‘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

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Prepared by

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NOTE TO THE READER

This nine month project began in June 2010 and was completed in February 2011.

Our approach was to undertake three discrete ‘work packages’, each with several research strands, to address the three project aims. In the event many of the findings from each work package overlapped and informed our overall thinking. For each of the three work packages this report provides a very brief description of our overall methods and key findings. A series of supporting appendices provide further details on each of the specific research strands. A separate set of ‘Policy Recommendations’ informed in part by the findings in this project report are also available.

The main challenge in this project report has been to synthesise - in a relatively short timeframe - the findings from the wide range of different methods we employed. More specific analyses could now be undertaken of several of the sources of evidence (for example, detailed statistical analyses of the NHS Choices and Patient Opinion datasets or by focusing on specific areas of interest through further analysis of the interview transcripts in the organisational case studies).

NRES has confirmed that its approval was not required for this project as it was deemed ‘service evaluation and development’. The project was approved by the King’s College London Ethics Committee. This research was funded by the Public and Patient Experience and Engagement (PPE) Division, Department of Health, and commissioned by the NHS Institute for Improvement and Innovation. We are grateful for feedback on an earlier draft of this report from participants in a workshop organised by the Department of Health and NHS Institute. The views expressed are those of the authors and not the funding organisations. The NHS Institute will use this report to develop guidance to support the NHS to implement its findings.
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**Aims of the Project**
The project had three aims as set out in the original specification:

1. To establish what matters to patients, particularly in the non-acute sector, and to analyse the implications for how feedback should be captured
2. To review what NHS organisations in England currently measure in relation to what matters to patients
3. To describe examples of NHS organisations in England which are using information and insights into patient experience to improve the quality and productivity of health care services.

**Summary of Main Findings**

<table>
<thead>
<tr>
<th>AIMS</th>
<th>KEY FINDINGS</th>
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</thead>
</table>
| 1. To establish what matters to patients, particularly in the non-acute sector | 1a. We know ‘what matters most’ to the majority of patients from a combination of a wide-range of existing studies  
1b. Complaints data is typically not collated or analysed at national or local levels in a way that is useful to local organisations for quality improvement. More meaningful complaints analysis and information is needed.  
1c. ‘Relational’ aspects of care (like dignity, empathy, emotional support etc) are very significant in terms of overall patient experience alongside ‘functional’ aspects (access, waiting, food, noise etc)  
1d. A generic framework can be applied to a wide range of conditions and treatments; for example, both the Institute of Medicine and Picker frameworks are broadly appropriate for ‘what matters most’ to patients in both acute and non-acute sectors (further work is required to confirm that this includes acute mental health conditions) |
| 2. To review what NHS organisations in England currently measure in relation to what matters to patients and identify the implications for how feedback should be captured in the future | 2a. Current data collection, analysis and reporting systems and processes are designed - or have evolved - to fulfil a wide range of different purposes (system performance management; local monitoring and governance; supporting ‘choice’; quality improvement)  
2b. Systems for measuring patient experience in other countries are largely dependent on large-scale survey programmes that post-date the NHS national survey programme  
2c. In the NHS, organisations use a combination of national (national patient survey) and local development/investment in other data collection instruments; there is little consistency in the choice (and wording) of questions asked  
2d. The national picture is that most of the data is (i) on patient experiences of acute care; (ii) relevant to services rather than patient journeys; (iii) not timely; and (iv) not representative (i.e. not subjected to case mix analysis) in the case of local surveys  
2e. Current systems and processes (at local and national levels) for capturing patient experience largely record what happens and what people say about it (‘research’ mode) rather than measuring achievement against standards (‘quality improvement’ mode) |
2f. Patient experience data is typically collected and reported separately from data on clinical effectiveness and patient safety

2g. Patients are asked for some information (appointment times, waits) that organisations should collect in other ways: the NHS should only seek feedback directly from patients on ‘what matters most’ to them if this information is (i) not already available and (ii) uniquely available from patients

3. To describe examples of NHS organisations in England which are using information and insights into patient experience to improve the quality and productivity of health care services

| 3a. | NHS organisations demonstrate a very wide range of capability and experience in relation to capturing, understanding and improving service user/patient experience |
| 3b. | Provider organisations use a variety of different methods and approaches to capture patients’ experience, but they make relatively little use of the information to improve quality |
| 3c. | Use of ‘real time’ approaches are common but typically (i) focus on ‘snapshots’ of individual experiences of care and do not reflect the wider context around such episodes, (ii) are highly dependent on staff time and willingness, (iii) typically confirm what is already known, and (iv) are unrepresentative. However, the results are ‘owned’ by clinical teams as they undeniably relate to their patients and thus enable staff to focus on patient experience |
| 3d. | There are poor links between staff (and resources) dedicated to measuring and improving patient experience, and education and training departments in the same organisation |
| 3e. | The majority of Higher Education Institutions (HEI) and NHS Trusts plan to develop the patient experience aspects of their training courses over the coming year but, worryingly, NHS trusts are less likely - compared to HEIs - to do so (even though they currently perform less well) |
| 3f. | Organisations simply do not know their own costs or the costs to the NHS of collecting service user/patient experience data (and therefore whether such activities represent value for money) |
| 3g. | Evidence on commissioners’ actions to improve patients’ experience of care (for example CQUIN) is scarce and their leverage in relation to service quality, under-developed |
| 3h. | Innovative provider work to improve patients’ experiences is often unrecognised by commissioners |
| 3i. | Commissioners and providers need to work together to capture patient stories across organisational and service boundaries and highlight issues of accessing services, transition and continuity of care that service-specific surveys usually do not capture |
| 3j. | 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. Currently, improving patient experience does not have the same status or value as improving these other two domains |
| 3k. | There are six universal challenges faced by NHS organisations in measuring and improving patient experience (structural, political, cultural, educational, emotional and technical); organisations are at an early stage on their quality improvement journey |
3l. Leading-edge provider organisations: (i) recognise and maximise the value of patient stories, (ii) use measures that allow comparison over time and between organisations, (iii) demonstrate leadership and organisational commitment, (iv) dedicate resources to the tasks of capturing, understanding and improving patient experience, and (v) establish clear links with commissioners.

Methods
Annex 1 to this report provides brief details of the methods adopted to address each of the three project aims; more detailed descriptions are provided in the supporting appendices.

Key Findings
In the remainder of this report we present our key findings. The relevant supporting appendices detailing the various research strands that informed each aim are cross-referenced where appropriate.

What matters to patients, Particularly In The Non-Acute Sector?
The first aim was to provide evidence about what matters most to patients and carers, with a particular focus on non-acute care settings, and appropriate measurement approaches. This work package comprised six research strands (which are detailed in supporting appendices 1-4):

- review of existing evidence on ‘what matters’
- survey of voluntary sector and patient group organisations
- interviews with patients/carers with one or more of five ‘tracer’ health conditions selected in consultation with the Department of Health. These were: chronic obstructive pulmonary disease (COPD), elective hip replacement, depression, stroke and diabetes
- secondary quantitative and qualitative analysis of NHS Choices dataset (GP and hospital postings)
- secondary quantitative analysis of Patient Opinion dataset
- examination of NHS Complaints dataset.

Here we, firstly, summarise what the various strands tell us about whether there are generic themes which relate to ‘what matters to patients’ (and, if not, how these differ across conditions and sectors); secondly, highlight which aspects of care appear to matter most to patients; and, thirdly, indicate which generic conceptual framework is most appropriate for capturing ‘what matters to patients’ across a wide range of conditions.
‘What matters to patients’ – generic themes?

Key findings:
1a. From a combination of existing studies we know which generic themes ‘matters most’ to the majority of patients
1b. Complaints data is typically not collated or analysed at a national or local in a way that is useful to local organisations for quality improvement

Findings from existing studies (including the previous Department of Health project exploring ‘What matters to patients, the public and staff’ (Department of Health, 2007) are extensive and broadly consistent, albeit they have employed different methods as well as wording of - and approaches to categorising - issues/themes that matter to patients (see appendix 1 Literature review). Of relevance to our first aim are the results of previous studies that ask people to rank aspects of healthcare in order the order of importance they have for them (‘importance studies’) which have informed the development of many existing patient surveys in the acute sector. Such work with NHS patients in Scotland and England has arrived at similar findings regarding the items patients consider most and least important:

Table 1 Scotland (Reeves & Bruster (2009), from 2,213 patients)

<table>
<thead>
<tr>
<th>10 most important items</th>
<th>10 least important items</th>
</tr>
</thead>
<tbody>
<tr>
<td>A clean ward</td>
<td>Being given help to eat my meals when I need it</td>
</tr>
<tr>
<td>Staff cleaning their hands before touching patients</td>
<td>Being given accurate information about ward routines</td>
</tr>
<tr>
<td>Being treated quickly in an emergency</td>
<td>Not having to wait around in hospital once I have been told I can go home</td>
</tr>
<tr>
<td>Getting the best treatment for my condition</td>
<td>Being given help to arrange transport home</td>
</tr>
<tr>
<td>Doctors knowing enough about my condition and treatment</td>
<td>Having a choice about which hospital I go to</td>
</tr>
<tr>
<td>Clear explanations about what will happen during an operation or procedure</td>
<td>Not having to pay too much to make phone calls</td>
</tr>
<tr>
<td>Being told the risks and benefits of any treatment in a way I can understand</td>
<td>My religious beliefs being respected</td>
</tr>
<tr>
<td>Clear explanations of my condition or treatment</td>
<td>Being able to watch television without having to pay for it</td>
</tr>
<tr>
<td>Being treated with dignity and respect</td>
<td>Being able to get an interpreter</td>
</tr>
<tr>
<td>Being told how my operation or procedure has gone in a way I can understand</td>
<td>Having access to food when I am hungry (not just at mealtimes)</td>
</tr>
</tbody>
</table>
Table 2  England (Boyd (2007), from 448 patients)

<table>
<thead>
<tr>
<th>10 most important aspects</th>
<th>10 least important aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td>The doctor knew enough about my medical history and treatment</td>
<td>I am told how to make a complaint about the care I receive</td>
</tr>
<tr>
<td>The doctors can answer questions about my condition and treatment in a way that I can understand</td>
<td>I have a choice of admission dates</td>
</tr>
<tr>
<td>I have confidence and trust in the hospital staff who treat me</td>
<td>I receive printed information about the hospital before admission</td>
</tr>
<tr>
<td>The doctors wash or clean their hands between touching patients</td>
<td>I have a choice about which hospital I am admitted to</td>
</tr>
<tr>
<td>The nurses know enough about my medical history and treatment</td>
<td>I receive help to eat my meals, at the time I need it</td>
</tr>
<tr>
<td>Before my operation or procedure, I get a clear explanation of what will happen</td>
<td>The hospital provides facilities that allow me to practice my religious beliefs</td>
</tr>
<tr>
<td>The risks and benefits of my operation or procedure are explained to me in a way that I can understand</td>
<td>A translator or interpreter is provided by the hospital</td>
</tr>
<tr>
<td>The nurses wash or clean their hands between touching patients</td>
<td>I have enough information about different hospitals so I can make a choice</td>
</tr>
<tr>
<td>The rooms and ward are clean</td>
<td>I have access to food when I am hungry (not just at mealtimes)</td>
</tr>
<tr>
<td>The doctors and nurses are open with me about my treatment or condition</td>
<td>I am not bothered by noise during the day</td>
</tr>
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Our interpretation of the results of the literature review suggest a need to shift attention from what we term (1) a ‘research’ mode ’ (i.e. further research to find out ‘what matters most’) to (2) a ‘quality improvement’ mode in which solutions are developed to meet patient ‘promises’ relating to what we (largely already) know matters most. Several key sources in the review highlighted the central importance of ‘relational’ aspects of care to patients (see section below).
Many of the findings from our survey of voluntary organisations show a remarkable consistency both across conditions and in relation to the various sectors (see appendix 2 Survey of Voluntary Organisations). Generic themes were:

- good information provision
- having confidence in health professionals
- awareness and understanding of specific health condition
- the right treatment from the right staff at the right time
- continuity of care
- being treated as a person
- partnership with professionals

The findings from our survey of voluntary organisations and patient groups therefore broadly support the argument that a generic framework of ‘what matters’ to patients could be applied across conditions and sectors (see section below); they also further support the importance of the ‘relational’ aspects of patient care. Voluntary organisations representing patients also identified a number of problems - and acknowledge the challenges - with the way that NHS organisations currently measure the aspects of patient experience that are considered important to them.

Twenty themes emerged from the 50 narrative-based interviews we conducted relating to what is important to patients when receiving care in relation to one of the five selected ‘tracer’ conditions (see appendix 3 Patient & Carer Interviews). Many of these were generic themes across all conditions but there were also a small number of themes that were condition-specific. The most common 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 (for example, patient & carer support groups)
- efficient processes
Again these findings support the arguments that a generic framework can be used across a range of conditions and that ‘relational’ aspects of care are important to patients:

Table 3 Functional or relational themes from patient interviews

<table>
<thead>
<tr>
<th>Themes</th>
<th>Functional</th>
<th>Relational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being treated as a person, not a number</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Staff who listen and spend time with patient</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Individualised treatment and no labelling</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Using language that is easy to understand</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Finding out about the latest technologies and innovations medications</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Feeling informed, receiving information and being given options</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Patient involvement in care and being able to ask questions</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>More public awareness about condition</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Efficient processes</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Knowledgeable health professionals</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Aftercare support</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Positive outcomes</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Continuity of care</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>Good relationships and positive attitudes among staff</td>
<td></td>
<td>√</td>
</tr>
<tr>
<td>The value of support services</td>
<td></td>
<td>√</td>
</tr>
</tbody>
</table>

Our secondary analysis of ratings by NHS patients relating to the care they received in primary care settings show that ‘being treated with dignity & respect’ and ‘involves me’ had the strongest correlation with a patient’s ‘overall rating’ of their experience (see appendix 4 NHS Choices). Thirteen ‘what matters’ themes emerged from our qualitative analysis of open comments that were posted in relation to experiences in primary care with the most common being (a) efficient appointment system, (b) friendly and supportive staff (particularly receptionists), and (c) feeling ‘listed to’/included in care (see appendix 4 NHS Choices).

