.

	Actions (Reference the findings within previous sections to show cause and effect)	Target Date	Lead Person	What action plan will this be built into?
7.1	Identify links with groups with protected characteristics and groups from whom we seldom hear.	12/2/13	Simon Wilson	Patient Experience Implementation group action plan
7.2	Organise engagement events taking into account considerations stated under AIM B above. Aim of consultation is i) to better understand patient experience from the protected groups perspectives, particularly in relation to the draft patient experience strategy ii) Develop ongoing meaningful and purposeful relationships	19/2/13	Simon Wilson	Patient experience Strategy Implementation group action plan Patient Experience Steering Group Plan

	Actions (Reference the findings within previous sections to show cause and effect)	Target Date	Lead Person	What action plan will this be built into?
	with protected characteristics groups			
7.3	Complete initial engagement events and visits to local groups as required.	21/3/13	Simon Wilson	PEXP strategy implementation group.
7.4	Theme and aggregate findings from engagement events / consultation into final strategy document, where these perspectives will be used for collaborative and inclusive action planning.	27/3/13	Simon Wilson & Jan Dewing	Patient experience strategy implementation group plan Final Strategy reported to CME, PSCIG and Trust Board
7.5	Review Equality and Human Rights Analysis form and update as required on the basis of the findings.	28/3/13	Simon Wilson	Patient Experience Implementation Group action Plan Patient Experience Steering Group Plan
7.6	Review Patient Experience Strategy Implementation Plan to take into account ongoing sustainable and meaningful engagement with groups with protected characteristic	1/4/2013	Simon Wilson	Patient Experience strategy implementation group action plan

\+ Insert more rows if necessary

Append this form to the main paperwork and send it to equality@esht.nhs.uk for quality assurance before ratification or approval. After this the form will then be published on the Trust's website.