Our quantitative analysis of hospital ratings posted on the NHS Choices website revealed that ‘doctors & nurses work well together’ and ‘dignity & respect’ (0.90) had the strongest correlation with patients ‘overall rating’ of their experience (see appendix 4 NHS Choices). Eleven themes emerged from the qualitative analysis of the hospital comments with the most common being (a) caring, dedicated and respectful staff, (b) friendly, kind staff, and (c) efficient processes (see appendix 4 NHS Choices).
Both the quantitative and qualitative analysis of the NHS Choices GP and hospital datasets further support the importance of ‘relational’ aspects of care (alongside ‘functional’ aspects, such as ‘efficient appointment systems’ in primary care). It should be noted that very few individual practices or hospitals had received more than three postings which is currently an important limiting factor in the potential use of these sources for local quality improvement purposes.

Our quantitative analysis of the Patient Opinion dataset (see appendix 5 Patient Opinion) showed that - on common rating questions - community services consistently scored higher than acute services (i.e. 61% of community ratings were reported as ‘very good’ in terms of ‘respect and dignity’ against 54% of hospital postings; 59% of community ratings were reported as ‘very good’ in terms of ‘service punctuality and timeliness’ against 38% of hospital ratings; and 61% of community ratings were reported as ‘very good’ in terms of ‘information/decision-making’ against 46% of hospital ratings).

Finally, the NHS Information Centre’s central analysis of all NHS complaints reported that the highest percentage of written complaints in Hospital and Community Health Services (42.2%) concerned ‘all aspects of clinical treatment’, the highest percentage of written complaints in Family Health Services (60.3%) concerned the ‘medical’ service area, and that common GP and dental health services complaints included ‘clinical’ (16,300) and ‘communication/attitude’ (11,677). It was not possible for us to undertake any further analysis via the NHS Information Centre due to the current system for collating ‘complaints’ from NHS organisations. Current analysis and categorisations of complaints are insufficient to inform quality improvement or identify priorities at a system level and, of course, complaints only represent the experiences of a small proportion of patients. Nonetheless, the Health Service Ombudsman for England recently commented (2010): ‘The NHS needs to listen harder and learn more from complaints. When it fails to do so, it is missing a rich source of insight and information that is freely and readily available and comes directly from service users’. Eight national bodies subsequently called for a better complaints system that enables relevant bodies to gain meaningful and comparable information that would ‘significantly help to drive improvements in health care and strengthen the quality of services for everyone’ (Care Quality Commission, 2011).

Relational and functional aspects of care

Key finding 1c. ‘Relational’ aspects of care (like dignity, empathy, emotional support) are very significant in terms of overall patient experience alongside ‘functional’ aspects (access, waiting, food, noise).

As well as identifying generic themes we also sought to establish which aspects of care are particularly important to patients. A recent King’s Fund report highlighted that providing a good patient experience is multi-dimensional: it is about both the what (functions or transactions) and the how (relational) of interactions with patients. Illes (2011) describes the ‘transactional’ aspect of care as a set of “efficient auditable transactions between consumers and providers”. She also speaks about the ‘covenantal’ aspect of care; “a covenant between care giver and care receiver…that
recognises that neither is an impersonal unit in a care transaction… but a whole richly multifaceted person whose physical responses are strongly bound to emotional ones.” (p36). She highlights the dangers of not taking into account both aspects of care: the “content of care” as well as the “nature of care” which is equally important for patient experience. Our analysis of the findings from the research strands in work package one supports the critical importance of ‘relational’ aspects of care alongside ‘functional aspects in terms of ‘what mattered most’ to patients.

Our analysis of the interviews with patients/carers (see appendix 3 Patient & Carer Interviews) revealed that when the twenty themes relating to what is important to patients when receiving care were categorised into ‘functional’ or ‘relational’ aspects of care, relational aspects of care were more common. Themes such as ‘being treated as a person, not a number’ and ‘staff who listen and spend time with patients’ were considered important aspects of care among patients. As noted above the importance of such relational aspects was also reinforced by the findings from the voluntary sector and patient organisation survey, and the secondary analyses of the NHS Choices datasets.

**Generic framework**

**Key finding 1d.** A generic framework can be applied to a wide range of conditions and treatments; for example, the Institute of Medicine or Picker frameworks are both broadly appropriate for ‘what matters most’ to patients in both acute and non-acute sectors (further work is required to confirm that this includes acute mental health conditions).

Overall, we found that there are clear and consistent themes about ‘what matters’ to patients and these can be formed into a generic framework that is appropriate for a wide range of conditions and in different healthcare settings.

Two generic frameworks are available that broadly capture the themes that ‘matter most’ to patients¹. Potential approaches (see accompanying ‘Policy Recommendations’ report for details and illustration) are:

1. To slightly adapt the wording of the Institute of Medicine (IoM) ‘dimensions of patient-centred care’ model in order to take account of our overall findings. However, this is subject to (a) the IoM domain of ‘respect for patients values, preferences and expressed needs’ being felt to adequately capture the patient-focused meaning of access (which is a key theme particularly in the non-acute sector), and (b) if it is acceptable that ‘timeliness’ is conceptualised as a separate dimension of quality from patient-centred care (and measured objectively through recorded waiting times)

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¹ The Institute of Medicine’s dimensions of patient-centred care model includes six dimensions: respect for patient values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support; and involvement of family and friends. The Picker framework includes eight domains: respect for patient-centred values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support; involvement of family and friends; transition and continuity; and access to care.
To use the Picker framework as this includes a specific dimension relating to 'continuity and integration' (and also includes 'access' as a separate dimension - in contrast to the IoM, see above); given the importance attached by patients to issues relating to ‘transition and continuity’ this may be a more appropriate framework (this dimension is folded into a broader dimension - 'coordination and integration' - in the IoM framework) particularly in the non-acute sector.

**What do NHS organisations in England currently measure in relation to what matters to patients?**

Our second aim sought to establish what is currently being measured in NHS organisations in terms of patient experience and how this compares to 'what matters' to patients.

Our findings drew on the results of the literature review described above, a scoping review of other national systems for measuring patient experience, analysis of the use of Dr Foster Patient Experience Trackers in NHS organisations and recent work already undertaken on behalf of the Department of Health by the King’s Fund; they are also informed in part by the findings of the organisational case studies we conducted to inform our third project aim (see below). Many of our key findings in relation to the second project aim have had significant implications for our policy recommendations (see accompanying report). The emphasis in the policy recommendations on the value of simplifying measurement of patient experience, and the importance of both timeliness and clinical credibility are a result of what we learned from the case studies of what is currently being measured in the NHS and social services.

**Types of measure**

| Key finding 2a. Current data collection, analysis and reporting systems and processes are designed - or have evolved - to fulfil a wide range of different purposes (e.g. system performance management; local monitoring and governance; supporting ‘choice’; quality improvement). |

As a recent King’s Fund report highlighted (Foot & Cornwell, 2010), there are a number of ways of measuring patients’ experiences of care (for example, measures of experience, satisfaction, patient reported outcomes (PROMS), and patient-defined and reported outcomes) and for several distinct purposes. The differences between the types of measure and reasons for collecting data on them are not semantic, they are real and important. For instance, measures of satisfaction have a commonsense and political appeal, but they are the measures that experts, including experts in quality improvement, consider the least useful on their own for improving patient experiences locally (Reeves & Seccombe, 2008; Davies & Cleary, 2005; Coulter, 2006).
Measuring patient experience: where are we now?

Internationally, the NHS led the way in mandating a national patient survey programme in England in 2001. The first public reporting of the equivalent Hospital Consumer Assessment of Healthcare Provider and Systems surveys in the USA was in 2008; Australia, Canada, New Zealand and most European countries (with the exception of Holland and Norway) do not have systematic arrangements for measuring and monitoring patients’ experience at national level although they do exist at regional and state levels in some countries.

Key findings:

2b. In the NHS, organisations use a combination of national (national patient survey) and local development/investment in other data collection instruments; there is little consistency in the choice (and wording) of questions asked

2c. The national picture is that most of the data is (i) on patient experiences of acute care; (ii) relevant to services rather than pathways; (iii) not timely; and (iv) not representative (i.e. not subjected to case mix analysis) in the case of local surveys

2d. Current systems and processes (at local and national levels) for capturing patient experience largely record what happens and what people say about it (‘research’ mode) rather than measuring achievement against standards (‘quality improvement’ mode)

2e. Patient experience data is typically collected and reported separately from data on clinical effectiveness and patient safety

2f. Patients are asked for some information (appointment times, waits) that organisations should collect in other ways; the NHS should only seek feedback directly from patients on ‘what matters most’ to them if this information is (i) not already available and (ii) uniquely available from patients

2g. Systems for measuring patient experience in other countries are largely dependent on large-scale survey programmes that post-date the NHS national survey programme

Acute hospitals in England have more data on patients’ experience from the national patient surveys than other parts of the health system. In mental health trusts, for example, users’ views have been canvassed seven times since 2003. PCT residents have had five national patient surveys in the same period, with GP practice surveys in 1998 and 2006. There has not as yet been a national survey programme for patients in community health services. Other health care sectors could learn important lessons from the acute sector experience (Foot & Cornwell, 2010).

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2 The PCT survey programme has now been replaced when the new GPPS survey became quarterly and expanded to incorporate the same issues.

3 From 2007, a series of surveys was developed to collect information to reward GP practices according to performance on elements of access and choice. These have been carried out by Ipsos MORI and although largely focused on issues of access do include some measure of patient experience.
England led the world in commissioning a national survey of patients’ experiences. The national survey data is valuable for monitoring purposes because it is based on randomly selected, representative populations; the questions are standardised; and it is possible to compare hospitals and track trends. However, perhaps paradoxically, in our view it is possible that the national survey programme contributed to the failure of trust Boards actively to reflect on their own responsibilities for collecting information from patients on their detailed experiences of services and using the data to improve service quality.

Two recent King’s Fund reports together provide an up-to-date overview of the current state of measurement of patient experience in the acute sector (Foot & Cornwell, 2010; The Point of Care, 2009). In summary, whilst hospital trusts have traditionally relied on the national patient survey programme to provide insights into specific aspects of patients’ experiences of care, they are increasingly deploying a wide range of other methods and approaches locally. There has been a relatively recent proliferation in methods and approaches to capturing patient experience that have been implemented by Trusts (or at least secondary data sources that are being drawn on in some way) to measure (and perhaps help improve) patient experiences. These include: ward-level surveys; interviews and focus groups; patient forums; informal feedback to PALS; formal complaints; comments on websites (e.g. NHS Choices); and feedback on the performance of individual clinicians for appraisal or revalidation purposes. The value of these innovations and initiatives lies in a greater sense of local ownership and service/clinical relevance. However, the implementation of local methods and approaches often lacks standard definitions of questions, creating difficulties in making sense of a plethora of data points that cannot be used to compare with other services/organisations or within the service over time.

A recent report helpfully explores the methods used and issues involved in gathering, collating and analysing real time patient feedback at ward level in just one single NHS SHA; what is most striking is the wide range of approaches and tools that have been adopted by local organisations (Brown et al, 2009). There are various private sector companies providing services, some of whom leave it to NHS staff to design the questions, whereas others use national survey questions. Trusts are increasingly using real time feedback to provide evidence for the CQUIN measures, and specific initiatives such as mixed-sex accommodation audits. Internationally, current measurement of patient experience remains heavily dependent on standardised national survey techniques, rather than real-time patient feedback systems.

Good examples of work undertaken in acute trusts include: King’s College Hospital Foundation Trust, Northumbria Healthcare Trust and Taunton Hospitals NHS Foundation Trust, all of which triangulate data from different sources to help them make sense of the quality of patient experience. Kings College Hospital has been doing this for the longest period of time and experience data is shown alongside clinical and financial and activity data in an integrated performance report for all clinical directorates. The experience data is based on patient exit survey at discharge, comments cards, complaints data and national survey results - all coded against a common set of definitions - making it easier to monitor issues and actions taken across the Trust. In Northumbria, they combine reporting on national patient survey questions with a Quick Exit survey (“2 minutes of your time”);
regular reporting on seven core domains of experience from a patient survey in targeted wards; and near time reporting using patient perspective surveys in outpatients and high volume inpatient areas. Taunton uses selected questions from the national patient survey (based on the US Consumer Assessment of Healthcare Providers and Systems (HCAPHS) survey which has only 27 questions) and a small staff survey at clinical directorate level.

Despite examples of ‘good’ practice, in research conducted by Dr Foster for a report in the Intelligent Board series (2010), non-executive trust and PCT directors (NEDs) said that patients’ experience of care has become more of an interest and a concern since the publication of the Mid Staffordshire report. Comments from the NEDs suggest that:

• many Boards are actively trying to improve their intelligence on patients’ experience
• Board directors are certain it needs doing but not sure how
• some Boards draw on patients’ stories and first hand observations of governors and mystery patients in their discussions
• building on practices developed in the patient safety movement, NEDs and executives are beginning to do walkabouts and ‘Go and See’ visits to clinical areas.

A review of Board agendas and minutes from a sample of Trusts for the same report found there a wide range of practices:

• the importance accorded to patient experience varies - from first agenda item to non-existent
• the approach to reporting varies - from routine monthly reporting to reporting only areas of concern
• the level of detail and analysis varies - from purely numerical (‘this many people complained’) to analysis and action (‘this many people complained, for these reasons, and here’s what we’re going to do about it’)
• the definition of ‘patient experience’ - and the reports received by boards under this heading - varies from trust to trust
• at some trusts ‘patient experience’ means just patient satisfaction ratings only; at others it covers a wider range of what happens to patients experience in hospital, from waiting times to delayed discharge.

Strikingly, over 95% of the time, the minuted action point on patient experience is to note the report and take no further action. Examples where patient experience data is used to spark debate and action were rare, as were examples of non-executive directors challenging performance.
Specifically relating to measurement of patient experiences Foot & Cornwell (2010) recommended that the DH should:

- increase capability to collect and use near real time measurement by regions, providers and commissioners
- use standard frameworks (such as the US Institute of Medicine’s nine dimensions of patient-centred care) and measures for national functions and for contracting and commissioning
- share learning and approaches to measurement and analysis methodologies across the DH teams
- support and encourage at regional and organisational level:
  - mapping customer journeys and coordinating data collection across pathways of care
  - collecting feedback from patients on core domains frequently
  - developing systems and processes to support collection and use of near real time data
  - building flexibility for local organisations/services/teams to capture locally relevant issues into data collection tools.

The overall conclusions in this earlier report were that:

- It is desirable to combine measures of experience with measures of outcome to obtain a rounded view of the quality of care
- There are a number of sources of information and approaches to measurement of experiences, dividing broadly into qualitative and quantitative methodologies. Both methodologies are useful but for different purposes
- Methods of collecting and reporting patients’ feedback should be tied as closely as possible to clinical services so that clinicians identify with the results
- Middle managers and clinical teams should monitor quality of care as often as they monitor budgets. They need relevant, accurate, timely, frequent information from their own patients to compare their own services with others and make improvements. This means access to ‘near real time’ feedback, based on standard questions, with demographic information to allow for assessment of population mix
- NHS trust commissioners, planners and policy makers should make use of the data collected to support management and improvement of front line services, and should avoid demanding fresh collections of data for their own purposes.
Dr Foster Patient Experience Trackers (PETs)

As part of establishing what the NHS currently measures in terms of patient experience we also analysed all the questions that have ever been posed using PETs in NHS organisations. Over seven million individual responses have been collected using PETs over the last few years, and this is currently increasing at a rate of over 300,000 per month. Strikingly we found that only 16 questions have been used on more than 10 different surveys and there is a wide variation in terms of how similar questions are worded; for example, there are 18 different ‘dignity and respect’ questions and only one of these has been used eight times and, similarly, there are 26 different examples of the ‘would you recommend…’ question, as well as several other ‘recommend’ questions in the dataset. Given the widespread use of this - and similar real time, electronic devices - a much smaller pool of core questions, already translated and available for all to re-use, would benefit services and patients (including facilitating benchmarking and allowing observation of changes over time). It should be noted that local versions of the national surveys are now available with a bank of questions so that organisations can be consistent and have some choice as to which questions to use.

So … are we measuring what matters to patients?

There are a number of distinctively different gaps in information about patients' experience (Foot and Cornwell, 2010):

1. Information about variations between different groups. We know from a range of sources that patients in different groups report differences in their experience but we do not understand the reasons. More targeted information from patients of different ages, health status and ethnic and religious affiliations would be helpful.

2. There are gaps in information from patients about their perceptions and experiences of their treatment/care journeys; a lack of information about experience of community health services, social care and individual clinical specialties.

3. Comparative international information about patients’ experience. Although patient surveys are becoming more common, the questions tend not to be standardised and the data collection instruments are different. The Commonwealth Fund runs international health policy surveys with measures of patients’ experience but they are based on very small samples and the questions tend to be posed at a high level of generality, asking patients for example to comment on their health system.

The research has highlighted the central importance of ‘relational’ aspects of care in terms of overall patient experience (alongside ‘functional’ aspects). Figure 1 below illustrates how delivering truly patient-centred care (as defined by the IoM) is dependent upon addressing both of these dimensions.

Yet we would argue much of what has been measured to date in terms of patient experience has focused on the more functional aspects (access, waiting, food, noise etc). We therefore recommend that policy makers attend much more closely to relational aspects of patient experience when considering the development of indicators of patient experience - importantly, such aspects (like compassion, empathy, emotional support etc) can be collected only from the patients themselves.

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4 Tools for measuring these relational aspects of care are in development (see Williams, 2008; 2009) for description of development of the ‘Patient Experience of Emotional Care in Hospital (PEECH)’ scale) and have recently been validated in the NHS setting and extended to the non-acute sector (as part of a NIHR funded study being led by Dr Jill Maben, King’s College London that is exploring the links between patient experience and staff wellbeing). Further details available on request.
Examples of NHS organisations in England which are using information and insights into patient experience to improve the quality and productivity of health care services

In this section of the project report we discuss the main findings from two substantial and linked pieces of work (the full reports are at appendices 6 and 7) and make recommendations for local NHS organisations. The findings are presented in terms of how organisations can (i) capture, (ii) understand and (ii) improve patient experience.

We carried out twelve organisational case studies to examine the actions the organisations were taking to capture, understand and improve the quality of patients’ and service users’ experience and also undertook a national survey of pre- and post registration education and training in patient experience improvement for health professionals. The twelve case studies represent a mix of NHS commissioners, provider organisations in different sectors, an independent healthcare provider and a local authority social service department.

In selecting the case studies, we deliberately looked for organisations with an established reputation for doing good work on patient experience. We compiled a long list of potential sites written up in publications and grey literature, and consulted with members of the NHS Institute Patient Experience Network; SHA patient experience and engagement leads; the Department of Health and social care and primary care policy leads at the King’s Fund. It was relatively easy to find

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5 We also draw on lessons from organisations in the NHS Institute ‘Patient Experience Network’ and two Dr Foster surveys carried out in 2010: (i) a postal survey of chairmen and non executive directors of NHS trusts, and (ii) a survey of twelve months of board papers in 33 NHS trusts.

6 Case study selection criteria are in Appendix 6. The twelve case studies comprised: one acute trust; two community service providers; one mental health trust, the to independent sector provider.
organisations that matched the criteria for selection in most categories, but difficult to find as many as two GP practices and two commissioning organisations that met the criteria. The GP practices and PCTs we finally selected were the best we could find, but nevertheless, their systems and processes for capturing, understanding and improving patient and service users experience are comparatively under-developed.

The case study data are qualitative, based on interviews with a range of staff, managers and a small number of patients and carers, and reviews of key documents. The data do not support inferences or generalisations about activities in the NHS as a whole or in different sectors/types of organisation. They do, however, describe the patient experience-related activity in organisations, and afford insights into the dynamics, structures, relationships and processes that drive these activities internally. To a lesser degree, the data provide insights into provider perspectives on the impact/influence of the external drivers in the system, notably the financial incentives in CQUIN; the movement towards a market; patient choice; and commissioning.

We gathered information on whether and how a focus on patient experience is covered in professional education and training by:

- A survey of all English providers of medical, nursing and allied health professions pre-qualification professional training.
- A survey of NHS trusts (including PCTs) in England, to access information about in-service training.

In total 265 people entered the survey - 88 from the Higher Education sector, 158 from NHS trusts and 19 from other types of organisation (e.g. SHAs). The lack of pre-existing information about the number of courses provided, and the number of course leaders who received the invitation email, makes it impossible to calculate exact response rates. The number of replies received from each sector is given in appendix 7 National training survey.

Capturing patients’ experiences

**Key findings:**

3a. NHS organisations demonstrate a very wide range of capability and experience in relation to capturing, understanding and improving service user/patient experience

3b. Provider organisations use a variety of different methods and approaches to capture patients’ experience, but they make relatively little use of the information to improve quality

3c. Use of ‘real time’ approaches are common but typically (i) focus on ‘snapshots’ of individual experiences of care and do not reflect the wider context around such episodes, (ii) are highly dependent on staff time and willingness, (iii) typically confirm what is already known, and (iv) are unrepresentative. However, the results are ‘owned’ by clinical teams as they undeniably relate to their own patients and thus enable staff to focus on patient experience
With some notable exceptions, most of the NHS case study organisations are focusing more on collecting data, measuring experiences and listening to patients’ stories than on using the data they collect to improve service quality. Many of the organisations are expanding and experimenting with the repertoires of tools and methods they use to collect patients’ feedback.

All the case study sites make use of the national patient surveys that are relevant for their services, but supplement these data with other data collected through quantitative and qualitative methods that they develop themselves, buy in from external suppliers or are required to use by their commissioners.

The wide range of methods in use includes:

- locally developed questionnaires
- various methods of administering questionnaires (self-administered; telephone surveys; administration by staff, volunteers and students)
- various methods of collecting free text comments (video boxes; SMS texting)
- near real time data collected using hand held devices called patient experience trackers (or PETs)
- creating opportunities for patients and carers to tell their stories
- analysis of comments on the internet from NHS Choices and Patient Opinion
- reflecting on complaints and compliments

All the case study organisations put staff time and resource into capturing and listening to patients’ stories and felt the effort was rewarded. In some sites, staff collect the stories; others use volunteers or peers (other patients) and students. Many NHS boards have created opportunities to listen to patients’ stories, typically focusing on complaints and adverse incidents more regularly than the more day-to-day or even the better experiences. Stories provide a more vivid and immediate medium for communicating experiences than formal reports using graphs and data; they keep staff sensitive to patients’ experiences, create more readily a sense of ownership and motivate staff to find solutions to problems. In most of the sites, stories were the only method in use for capturing issues to do with continuity of care and transitions between sectors.

With the notable exception of the GP practices and PCTs in our sample, all the NHS organisations had experimented with near real time data collection tools. Some had tested and abandoned hand-held devices and moved on to other methods, others continued to find them useful. Staff often used the devices to collect data on questions they (the staff) felt were important issues (i.e. highly relevant to their patients) but that management overlooked. There was a range of views on the accessibility and utility of the hand-held devices: some felt patients who do not read English well and patients with communication difficulties found them difficult to use, and there worries about whether it was only the friendlier and more cooperative patients whose opinions were sought. Where staff felt pressed for time, there were concerns about whether staff could find the time to collect the data themselves.

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7 Outside of our study sample there has been a national project to examine real time feedback in General Practices.
On the whole, however, staff and managers felt that the near real time data cultivated a greater sense of staff ownership; a greater a sense of dialogue between staff and patients; and fostered a greater interest in the consistency of the quality of services across an organisation.

Most of the case study organisations either collect and analyse patient experience data from the perspective of a single team, or a service or of the organisation itself. Collecting data in this way enhances local ownership of the results and helps motivate staff to act on the results (“these are our patients, talking about our service”). It does not however reflect the experiences of patients as they progress through a service or along a pathway of care involving teams / staff with different employers.

Two organisations were trying to capture patients’ experience across organisational boundaries. Typically, it was commissioners who driving strategic change that required planning across service boundaries who instigated the effort to capture experiences across the whole pathway of care. In NHS Birmingham commissioners had required providers to capture data on the end of life care pathways, and the solution found was to charge key workers in multi-disciplinary teams with collecting the data from patients. In Essex, the Adult, Health and Community Well-Being directorate had developed questionnaires that could be personalised to capture data about different packages of services provided to individuals.

Some NHS organisations involve patients in active roles on governance and planning committees and as collaborators in service planning and re-design. Where this happens, it tends to be in organisations that believe deeply in the value and importance of patients’ and service users’ experiences and paying attention to patients’ personal needs is more deeply embedded in the organisational culture. The local authority stood out above even the most user-focused of the NHS organisations, as taking user and carer involvement in all its governance, planning and improvement activities much more for granted.

Understanding patient experience

Key findings:

3d. There are poor links between staff (and resources) dedicated to measuring and improving patient experience, and education and training departments in the same organisation

3e. The majority of HEIs and NHS Trusts plan to develop the patient experience aspects of their training courses over the coming year but, worryingly, NHS trusts are - compared to HEIs - less likely to do so (even though they currently perform less well)

3f. Organisations do not know the costs to the NHS of collecting service user/patient experience data (and therefore whether such activities represent value for money)
To be useful, data on patient experience have to be collated, analysed and presented in ways internal audiences find intelligible, and organisations have to have created the fora (the team and directorate meetings; governance committees and board meetings) in which front line staff, managers and senior leaders will review and respond to the information. Ideally, qualitative data (from complaints, for example, from patient stories, focus groups and observations) will be triangulated with quantitative data on clinical quality, activity, costs and – more rarely – on staff experience. They will also be presented in a way that they tell a story: about whether and how the quality of experience is changing over time? Whether it is reliable across the organisation? And how it compares with the quality of services elsewhere?

Some NHS organisations are beginning to bring different types of data together in a sophisticated way to identify organisational ‘hot spots’ – services where patients may be especially at risk owing to poor quality, shortages of staff or demand pressures. But in the main, patient experience data are under used and poorly understood. There were relatively few examples of services or organisations systematically comparing their performance on patient experience with others. One site rejected the notion of benchmarking altogether on the grounds that all their services were unique and it would be unfair to do so; others encouraged it but felt it was difficult to achieve.

In the board papers surveyed by Dr Foster, the level of sophistication and detail brought to the analysis and interpretation of patient experience reporting varied widely: at one end of the spectrum a trust summarised all the information about patient experience with a single traffic light; at the other, boards received pages of undigested comments from individual patients. The length of performance reports varied widely from brief summaries to over 100 pages of close-packed detail.

There were six main approaches to reporting patient experience data to boards (some were over-lapping):

- no reports of patient experience data at all (3%)
- monitoring of patient experience entirely delegated to sub-committees 96%
- a focus on areas of concern only (9%)
- numerical reports on patient experience only (e.g numbers of complaints; numbers of PALS contacts) without any form of commentary (21%)
- report and analysis of patient experience data to identify areas of weakness (18%)
- reports and analysis of patient experience data to identify areas of weakness and summarise key actions (42%)
Health organisations require the same level of skill in data collation, analysis and interpretation to monitor and assure patient experience as to monitor and assure clinical quality, service activity and financial budgets, but in the main, the deficits in technical knowledge and skill are not recognised. The training and education surveys we carried out showed only weak relationships between trust strategies for patient experience and strategies for education and training. In the case study sites, views on the need and value of training in data analysis, measurement and reporting were mixed. Some patient experience leads had data related skills which they had acquired in the organisation or elsewhere, before coming into post. Some identified training needs that were not being met; others did not see a need for any kind of training.

On the NHS Institute Patient Experience Learning Programme, where the majority of the participants were leading patient experience in their organisations, workplace project evaluations highlighted that they often struggled with data collection and analysis. Common challenges included: finding sufficient resource to collate and analyse patient feedback; ensuring data collected was of sufficient quality and robustness; and harnessing specialist skills in data analysis, particularly qualitative analysis (Shared Intelligence, 2010).

The training and education survey asked a question about “Measurement: how patients’ experience can be gathered, analysed and acted on”? More than eighty percent (82%) of the respondents in higher education said training in measurement is essential, but less than half (43%) thought the courses available now covered the topic extensively. In NHS trusts, three out of four (77%) patient experience leads said training in measurement was essential; one in three (33%) believed it was covered extensively.

The importance of the patient experience is widely recognised by national bodies including the education regulators, and by those providing education and training courses that took part in our survey. But provision of patient experience training is patchy. Generally speaking, courses provided within NHS trusts cover fewer aspects of the patient experience and do not include patients as much in planning, delivering and evaluating whether courses lead to improvement. The majority of respondents planned to develop the patient experience aspects of their courses over the coming year but those in NHS trusts were least likely to do so (even though the trusts currently perform less well compared to Higher Education Institutes).

None of the organisations in the case studies were able to identify a budget for ‘patient experience’ work. They did not calculate and create budgets to manage patient experience activities that would necessarily include items such as training and education; data collection tools; data analysis; data reporting; staff time; and expenses incurred by patients and carers and volunteers. The reasons for the lack of precision about budgets are hard to pin down but seem to be partly technical (costs are often split between different activities and reporting lines, are difficult to disentangle from other management and information costs and it may not be clear what to include). In the main, however, they seem to reflect a lack of priority and value that senior leaders have so far accorded to understanding and improving the experience of the people who use their services.
None of the NHS case study sites have attempted to define the resources required to put the quality of patient experience on the same footing as clinical quality and patient safety and most lacked the necessary infrastructure to do the work. The hidden nature of the costs has consequences because it makes it difficult to make or defend decisions about increasing or decreasing the volume of activities to seek out patient experience.

### Improving patients' experience

#### Key findings:

3g. Evidence on commissioners’ actions to improve patients’ experience of care (for example CQUIN) is scarce and their leverage in relation to service quality, under-developed

3h. Innovative provider work on patient experience is often unrecognised by commissioners

3i. Commissioners and providers need to work together to capture patient stories across organisational and service boundaries and highlight issues of accessing services, transition and continuity of care that service-specific surveys usually do not capture

The two main attributes of the organisations that were collecting experience data and using it to make changes were visible leadership and an organisational culture in which staff knew that patient experience was a priority. The most advanced organisations explicitly saw themselves as on a journey of cultural change. They recognised that serious efforts to value patient experience require changes in traditional ways of working that can pose a threat to staff members and that as a consequence, staff need support to change.

Visible and effective leadership was manifest in the actions and words of individual non-executive and executive directors and in the workings of the boards. Boards discussed patient experience as part of their discussions about quality and safety; they received reports on quality and safety at every meeting and spent time to understand the issues and make decisions.

Some trusts felt that the effort to acquire foundation status had focused minds on patient experience. And having achieved foundation status, some were giving foundation governors the role almost of organisational conscience in relation to patient experience. Governors collected and contributed their own evidence on patient experience and presented it to boards and committees. One trust saw the governors as a potential resource for reaching into the community to bring in additional information from and about patients.

Designating an individual at senior level as patient experience lead strengthens efforts to improve patient experience operationally and symbolically. Where there were designated posts, they provided practical support and challenge to front line staff and were having an impact on services that might otherwise have not have engaged with the need and the effort to raise awareness of patient experience, encouraging them to learn from those who are further ahead.
The case study interviews did not discuss the external influences on provider activity in detail, but they also provide little evidence that system drivers that are intended to promote patients’ experience as a priority for NHS providers and commissioners are making much of an impact. The interviews were characterised by silence on the part of the people most involved in day to day patient experience activities about the relevance or importance for their work of the financial incentives in CQUIN; the commercial consequences (positive or negative) for the organisation of its reputation for quality of patient experience and the commercial consequences of patient choice or commissioners’ decisions. There were however a few examples of commissioners and providers working on patient pathways well together.

**Implications of our findings from organisational case studies**

**Key findings:**

3j. 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. Currently, improving patient experience does not have the same status or value as improving these other two domains

3k. There are six universal challenges faced by NHS organisations in measuring and improving patient experience (structural, political, cultural, educational, emotional and technical); organisations are at an early stage on their quality improvement journey

3l. Leading-edge provider organisations: (i) recognise and maximise the value of patient stories, (ii) use measures that allow comparison over time and between organisations, (iii) demonstrate leadership and organisational commitment, (iv) dedicate resources to the tasks of capturing, understanding and improving patient experience, and (v) establish clear links with commissioners

In the literature on quality improvement in health care systems there is growing evidence that efforts to improve service quality in all health systems are universally limited and constrained by systemic problems, that require high calibre leadership both at senior level and at the level of clinical teams; sustained commitment long periods and considerable investment in infrastructure and change capability to overcome (see for example: Pronovost, P et al 2011; Bevan, Ham et al, 2010; Baker, R 2006).

Achieving major improvement in service quality takes time. Typically, organisations with a reputation for delivering a great patient experience have taken at least ten years of sustained effort to achieve measurable results (Shaller 2007). They only reach that stage when they have included patient experience in a strategy that has prioritised quality and patient safety over a long period, have sustained an investment in infrastructure and management process, and embedded the systems and processes required to create the conditions for better outcomes in the organisation’s culture and the way it does its business.
Organisations have their own distinctive histories and contexts that shape the course they take towards improvement, but it is possible to identify five distinctively recognisable stages along the route (Baker, 2011):

**Stage 0** - regulatory compliance

**Stage 1** - false starts - project mentality characterized by various tactical improvement activities

**Stage 2** - traction - alignment of projects to strategy, attention to leadership and management of process

**Stage 3** - integration - clear linkage of process management and improvement to operational results

**Stage 4** - sustaining - continuing to embed quality improvement in the organisation

Mapping the NHS case studies onto the route we can see that most have moved beyond Stage 0 - regulatory compliance into stage 1 - false starts (characterised by patient experience ‘projects’ with relatively little linkage to other quality improvement activities in the organisation). Sooner or later, most will reach a critical point where they will either have to reframe the effort required to improve patients experience as strategic priority for the organisation and recognise the serious investment in infrastructure and process that is needed to achieve results, or find that their quality and experience-related projects and initiatives peter out. Some sites are heading towards, or have reached, stage 2. These are the organisations that explicitly talk about a journey of cultural change and are thinking about the kinds of measurement and change capabilities, communication systems and support for staff that are needed.

Research into efforts to improve quality in health systems, and with the minority of organisations that perform exceptionally well, shows that there are six common uses and challenges that all organisations face in relation to quality improvement that can be described as: structural, political, cultural, educational, emotional and physical and technological (Bate et al, 2008). Annex 4 shows the different kinds of failure associated with each of the six challenges causing improvement efforts to fail or underachieve in different ways.

All the case study sites were facing these core challenges to a greater or lesser degree. In most organisations, the people closest to patient experience activity are deeply committed and emotionally engaged; some progress was being made with the technical challenges of collecting, analysing and reporting information about patient experience, and some people were thinking about educational needs and how to meet them. The most immediate and most serious challenges for all the NHS organisations were the fundamental challenges to structural, political and cultural processes that are only met when leaders have the vision, the skill and the time to help services and organisations progress to the next stage of their journey.
Recommendations for local NHS organisations
Based on the findings from the organisational case studies we make the following recommendations to all NHS organisations. These recommendations should be read in the context of our accompanying policy recommendations:

1. Recognise and maximise the value of patient stories

2. Use measures that allow comparison over time and between organisations:
   • collect and use near real time data
   • triangulate quantitative and qualitative data to create a narrative
   • make better use of investment in data collection by making sure it is analysed and reported and integrated into routine governance and management process

3. Demonstrate leadership and organisational commitment
   • integrate patient experience into clinical and financial strategies and establish service level reporting on all the dimensions of quality
   • receive regular reports at the board to create momentum
   • appoint/designate patient leads
   • link patient experience to training and education

4. Dedicate resources to the tasks of capturing, understanding and improving patient experience

5. Establish clear links with commissioners

Recommendations for policy makers and the NHS Institute
Given the relatively early stage of development (see page 28) at which most NHS organisations are in terms of systems and processes for capturing, understanding and improving patient experience we recommend that a structured, reflective tool for enabling organisations to assess where they are in terms of responding to the common challenges they all face should be developed and piloted.

Such a tool would highlight to senior managers in NHS organisations that (as with clinical effectiveness and patient safety) improving patient experience at an individual level requires a consistent and coherent organisational response addressing the following key challenges (Bate et al, 2008):

- how are efforts to improve patient experience structured, planned and co-ordinated?
- how are the politics of improving patient experience negotiated?
- how are shared understandings & commitment to improving patient experience built?
- how do staff learn about how to improve patient experience?
- how are individual and collective enthusiasm for improving patient experience engendered and supported?
• how is the physical, informational and technological infrastructure used to support improvements in patient experience?
• how do the senior levels of an NHS organisation and frontline services contribute to each of above?
• what are the respective roles of the senior management team and frontline services in terms of the successful implementation and spread of efforts to improve patient experience?

Postscript
The preceding pages provide a very brief description of our methods and key findings for each of our three work packages:

1. To establish what matters to patients, particularly in the non-acute sector, and to analyse the implications for how feedback should be captured
2. To review what NHS organisations in England currently measure in relation to what matters to patients
3. To describe examples of NHS organisations in England which are using information and insights into patient experience to improve the quality and productivity of health care services.

A series of supporting appendices provide further details on each of the specific research strands. A separate set of ‘Policy Recommendations’ informed in part by the findings in this project report are also available.
References


• Foot C and Cornwell J. (2010) Improving patients’ experiences: an analysis of the evidence to inform future policy development. London; The King’s Fund


### Annex 1: Summary of work packages and research methods

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<th>Methods</th>
<th>SAMPLE SIZE/DATASETS</th>
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<td><strong>WORK PACKAGE 1</strong></td>
<td></td>
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<tr>
<td><strong>Literature review</strong></td>
<td>Searched the grey literature and electronic databases for studies that explore ‘what matters’ to patients 24 publications that we categorised into: (a) secondary analyses of national surveys; (b) systematic reviews; (c) fieldwork to design survey instruments, and (d) generic frameworks</td>
</tr>
<tr>
<td><strong>Survey of voluntary sector organisations</strong></td>
<td>Letter/email sent to over 300 organisations. Sought information from the websites of relevant organisations. Replies were received from 36 organisations with written materials and/or offer of interview. Analysed over 60 submitted documents. Conducted 18 follow-up telephone interviews.</td>
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<tr>
<td><strong>Patient interviews in five tracer conditions</strong></td>
<td>Narrative-based, tape-recorded interviews with NHS users (patients) and carers with one or more of the following ‘tracer’ conditions: chronic obstructive pulmonary disease (COPD); elective hip replacement; depression; stroke; and diabetes Thematic analysis of all transcripts: initially the researcher looked for emerging themes and patterns that were specific to each of the conditions and then compared the themes across all conditions to determine whether themes were generic or condition-specific 50 interviews were conducted (47 patients and 3 carers) in total; 10 in each of the five tracer conditions</td>
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<td><strong>Secondary analysis of ratings and comments from NHS Choices dataset</strong></td>
<td>(1) Quantitative analysis of GP and hospital ratings (2) Qualitative analysis of GP and hospital comments (1) 3,008 GP postings (14 April to 4 July, 2010) and 454 hospital postings (one week from each of four previous quarters) (2) 550 GP and 550 hospital ‘open’ comments were analysed (coded based on emerging themes using NVIVO qualitative analysis software)</td>
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<tr>
<td><strong>Secondary analysis of ratings from Patient Opinion dataset</strong></td>
<td>Quantitative analysis of ‘Patient Opinion’ postings across 4 service types (but note no overarching indicator/metric) 500 postings relating to community services and 6,700 relating to acute services</td>
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<tr>
<td>WORK PACKAGE 2</td>
<td>Secondary analysis of Dr Foster ‘Patient Experience Tracker’ questions</td>
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<tr>
<td>Review of other countries national approaches to measuring and improving patient experience</td>
<td>Description of contemporary approaches to issue by country</td>
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<tr>
<td>WORK PACKAGE 3</td>
<td>Organisational case studies</td>
</tr>
<tr>
<td>National training survey</td>
<td>An online survey of (a) all English providers of medical, nursing and allied health professions pre-qualification professional training, and (b) of NHS trusts (including PCTs) in England, to access information about in-service training. Case studies following up the survey results.</td>
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Appendix 1: Literature review

We searched the grey literature and electronic databases for studies that explore ‘what matters’ to patients and/or the implications of this for capturing patient feedback. We reviewed 31 publications (see table 1 for details) which can be broadly categorised into:

a. secondary analyses of national surveys studying, for example, correlations in ratings (between either composite measures or single items with overall ‘patient satisfaction’), free text comments or responses from specific sub-groups
b. systematic reviews (for example, of care of the elderly)
c. fieldwork to (a) design survey instruments, including ‘importance studies’ (for example, by Picker or by the Scottish Government), or (b) qualitatively explore views of specific sub-groups (for example, children and young people)
d. conceptual frameworks of ‘what matters most’ to patients (for example, the Institute of Medicine’s six core dimensions of patient-centred health care) and the primary research that underpins them
e. expert opinion and commentary pieces on how the NHS is and/or should capture and use feedback from patients

Other sources provide a wider bibliography of materials relating to patient experience, including the ‘Point of Care - improving patients' experience’ reading list available from the King’s Fund library. The findings from the literature review have informed our findings and recommendations in the main body of our report.

Key findings relating to ‘what matters’ to patients

The fundamental finding from the literature review and our wider knowledge of this topic area is succinctly captured by Shaller (2007) when he quotes one of the experts he interviewed for his project:

“we’ve gathered tons of data, done many focus groups: we know what patients want. The hard part is delivering it.”

Many of the other studies and commentaries summarised in table 1 make the same point by drawing attention to the similarities between their own findings or views and that of previous researchers. For example, Sizmur & Redding point out the ‘core domains’ emerging from their secondary analysis of the 2008 NHS inpatient survey are “similar to those which have emerged, both from other analyses of the same type of data, and from other kinds of research and analysis of what patients value”. Similarly, Bruster (2008) draws close comparison between the findings from his own qualitative work in Scotland and with the five elements of Public Service Agreement on patient experience as identified by the DH in England. And Boyd (2007) reports consistency between the 2002 ‘importance’ study in England with the results of his later repeated study. Given the extensive evidence-base to draw on it is tempting to try to synthesise all the findings into a single over-arching, comprehensive framework; Cronin (2004) previously attempted just such a meta-synthesis of all the different frameworks and proposed sets of domains of patient-centred care or ‘what matters’ to patients. Overall, however, it is important to note that the two best known generic frameworks of patient-centred care are based broadly on the same primary research and that the main findings from this original research (from the early 1990s) have remained relatively unchallenged with only minor modifications and suggested slight reconceptualisations of their constituent domains or dimensions.

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9 We have included these seminal early studies (the IoM (2001) ‘Crossing the Quality Chasm’ report and the Picker/Harvard ‘Through the Patients Eyes’ book (Gerteis et al, 2003) in table 1) although they are not derived from NHS patients.
We would also highlight the increasing attention being paid to the distinction being relational and transactional aspects of care; for example, Parry et al’s detailed analysis of the inpatient and outpatient survey results in the mid-2000s which - whilst also raising concerns about the value of composite measures as we echo elsewhere in our main report - suggests that ‘the quality of relationship with health care professionals, and doctors in particular, does … seem to be an enduring issue in determining satisfaction.’ Similarly, Bridges et al’s (2010) systematic review of the views of older patients highlights the importance of relational aspects of care in terms of determining overall experience.

**Implications for capturing patient feedback**

There are several recent sets of recommendations to NHS organisations as to how to capture patient feedback and use it to improve patient experience (for example, Coulter et al (2009), Department of Health (2009), and NHS Confederation (2010)). In addition, there are various reviews focusing on specific aspects or challenges relating to patient feedback, for example, Brown (2009) on the use of real-time feedback technologies, the National Centre for Health Outcomes Development (2006) on outcome measures for selected chronic conditions, or Wilkinson et al (2009) on surveying hard to reach groups.

A recent, broader review by Picker Institute Europe suggests that the most effective ways to improve patient experience are (a) communications training for health professionals, and changing their consultation style and length to be more patient-centred, (b) making full use of patient feedback to identify priorities for quality improvement, (c) patient-reported outcome measures (PROMs) to improve diagnosis and condition management, and (d) public reporting of these data to stimulate hospitals to improve.

We did not include in the review (the many) sets of recommendations from policy institutes and healthcare improvement agencies in the US on what actions health care organisations should take in order to deliver patient-centred care (for example, Planetree, IHI, Picker US). However, the Point of Care programme at the King’s Fund draws on this evidence-base and collaborates with many of these leading organisations; this thinking has therefore informed our main report and recommendations particularly in respect of advice to practitioners and the need to attend to actions at various levels (individual, team, organisation, system) in order to improve patient experience.
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<tr>
<th>Author, year</th>
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<th>Setting; patient group/condition</th>
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<td>Boyd, 2007</td>
<td>To investigate how inpatients rated the importance of the aspects of care covered by the questions in the 2006 inpatient survey in England</td>
<td>448 patients from eight acute NHS trusts.</td>
<td>Postal questionnaire consisting of 82 statements using a 5-point scale. 54 of the statements were based on core items from the 2006 inpatient survey, 12 from the question bank for the inpatient surveys and 16 were created at the request of the DH. Cognitive interviews with 8 ethnically diverse volunteers with recent experience of inpatient stays in England were conducted to test the questionnaire.</td>
<td>Confidence in the clinical competence of doctors and nurses rate as four of the five top aspects of care; hand washing/cleaning and cleanliness of hospital also rate highly. Top 10 most important (weighted by ethnic group): • doctors know enough about my medical history and treatment • doctors can answer questions about my condition and treatment in a way that I can understand • I have confidence and trust in the hospital staff who treat me • doctors wash or clean their hands between touching patients • nurses know enough about my medical history and treatment • before my operation or procedure, I get a clear explanation of what will happen • risks and benefits of my operation or procedure are explained to me in a way that I can understand</td>
<td>Recommendations made relating to: • the addition of new questions to the national inpatient survey in domains of the core and developmental standards not previously included in acute surveys • current questions that are less useful for performance indicators or quality improvement purposes and could therefore be removed from the questionnaire</td>
<td>Least important of the 82 items was ‘I am not bothered by noise during the day’; another of the ten least important aspects was ‘having a choice about which hospital I am admitted to’.</td>
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<td><strong>Bridges et al (2010)</strong></td>
<td>To explore older people’s and their relatives’ views on and experiences of acute health care.</td>
<td>Older patients’ and their relatives in acute hospital settings</td>
<td>Systematic review of worldwide grey and published literature written in English between January 1999 and June 2008 identified from databases: CINAHL, Medline, British Nursing Index, EMBASE Psychiatry, International Bibliography of the Social Sciences, PsychINFO, and AgeInfo. 42 primary studies and 1 systematic review met the inclusion criteria.</td>
<td>• nurses wash or clean their hands between touching patients  • rooms and ward are clean  • doctors and nurses are open with me about my treatment or condition</td>
<td>A number of themes emerged. The quality of technical care is often taken for granted by older patients, and good or bad experiences are described more in terms of relational aspects of care. Older patients in hospital may feel worthless, fearful or not in control of what happens, especially if they have impaired cognition, or communication difficulties.  Three key features of care consistently mediated these negative feelings and were linked to more positive experiences: “creating communities: connect with me”, “maintaining identity: see who I am” and “sharing decision-making: include me”.</td>
<td>These findings highlight the perspectives of older people and their relatives on the delivery of personalized and dignified care in acute settings. They lend support to previous calls for relationship-centred approaches to care and provide a useful experience based framework for practice for those involved in care for older people.</td>
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<td>Brown, 2009</td>
<td>To explore the methods used and issues involved in gathering, collating and analysing real time patient feedback</td>
<td>n/a</td>
<td>Literature reviews. Initial data gathering exercise via the worldwide web in order to glean an overview of the extent to which real-time feedback data gathering was taking place within a range of organisations, the types of methodologies used to do so, the suppliers of these methods and their customer base.</td>
<td>n/a</td>
<td>• the gathering of real-time feedback can bring clear advantages to an organisation. However it should be clear from the outset where real time fits into its overall strategy for gathering and using feedback • real time can increase the chances of feedback being put to effective use as staff recognise the ‘freshness’ of the information and perceive it as having greater validity. Staff particularly appreciate receiving feedback in the patient or user’s own words as this makes the comments more ‘real’ to them. By effecting immediate changes, based on real-time data, it should also be possible for organisations to better understand what actions have had what specific effect • organisations will need to take into account the needs of all potential users when considering which technology it may wish to introduce all of the above should be considered</td>
<td>Discusses best practice in terms of the methodologies and techniques used and how this feedback is acted upon by organisations across both NHS and non-NHS settings. Authors suggest there are two important questions that remain to be answered: (1) are organisations willing to take the risk and be prepared to innovate in the absence of robust research evidence about whether real time patient feedback makes a difference; and (2) what would be/is a significant enough response rate, for an organisation to act and invest in making changes?</td>
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| Bruster, 2008 | To qualitatively examine the aspects of health care that Scottish patients view as being important | Hospital inpatients; people with a long-term health condition; people with views about general practice services | Eight focus groups and four in-depth interviews. Two additional focus groups to cover BME groups and people from religious/faith groups. Six interviews with lesbian, gay, bisexual and transgender people. Total of 82 patients/service users included in the research. | There were 5 main themes:  
• access to systems and staff  
• environment and facilities  
• good communication and information  
• expert clinical care  
• continuity and co-ordination | Identified what patients and users see as most important issues for them. | Relatively small sample of patients but these findings used to develop larger ‘importance’ study described below (Reeves & Bruster, 2009) |
| Cleary et al, 1991 (non-NHS) | To determine which specific aspects of inpatient care are most important to patients and to document patients’ perceptions of those aspects of care in hospitals nationwide. | 6,455 adult patients recently discharged from the medical and surgical services of sixty-two hospitals selected to represent different hospital types and all regions of the United States. | A national telephone survey about selected aspects of care. The survey questions were designed to focus on specific actions taken by hospital staff. For example, rather than asking patients to rate general aspects of their care such as “the courtesy and helpfulness of your doctor,” survey asked such questions as, “Were you told about the purpose of your medications in a way that you could understand?” | • for twenty-six of the fifty-two questions asked, fewer than 10 percent of patients gave a response indicating a problem.  
• the most common complaint was that patients were not told about the daily routine in the hospital (45 percent).  
• more than 30 percent of patients said that they were told neither what foods they could or could not eat nor important side effects of their medicines.  
• twenty-two percent of the patients said their physicians spent less than five minutes with them | To solicit data that are useful for developing quality improvement initiatives, questions must be as specific as possible. | Although patient characteristics were strong predictors of the number of problems experienced, they explained only 9 percent of the variation in problem scores. This implies that other important organisational and system characteristics may influence the likelihood of problems occurring. |
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<tr>
<td>Coates-Duton &amp; Cunningham-Burley, 2009</td>
<td>To explore the aspects of health care that are most important to children and young people who use NHS services in Scotland</td>
<td>Children and young people in Scotland</td>
<td>Five focus groups comprising 25 children and young people. Some had inpatient experience, most had experience with general practice and other services, and some with long-term conditions or disabilities</td>
<td>Most response options were dichotomous (yes/no), with some follow-up questions to elicit more information about problems reported.</td>
<td>discussing what to do at home, and 37 percent said nurses spent less than five minutes.</td>
<td>Seminal early study that informed development of Picker framework for patient-centred care. See Gerteis et al, (2003) below.</td>
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| Coulter, 2005 | Patients have diverse needs and expectations leading to different, and sometimes conflicting, views on priorities, but it is possible to discern themes: what does the evidence show? | Primary care | National patient survey carried out in all primary care trusts in England, which obtained responses from 116,939 patients (a response rate of 47%). | **Positive experiences:**  
- 92% said they were treated with dignity and respect by the doctor  
- 82% said the doctor listened carefully to them  
- 74% said they definitely had enough time with the doctor to discuss their problem  
- 76% said they had complete confidence and trust in their doctor  
- 85% had complete confidence and trust in other primary care staff  

**Negative experiences:**  
- 41% would have liked more say in decisions about medicines  
- 39% of those prescribed new drugs wanted more information about side effects  
- 70% of patients referred to a specialist were not given copies of referral letters  
- 57% of patients who had phoned the practice had had difficulty contacting the practice  
- 19% of smokers who wanted help to quit smoking had not been offered it | Patients in primary care want:  
- fast access to reliable health advice  
- effective treatment delivered by trusted professionals  
- participation in decisions and respect for preferences  
- clear, comprehensible information and support for self care  
- attention to physical and environmental needs  
- emotional support, empathy, and respect  
- involvement of, and support for, family and carers  
- continuity of care and smooth transitions | Cites a systematic review of the literature on patients’ priorities for general practice care, which examined studies published between 1966 and 1995, found that the most important factor was “humaneness,” which ranked highest in 86% of studies that included this aspect. This was followed by “competence/accuracy” (64%), “patients’ involvement in decisions” (63%), and “time for care” (60%). | 7 |
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| Coulter, 2009 | To provide a brief guide to the various methods for measuring patients’ experience to help trust boards and other interested parties decide which measurement and feedback tools are appropriate for their requirements. | Acute hospitals                  | Expert opinion               | n/a                       |                                 | • key to strategy is robust evidence on the quality of patients’ experience, and that of their families; direct feedback from patients is likely to remain the core method for measuring patients’ experience  
• NHS trusts and commissioning bodies need more detailed and more frequent forms of feedback  
• ensuring that you are measuring the things that matter most to patients is an essential component of a successful strategy for improving patients’ experience; it is important to choose methods that are fit for purpose  
• important to understand the difference between patient experience and patients’ satisfaction, and to be clear about the distinction between patients’ experience of the care process and patient-reported outcome measures (PROMs) |
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<td>Cronin, 2004</td>
<td>To identify similarities and differences across the varying definitions and descriptions of patient-centered care.</td>
<td>n/a</td>
<td>Medline search that identified over 2,800 articles on patient-centred care. Led to review of nine models of patient-centred care.</td>
<td>Forty-five ‘concepts’ were embedded in the models that were reviewed. Six elements appeared in more than two models: • education and shared knowledge (in five of the models) • involvement of family and friends (in five) • collaboration and team management (in four) • sensitivity to non-medical and spiritual dimensions (in four) • respect for patient needs and preferences (in three)</td>
<td>There is no lack of definitions of patient-centered care, and there is substantial convergence and commonality across at least half a dozen key attributes</td>
<td>Used to inform Shaller (2007) – see below.</td>
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<td>Cunnett, 2010</td>
<td>To understand from the perspective of patients and patient representatives ‘what good looks like’?</td>
<td>Patients and patient representatives at Mid-Staffordshire NHS Trust</td>
<td>Four focus groups. Two groups were aimed at patient representatives (n=31) whilst the other two groups were aimed at patients (n=9) who used either inpatients or outpatient services at Mid Staffordshire NHS Foundation Trust</td>
<td>All comments bar a small number of specific statements could be grouped in the following themes (in order of how frequently they were raised): • communication – 26% of total recorded comments • public perception – 22% • management – 15% • being treated as an individual – 9% • dignity and care – 9% • environment – 7% • clinical outcomes – 6% • administration – 4% • hospital as part of the community – 2%</td>
<td>The importance of effective communication at every level cannot be under-estimated, with recognition of the far-reaching personal consequences of not communicating well. The impact on peoples trust and confidence in a hospital due to negative stories, experiences and media is clear and has a profound impact on how a hospital is used and the levels of expectation that are placed upon it.</td>
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<td>Davies, 2005</td>
<td>To develop a framework for understanding factors affecting the use of patient survey data in quality improvement.</td>
<td>A quality improvement collaborative in Minnesota, USA involving teams from eight medical groups, focusing on how to use patient survey data to improve patient centred care.</td>
<td>Qualitative interviews with senior health professionals and managers and a review of the literature.</td>
<td>n/a</td>
<td>Respondents reported three types of barriers before the collaborative: organisational, professional and data related. Organisational barriers included lack of supporting values for patient centred care, competing priorities, and lack of an effective quality improvement infrastructure. Professional barriers included clinicians and staff not being used to focusing on patient interaction as a quality issue, individuals not necessarily having been selected, trained or supported to provide patient centred care, and scepticism, defensiveness or resistance to change following feedback. Data related barriers included lack of expertise with survey data, lack of timely and specific results, uncertainty over the effective interventions or time frames for improvement, and consequent risk of perceived low cost effectiveness of data collection.</td>
<td>Authors concluded that (1) using patient survey data may require a more concerted effort than for other clinical data; (2) organisations may need to develop cultures that support patient centred care, quality improvement capacity, and to align professional receptiveness and leadership with technical expertise with the data.</td>
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<td>Department of Health, 2003. Opinion Leader Research</td>
<td>To develop a ‘Patient Experience Statement’ to encapsulate how patients would like to experience the NHS, with a focus on emotional rather than physical aspects of care.</td>
<td>Former secondary care patients (n=32); participants with experience of private health services (n=16); young people with recent hospital experience (n=6); and people with recent mental health treatment (n=3).</td>
<td>1-day workshops; 1.5hr discussion groups; 1 hour interviews; ‘on-street’ interviews; consultations with public, patients and professionals to inform and test reaction to draft statement.</td>
<td>Although “participants recognised demands on staff and the need for prioritization... there was a strong call for more individual treatment” (p.42); in care of the elderly “those less likely to complain and make demands could lead to their being ignored and staff not spending so much time with them” (61). Value of continuity of involved relationship with health professional and treatment as an individual noted (p.13); participants referred back to traditional values of family doctor (know patient and individual history well) (p.14).</td>
<td>Factors that appeared to have promoted data use included board led strategies to change culture and create quality improvement forums, leadership from senior physicians and managers, and the persistence of quality improvement staff over several years in demonstrating change in other areas.</td>
<td>Small sample of patients 12</td>
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| Department of Health, 2007 | To develop understanding of what matters to patients, public and staff to help connect the transformation of the NHS with these groups | NHS patients | Looked at a wide variety of existing surveys to see what could be learned from them. Then tested initial findings with groups of patients, asking them to refine and prioritise the areas, as well as to put what matters into their own language. Then tested what found with some NHS leaders. | Four areas that really matter to patients:  
• get the basics right (ensure staff are competent; don’t lose my notes; keep the place clean)  
• fit in with my life (make the service easy to access; give me convenient options; don’t waste my time)  
• treat me as a person (listen to me and take me seriously; understand the wider context of my condition; treat me with respect and dignity)  
• work with me as a partner in my health (encourage me to keep control of the process; equip me to look after my own health; give me the support I need) | Preliminary research also identified four very different groups of patients:  
• “better to be safe than sorry” (seeks to minimise uncertainty and manage risk)  
• “health starts with healthy living” (seeks to maintain control over all aspects of health)  
• “really, I’m fine” (seeks to avoid perception of self as weak or a hypochondriac)  
• “I’ll deal with it if it happens” (seeks to minimise pain and inconvenience (including the inconvenience of using the NHS) | Important for three reasons:  
• it makes a difference to how and whether people access services  
• it makes a difference to how they might look after themselves, and hence comply with self-management or medication regimes  
• it makes a difference to health outcomes and patients’ experiences of care. | 13 |
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| **Department of Health, 2009. Understanding what matters.** | Guidance to help commissioners and providers use feedback based on patient and service user experience to transform the quality of services | n/a | n/a | n/a | **The guidance outlines the 8 stages within an ‘experience feedback cycle’:**  
• understand the benefits of patient feedback  
• clarify the purpose and business context for using patient feedback  
• work with patients and staff on methods and measurement  
• collect data on patient experience  
• analyse feedback to provide meaningful information on patient experience  
• use feedback to design and implement service improvements  
• evaluate the results and the impact of the improvements  
• show how feedback has transformed services | Includes ‘top tips’ and questions for Board Members. | 14 |
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<tr>
<th>Author, year</th>
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<tr>
<td>Gerteis et al, 2003 (non-NHS)</td>
<td>To explore the experiences and needs of patients and models of care that can make the experience of hospitalisation more humane.</td>
<td>Acute hospitals</td>
<td>Draws on research conducted by the Picker/Commonwealth Program for Patient-Centered Care - including a national survey of over 6,000 hospital patients (see Cleary (1991) above) and 2,000 care partners from sixty-two hospitals; and focus groups with patients and their family members.</td>
<td>Identified eight dimensions of patient-centred care: • respect for patients’ preferences and values • emotional support • physical comfort • information, communication and education • continuity and transition • coordination of care • the involvement of family and friends • access to care</td>
<td>n/a</td>
<td>This framework clearly defined the patient’s perspective for the first time and served as the foundation for the NRC Picker surveys measuring patient experience of health care.</td>
</tr>
<tr>
<td>Goodrich &amp; Cornwell, 2008</td>
<td>To “consider how we can improve patients’ experience of care”.</td>
<td>NHS acute trusts</td>
<td>The research was carried out in three ways: • qualitative research with patients and families • qualitative research with hospital and trust staff in four hospitals • a literature review. Interviewed eight patients plus two daughters who talked about their mothers’ care in hospital and 10 staff who worked at the same London teaching hospital.</td>
<td>• it is difficult to make meaningful generalisations about patients’ experience of care in English hospitals. • the main sources of information have some strengths and limitations, they can be difficult to interpret and can appear contradictory • need much more detailed data to understand variations in patients’ experience of care within as well as between hospitals, over time and between patient groups.</td>
<td>• ambitions to improve patients’ experience of care will be realised only with the willing co-operation and effort of all staff in direct contact with patients and if the wider organisation provides support and encouragement • patients’ experience in hospital is shaped, directly and indirectly, by organisational and human factors interacting in complex ways at four levels: the individual member of staff, the team and clinical micro-system, the institution and the wider health system</td>
<td>Introduces current debates and dilemmas in relation to patients’ experience of care in hospital, presents factors that shape that experience, and assesses the evidence to support various interventions that are designed to tackle the problems.</td>
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<td>Two qualitative methodologies were used with wider group of hospital staff from four trusts: (1) five mini-focus groups of approximately 75–90 minutes duration.; and (2) nine individual or paired depth interviews of approximately 20–60 minutes duration.</td>
<td>• the standard definition of quality recognised internationally, that of the US Institute of Medicine, has six criteria: patient-centred, safe, effective, timely, efficient, and equitable • the concept of ‘patient-centred care’ is the most frequent in the literature, but means different things to different people. • research investment into the six dimensions of patient-centred care has been uneven and highly specialised; the research evidence is full of gaps</td>
<td>• leadership for improvement at team and institutional levels is absolutely necessary • overall, the evidence of the effectiveness of interventions to improve patients’ experience is patchy, fragmented, and tends to be descriptive</td>
<td>No</td>
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‘How to deliver high-quality, patient-centred, cost-effective care’ (year unknown)

To identify the five key themes that the health and social care system must embrace to be sustainable and to ensure quality.

Range of conditions represented by leading voluntary sector organisations.

Ten leading health and social care organisations in the voluntary sector each submitted evidence to The King’s Fund, which independently analysed and assessed each submission and worked with the organisations to establish a common position.

The five key themes that the health and social care system must embrace to be sustainable and to ensure quality are:

• co-ordinated care
• patients engaged in decisions about their care
• supported self-management
• prevention, early diagnosis and intervention
• emotional, psychological and practical support

n/a

1. having a view of the entire cost of a pathway or patient journey is fundamental to decision-making in the future.

2. the themes identified are linked. Quality will not be improved nor savings made by implementing changes piecemeal. Pathways and patient journeys must be commissioned as an integrated whole.
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<td><strong>Inpatient survey, 2007</strong></td>
<td>To analyse the free text comments written by respondents at the end of the 2007 national inpatient survey</td>
<td>115,209 patients who responded to the 2007 national inpatient survey (almost 60% wrote at least one comment)</td>
<td>Coding frame developed on basis of analysis of small sub-set of comments with new codes added when different themes arose.</td>
<td>One in five patients who commented made a general positive comment about their care and treatment. One if five patients who commented made a general positive comment about the staff. Most frequent negative comments were about understaffing and food.</td>
<td>Most frequently coded comments covered issues that were included in the questionnaire; suggests that questionnaire covers most important issues to readers. Exploratory analysis comparing patient comments with responses to survey questions show that patient comments can go some way to explaining and elaborating the survey findings.</td>
<td>Analysis shows that trusts could use comments to provide further insight into why patients gave poor ratings to certain questions and inform action plans.</td>
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<td><strong>Institute of Medicine, 2001</strong> (Crossing the Quality Chasm report)</td>
<td>The Committee on the Quality of Health Care in America was formed in June 1998 and charged with developing a strategy that would result in a substantial improvement in the quality of health care over the next 10 years.</td>
<td>US healthcare</td>
<td>Detailed review of the literature on the quality of care; a communications workshop to identify strategies for raising the awareness of the general public and key stakeholders of quality concerns; identified environmental forces that encourage or impede efforts to improve quality; developed strategies for fostering greater accountability for quality; and identified important areas of research that should be pursued to facilitate improvements in quality.</td>
<td>Six domains of patient-centred care: • responsiveness to needs, values and expressed preferences • co-ordination and integration • information, communication and education • physical comfort • emotional support, relieving fear and anxiety • involvement of family and friends</td>
<td>The report set out several rules to redesign and improve patient-centred care, including ensuring that care is based in continuous, healing relationships; customising care based on patients’ needs and values; ensuring the patient is the source of control; sharing knowledge and information freely; and maintaining transparency. Also outlined four levels that further define quality care and the role of patient-centred care in each level:</td>
<td>The IoM defined patient-centered care as &quot;providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions&quot;. Goodrich &amp; Cornwell (see above) report that research into the six dimensions of patient-centred care is uneven and highly specialised and the evidence is full of</td>
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<td>IPSOS/MORI 2008</td>
<td>To explore what is driving patient perception, and identifying key local factors that had very significant effects on patient perception.</td>
<td>Explore factors underlying the patient experience from a range of patient surveys (using secondary analyses).</td>
<td>Primary care: Analyses patient experience data for all PCTs and using regression analysis techniques, identified those Trusts which perform best and worst – after taking into account local conditions. Acute care: uses data from the 2006 inpatient survey to study relationship between specific aspects of the patient experience and patients’ overall assessment of the care received.</td>
<td>Acute sector: a limited number of individual aspects of care are highly correlated with overall patient experience. Analysis shows three areas as key drivers of overall inpatient ratings: • treating patients with dignity and respect • involving them in decisions • the cleanliness of the hospital room or ward</td>
<td>Primary care: analysis shows that objective performance measures, such as the standardised mortality ratios and expenditure per patient (reference costs), have little relationship with patient ratings of primary care services. Instead, the nature of local communities has far more impact. Analysis shows that PCT services in areas with high ethnic fractionalisation (the extent of different ethnicities in an area) are highly correlated with overall patient experience.</td>
<td>Authors note that the one gap in their analysis is understanding what PCTs can do to increase patient satisfaction. It’s a gap because the data we’ve been able to access for this report does not provide a ready route into this question.</td>
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1. The **experience level** refers to an individual patient’s experience of their care.  
2. The **clinical micro-system level** refers to the service, department or program level of care.  
3. The **organisational level** refers to the organisation as a whole.  
4. The **environment level** refers to the regulatory level of the health system.
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<td>Breaking down the concept of “dignity and respect” highlights a close association with a number of other individual aspects of care. It confirms the importance of involvement in treatment decisions and cleanliness and also shows associations with the privacy of treatment and pain control.</td>
<td>area), high deprivation, those with a younger population and those situated in London nearly always receive lower ratings of satisfaction than those serving wealthier, older, more homogenous populations. Argues for a more comprehensive measurement of patient experience, taking all these factors into account. Acute sector: found that the nature of the place has much less impact, although as with PCTs, and indeed ratings of the NHS by non-patients, London faces particular challenges, as do trusts serving younger, more ethnically fractionalised populations.</td>
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<td>McKissock, 2008</td>
<td>To collect information and views from a representative sample of the Scottish population regarding their expectations and priorities for the provision of GP services.</td>
<td>1,040 interviews with representative sample of Scottish population.</td>
<td>Respondents asked to rank items across a number of categories that related to patient’s experience of GP practices.</td>
<td>When contacting the GP surgery, ‘getting the right appointment’ was the priority for people. When thinking about visiting the GP surgery a GP surgery which was easy to get to was of principal importance. When seeing a healthcare professional the healthcare professional having personal knowledge of the persons medical history and having access to medical records and test results were of prime importance. When talking to a healthcare professional the healthcare professional having time to not only talk to patients but also having time to listen to them were the main priorities. When being prescribed medicines a range of issues were considered important (being told about side-effects, how and when to take medication, and what the medicines are for)</td>
<td>Findings used to inform the development of a Scottish GP patient survey. Recommends the focus groups and cognitive testing of research tools is undertaken if more detailed prioritisation of factors required.</td>
<td>Large interview-based survey. Note that significant proportion of respondents found it difficult to offer an opinion regarding what aspects of GP services were ‘least important’ to them.</td>
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<td>National Centre for Health Outcomes Development, 2006</td>
<td>To inform the future selection of multi-dimensional measures of patient-perceived health care quality</td>
<td>Asthma, COPD, diabetes, epilepsy, heart failure, and stroke.</td>
<td>A structured synthesis of published evidence for the measurement and practical properties of patient-reported measures that communicate patients’ experience of health care quality of relevance to long-term physical conditions or chronic disease management. A relatively small final total of 22 articles contributed required evidence of development, measurement and/ or practical properties for the included measures.</td>
<td>n/a</td>
<td>Overall, there is limited supporting evidence for the patient reported evaluation of health care quality of relevance to chronic disease; and where evidence is available this is generally not available within a UK setting. No single measure fulfilled all requirements of scientific rigour, content, feasibility and relevance to the UK policy context. However, there is growing convergence towards key dimensions of relevance to the provision of good quality health care for individuals with long-term chronic conditions.</td>
<td>Highlights the need for a well-developed, multi-dimensional, patient-reported measure of health care quality of relevance to chronic disease and the UK policy setting.</td>
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<td>NHS Confederation, 2010</td>
<td>Explores what we know about improving patients' experiences of hospital care and shares the approaches of both UK and USA hospital providers that have made</td>
<td>NHS acute hospitals and US hospitals</td>
<td>Seven organisational case studies</td>
<td>n/a</td>
<td>Common factors across case studies were: • transformational leadership has played a key part • change is effected across the whole system • patients and their families are engaged in care and those experiences are viewed from the users’ perspectives</td>
<td>Brief overview of organisational case studies.</td>
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<td>significant progress in providing services that are truly patient-centred.</td>
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<td>• there is an emphasis on continual feedback from patients, families and carers and measurement for improvement</td>
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- there is a consistent, integrated programme of activities, rather than a series of small random projects
- there is recognition of the importance of embedding desired values and behaviours across the organisation
- staff are enabled to deliver excellent patient experience and empowered to make changes themselves
- there is greater clinical engagement and professional empowerment
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<td>Parry et al, 2005</td>
<td>To assess the coherence between existing domain scores and the items which contribute them. To undertake a factor analysis to either confirm that existing domains are soundly based, or to derive a set of domains. To undertake regression analysis to determine the relative importance of individual domains in contributing to the overall level of satisfaction. To determine whether the relative importance of domains differs in different patient subgroups.</td>
<td>90,763 responses to 2002/03 outpatient survey and 88,308 responses to the 2003/04 inpatient survey</td>
<td>A reliability analysis of the five pre-defined domains (clean, comfortable, friendly place to be; access and waiting; safe, high quality, coordinated care; better information, more choice; and building relationships) Three factor analyses included: • all items used to calculate CHI domains • all items used to calculate PSA domains • all scored items in the questionnaire, irrespective of whether they contribute to a pre-defined domain</td>
<td>Would appear that the relationship between the patient and the healthcare professional they see is a key overall determinant of patient satisfaction, along with the cleanliness of the hospital. Patient characteristics are an important determinant of overall satisfaction: NHS Trusts serving older and sicker patients are likely to have lower satisfaction scores than those serving younger and less sick patients.</td>
<td>The five domains may have some value as ‘broad brush’ headings for aspects of care but they are probably unhelpful in detailed thought and analysis of what determines patient satisfaction.</td>
<td>Findings suggest that the CHI and PSA domains (at the time of this study) for aggregating patient satisfaction surveys may provide some interesting broad-brush conclusions but that the items comprising the domains are not sufficiently coherent to inform policy making aimed at improving patient satisfaction.</td>
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<td>Picker Institute Europe</td>
<td>n/a</td>
<td>Evaluated 31 systematic and high-quality narrative reviews on various initiatives to improve patients’ experience, including studies of direct and indirect feedback from patients (including patient experience and satisfaction surveys); service user involvement in evaluations; consultation styles; and communication skills training.</td>
<td>n/a</td>
<td>Impact on patients’ knowledge: training health professionals to communicate information about medicines improves patients’ knowledge and understanding. Longer consultations in primary care can increase patients’ confidence to take action in relation to their health. Educational material can be helpful for carers. Impact on patients’ experience: patient surveys can stimulate quality improvements, but provider organisations need additional help to implement changes. Patient feedback surveys need to be well planned and carefully implemented. Patient-centred communication and longer consultations in primary care increase patient satisfaction. Communication skills training for clinicians can lead to improved communication, reduced anxiety and greater patient satisfaction.</td>
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<td>Impact on service use and costs: public reporting of hospital performance data can stimulate providers to improve quality. If it is well disseminated and published in a format that patients can understand, this type of information influences public perceptions of a hospital’s reputation, making it more likely that patients will want to go there. One review suggested that improved continuity of care reduces costs.</td>
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<td>Impact on health behaviour and health status: communication skills development for clinicians may improve health outcomes, but some reviews have reported conflicting findings. Reviews of patient-centred consultations found mixed results in relation to impact on health status.</td>
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<td>Raleigh et al, 2007</td>
<td>To examine ethnic differences in patients’ experience of community mental health services</td>
<td>Multiple regression analysis of 2004 and 2005 national surveys of users of community mental health services</td>
<td>27,398 services users (2004) and 26,555 service users (2005)</td>
<td>In the 2004 survey, living alone, detention and hospital admissions were stronger predictors of patient experience than ethnicity. Self-reported mental health status had the strongest explanatory effect. In the 2005 survey the main negative differences relative to the White British were for Asians.</td>
<td>Ethnicity had a smaller effect on patient experience than other variables. Relative to the White British, the Black group did not report negative experiences whereas the Asian group were most likely to respond negatively. There is a need for improvements in services for minority ethnic groups, including access to talking therapies and better recording of ethnicity.</td>
<td>Example of how secondary analysis of survey results can focus on specific sub-groups/patient conditions and highlight ‘what matters’ relative to wider population.</td>
</tr>
<tr>
<td>Reeves &amp; Seccombe, 2008</td>
<td>To assess current attitudes towards the national patient survey programme in England, establish the extent to which survey results are used and identify barriers and incentives for using them</td>
<td>National Health Service (NHS) hospital organisations (trusts) in England.</td>
<td>Qualitative interviews with hospital staff responsible for implementing the patient surveys</td>
<td>n/a</td>
<td>Perceptions of the patient surveys were mainly positive and were reported to be improving. Interviewees welcomed the surveys’ regular repetition and thought the questionnaires, survey methods and reporting of results, particularly inter-organisational benchmark charts, were of a good standard. The survey results were widely used in action</td>
<td>The authors suggest that the national patient surveys are viewed positively, their repetition being an important factor in their success. However, they also argued that the results could be used more effectively if they were more specific to smaller units.</td>
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<td>Reeves &amp; Bruster, 2009</td>
<td>To establish a hierarchy of issues important to Scottish patients receiving hospital inpatient care and to test for differences in priorities among demographic groups.</td>
<td>2,213 people who had been treated as inpatients across in Scotland.</td>
<td>Postal questionnaires asking respondents to rate the importance of 60 items on a five-point scale.</td>
<td>The items with highest importance were grouped into:  - cleanliness and hygiene  - prompt treatment in an emergency  - high quality clinical care  - clear explanations of the patient’s condition, treatment and any risks or dangers  - being treated with respect and dignity</td>
<td>Results used to inform the development of tools to measure inpatient experiences across Scotland.</td>
<td>Striking lack of significant differences in hierarchy of prioritisation among patient demographic groups and among patients who had been treated in different geographical areas.</td>
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| Shaller, 2007 | To explore what it will take to achieve more rapid and widespread implementation of patient-centred care | Inpatient and ambulatory healthcare settings | Interviews with opinion leaders selected for their experience and expertise in designing or implementing strategies for achieving excellence in patient-centred care. | Top 10 most important:  
• a clean ward  
• staff cleaning their hands before touching patients  
• being treated quickly in an emergency  
• getting the best treatment for my condition  
• doctors knowing enough about my condition and treatment  
• clear explanations about what will happen during an operation or procedure  
• being told the risks and benefits of any treatment in a way I can understand  
• clear explanations of my condition or treatment  
• being treated with dignity and respect  
• being told how my operation or procedure has gone in a way I can understand | Includes several examples of integrated, comprehensive ways to achieve high-levels of patient-centred care. Report then identifies strategies to overcome barriers and help leverage widespread implementation of patient-centred care. | Interesting to note least important of the 60 items included ‘having a choice about which hospital I go to’ (similar finding to Picker ‘importance’ study above – see Boyd). |

See also Cronin’s review of frameworks of patient-centred care (as summarised above) which informed Shaller’s recommendations.
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<td>Sizmur &amp; Redding, 2009</td>
<td>Which aspects of patients' experiences of acute care have the strongest relationship to patients' overall satisfaction? Can the national patient survey questions be grouped to provide 'core domains' of patient experience that can be prioritised</td>
<td>Inpatients</td>
<td>Secondary analysis of data from 72,584 respondents to 2008 national patient survey.</td>
<td>The ‘core domains’ for assessing patient experience of acute hospital inpatient care are identified as: • consistency and co-ordination of care • treatment with respect and dignity • involvement in decisions • doctors • nurses • cleanliness • pain control</td>
<td>Seventeen questions identified from national patient survey that, working together, can measure these domains. These questions recommended as priority measure of patient experience.</td>
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<td>Includes (1) organisation-level strategies (leadership development and training; internal rewards and incentives; training in QI; practical tools derived from an expanded evidence base), and (2) system level strategies (public education and patient engagement; public reporting of standardised measures; accreditation and certification requirements)</td>
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<tr>
<td>Wilkinson et al, 2009</td>
<td>To develop a sampling strategy and a set of methods for collecting Hard to Reach patient feedback</td>
<td>Travellers; migrant workers; looked after children; individuals within the criminal justice system; asylum seekers and refugees; BME groups; people with learning disabilities; people with long-term mental health problems; lesbian, gay, bisexual and transgender people; homeless and insecurely housed people.</td>
<td>Literature review</td>
<td>n/a</td>
<td>Broadly speaking, there are two different groups within the Hard to Reach category: On the one hand, there are people who are not ‘heard’, and on the other hand, there are groups of people who do not want to be ‘reached’. The first groups feel that they are consulted and over-researched, but that nothing is done for them, whereas the second groups feels that research on them is an intrusion into their lifestyles. A model for a sampling strategy for Hard to Reach groups has been developed and each of the Hard to Reach groups are discussed individually.</td>
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About the survey
This survey of UK voluntary sector organisations formed part of the scoping work in Work Package One (WP1) of the project - What Matters to Patients being conducted by the King’s Fund and Kings College London, commissioned by the Department of Health. The survey aimed to gather evidence from a wide range of voluntary sector / patient and carer organisations, covering different conditions and groups of people. The study also focused specifically on organisations concerned with the five conditions / pathways identified by the Department of Health as of particular interest for this project:

• Stroke
• COPD
• Diabetes
• Depression
• Elective hip replacement.

Method
We sent a letter / email requesting material to over 300 organisations through various umbrella organisations. We also sent a direct request to some organisations identified as being particularly pertinent to the study as they are concerned with the above conditions / pathways. A reply slip encouraged organisations to offer a telephone interview to further discuss the material and explore other issues in order to gain a good understanding of what matters to the group of patients they were concerned with. We also sought some information from the websites of relevant organisations.

Replies were received from 36 organisations with written materials and / or offer of interview. We analysed and noted over 60 documents, including surveys of members, reports of commissioned research, manifestos, consultation responses, collations of patient stories and experiences, and postings to on-line forums.

We conducted 18 telephone interviews (see annex 1) to explore:

• what matters to people when using health services
• what particularly matters in primary care and community settings
• how they felt these were currently measured by the NHS
• Suggestions for how these aspects might be better measured.
Profile of the organisations
The responding organisations were mostly UK wide (though we received some information from local Age Concern groups). Their intelligence on what matters to patients is drawn from a number of sources. They are nearly all membership organisations providing a range of services to their members and the wider public, including:

- Helplines
- Web-based help with enquiries
- Web-based chat rooms and forums
- Outreach work with local groups
- Support groups
- Direct support services
- Specialist clinics and nurses.

Many also conduct regular surveys of their membership and commission wider surveys and research to seek views and experiences. The intelligence gained from all these sources enables the organisations to have an insight into the concerns of their members and others who use health services and / or live with particular conditions.

How typical are the responses?
It should be noted that strong and established patient organisations with an engaged membership are most likely to be able to respond to a survey of this type. Such organisations tend to be concerned with long-term conditions and so generally may not reflect the views of more episodic users of health services. (It is harder to seek the views of people who have had elective surgery, for instance, through this route). Also, some of the organisations are concerned with relatively uncommon health conditions.

It should also be noted that one organisation made the point very forcefully that some mental health service users either conceptualise mental health in a fundamentally different way to the majority of NHS commissioners and providers, or they may feel that they have been treated so oppressively by mental health services that they choose not to use services if they can avoid doing so. These non-users are unlikely to feel able to make their views known thorough the majority of patient organisations and the extent of their dissatisfaction may therefore go unreported. It is possible that similar considerations may apply to people who cease to use services for physical health conditions too if they feel that their condition and their concerns are not understood.

On the whole though, and considering that we talked to generic organisations such as Age UK, the survey is likely to have captured the views of those who use health services most frequently.
1. **MAIN THEMES**

1.1 **Good information provision**
Information that:
- Is tailored to the individual
- Signposts to further sources of support / information (including non-medical support)
- Communicates what people can expect of the service and their care and treatment plan - setting out who is doing what and when
- Is timely.

1.2 **Having confidence in health professionals**
Health professionals who:
- Are knowledgeable about a range of health conditions and aware of the needs of people with mental health problems, dementia, people with communication difficulties, long-term conditions etc.
- Are able to facilitate speedy access to an accurate diagnosis and to the most effective and preferred treatments and therapies
- Recognise that people are more than an illness or a set of health conditions and are able to understand a health condition in the context of people’s lives.
- Listen to service users (and carers) and treat people as equal partners in their care and treatment
- Respect people’s privacy and dignity
- Are supported by staff (receptionists, porters etc.) who also respect the dignity and privacy of patients.

1.3 **Awareness and understanding**
Our members said that the single issue of most concern is the lack of awareness amongst the medical professionals! (Dystonia Society- Membership survey – the results, 2008)

A common theme across all the organisations we spoke to and across all conditions is the need for more understanding and awareness amongst health professionals about various health conditions. This issue is of particular concern in relation to GPs, and other generalist community based health professionals, but also relates to hospital staff and those working in Accident and Emergency care. This concern was expressed, not only in relation to relatively uncommon conditions, but we were told repeatedly about a lack of awareness in health professionals in relation to common conditions such as depression, diabetes and dementia.

*The main thing is that people often do not get care from health service staff who understand dementia and this causes a lot of problems including communication problems. There is a general lack of awareness and training. People with dementia are core users of health and social services. All staff need some level of training and awareness including porters and receptionists etc. (Alzheimer’s Society, interview)*

This lack of awareness, particularly of long-term conditions, in hospital settings can lead to inappropriate care. When people with diabetes are in hospital, for instance, it really matters that they are able to get suitable food at the times they need it. They also need staff who understand diabetes sufficiently to be able to support them to self-manage their condition. We heard similar concerns in relation to other conditions, such as Parkinson’s disease.
A lack of awareness amongst GPs can cause problems in referring appropriately for diagnosis and specialist care when they fail to recognise or interpret symptoms accurately. Many voluntary organisations consider this to be the cause of delays for patients in getting an accurate diagnosis and access to appropriate treatment and services.

*GPs’ awareness of conditions and their lack of knowledge. They have a lack of awareness of signs and symptoms and an inability to refer appropriately* (Breakthrough Breast Cancer, interview)

*People go to their GP and the response they get is the luck of the draw. Some are fantastic and some are appalling. In many cases only valium is prescribed* (Depression Alliance, interview)

Specialist nurses were commended for their expertise and for being a resource for patients.

1.4  **The right treatment from the right staff at the right time**
A collection of concerns can be summed up as getting the right treatment at the right time from the right staff and in the right setting.

**Access to GPs**
We heard from a number of organisations about the problems people have accessing GPs. People with long-term conditions, and older people, are often concerned to see a particular GP who knows them and has some knowledge of them and their condition. However, they are not always able to see the GP of their choice within a reasonable time.

*Speed of access is an issue. It can take a long time to access help other than medications. But by the time people have plucked up courage to see their GP they may feel they need help quite quickly.* (Together, interview)

*I want to be able to see my doctor when I need to and be able to stay in my home for as long as possible with help* (Extract from Good Life – What is It? Blackburn with Darwen 50+ Partnership, 2008)

Older people, in particular, also want to be able to have a home visit from a GP when they need it.

**Access to a full range of treatments**
Being able to access the full range of treatments and therapies that may be available for a condition, and having some choice over these is very important to people – especially in mental health services.

*Effective treatments exist but only a quarter of all the individuals affected are in any form of treatment – compared with over 90% of people suffering from physical illness. The lack of help offered to older adults with depression and anxiety is particularly shameful* (We need to talk – MIND, 2008)

*There seems to be unanimity that a very important factor is the level of confidence that service users have in their GPs, social workers and psychiatrists, considered as providers of the right type of support* (What matters to mental health patients and their families and carers, Mental Health Foundation, 2010)
Access to knowledgeable staff
It also important for patients to be able to access knowledgeable professionals – specialists and specialist nurses and specialist teams.

Specialist Parkinson’s Disease nurses, however, are phenomenal – a fantastic resource where people can get access to them. (Cure Parkinson’s Trust, interview)

Respondents to the consultation were overwhelmingly positive about specialised stroke units. Many cases highlighted the enormous disparities in care between those who went to specialised stroke units and those who were left in general wards. (Five Demands for Action – The Stroke Survivors’ View, The Stroke Association, 2008)

Support to understand and navigate the system
A number of organisations suggested that people have a better experience when they have a good understanding of the health system and what is available. Voluntary organisations are often providing this help in navigating the system and informing people about the range of treatments and therapies they might find helpful.

1.5 Continuity of care
Continuity – knowing the person offering services and that they know your history and you don’t have to keep repeating yourself. Having to tell the story over and over increases stress. (Age UK, interview)

Continuity of care is a common theme in responses to the question what matters to patients. People want to know what will happen next - what is the plan, who will be providing which parts of their care and how they can contact them.

When transferring from one care setting to another
Good assessment and planning on discharge from hospital or community services is very important and key to the provision of continuity of care. Good support being available in the community, particularly for people following stroke or with other long-term rehabilitation or support needs, is also very important.

Leaving hospital after a stroke can be the most difficult and frightening experience and is the time when stroke survivors suffer the greatest feeling of abandonment. It is startling how many people reported not receiving information on their condition or on local services that are available. Also, it would appear that individual care plans are not issued as standard and therefore many people fall through the safety net, go home and receive no further care. (Five Demands for Action – The Stroke Survivors’ View, Stroke Association, 2008)

I was not given much warning of the ending with my CPN, only told that this would be our final meeting that day. There was no handover or phased ending (What matters to mental health patients and their families and carers, Mental Health Foundation, 2010).

For people with life-long conditions, such as diabetes, the quality of the transition from child to adult services is also very important.
Joined up care
On the whole, people value the professionals involved in their care talking to each other and are frustrated when this does not happen. Having coordinated appointments to avoid the experience of having to attend a number of different appointments about the same condition within a short space of time is greatly valued and demonstrates recognition that people have lives other than their illness.

Again, specialist nurses are valued for the continuity they provide and the fact that they often provide contact phone numbers, including for out of hours contact, and will respond to email enquiries from patients.

1.6 Being treated as a person
Across a range of conditions, we heard that patients want to be treated as a person, not just seen in terms of their illness or as a collection of symptoms.

They wanted a health service that:

- Recognises that people have lives beyond their relationship with the health service and ensures better coordinated care and more flexible access in order that people are better enabled to fit management of their health and illness around their work, caring and family responsibilities.
- Ensures that on-going support is available to people once they have left hospital with long-term rehabilitation needs or a long-term condition.

Linked to this is the commonly expressed view that the effects of illness are not just pain, immobility or other symptoms. People are concerned about the effect of their condition and on everyday life, for example, on their ability to work, maintain relationships and enjoy life.

We need a compassionate care approach – to treat someone a bit kindly – to see them as a person (Alzheimer’s Society, interview)

People like to be treated as individuals with their own lives, and not just as a mental health problem with a person attached. The person should always come first and those providing services need to recognise that people do not want to be defined solely in terms of their mental health problems (What matters to mental health patients and their families and carers, Mental Health Foundation, 2010).

Communication
Good communication helps people feel that they are being seen as individuals, with a range of needs. Basic aspects of communication, such as access to interpreters, and appropriate communication with people with disabilities were mentioned by some groups and are clearly important, but more frequently, it is the ability (or otherwise) of staff to listen and to show that they care about the person that defines how communication by health staff is perceived.

What matters to me is being listened to, believed, taken seriously and feeling like what I say matters and having a say in what happens to me.

(Crisis service user in What matters to mental health patients and their families and carers, Mental Health Foundation, 2010)

It is clear that good communication is not a luxury or an optional extra. As well as impacting on personal wellbeing, it can affect patient safety, the quality of patient consent and the integrity of the care plan.
A PEG was inserted on the Friday. "Just sign here" a note written across the medical records to indicate I was giving my consent. I gladly gave that consent but I was not told of the implications of that consent, i.e. not being able to withdraw it if the situation changed. (John Backhouse RIP)

(Survivors’ stories – strokes in adulthood, Different Strokes, 2010 http://www.differentstrokes.co.uk/)

My psychiatrist used to come to my care plan meeting and he wouldn’t say a word to me, if he said anything it would always be to one of the professionals. I felt like he was looking down his nose at me. It made me feel really bad about myself and it made my mental health get worse. I got more and more depressed. It matters to me that I am treated like a person, not a problem.

(Crisis service user in What matters to mental health patients and their families and carers, Mental Health Foundation, 2010)

Several organisations suggested that training for staff is necessary and could help both their awareness of a range of conditions, and their communication skills.

**Being treated with dignity and respect**

Older people are particularly vulnerable to seriously poor practice such as having to use a commode behind a curtain or being disregarded because of their age.

The need for respect applies just as much to smaller things such as being wrongly addressed or being patronised and there were occasional reports of patients being reluctant to access services for fear of being looked down on. Individual kindness is important too. Indeed, it is apparently smaller things that can transform a patient’s experience, for better or worse. These are only small things in so far as they are not directly about patient safety or clinical care – but they matter greatly to patients.

It’s impossible to overestimate the value of a really good, efficient, friendly receptionist (Walking Through The Patient Journey, The Breast Cancer Group for Cancer Reform - Breakthrough Breast Cancer)

When you have a lifelong condition, you need a feeling of trust and rapport with the medical team. If you feel they are not listening to you and being understanding that can be a source of distress. It does happen. (National Rheumatoid Arthritis Society, interview)

**Respect for culture and diversity**

Respect must be based on a recognition of diversity, and several organisations reported room for improvement. For example, a group of older people reported a lack of understanding of religious beliefs from staff, as well as insufficient sensitivity to the requirements of elders who asked specifically for either a male or female member of staff.

A mental health organisation pointed to their research findings about men feeling that GPs/primary care services are aimed at women, for example, on posters and in the healthcare environment. We were also informed that the specific needs of gay men are not always well addressed.
Understanding emotional and psychological issues
Most organisations highlight the importance of emotional and psychological support, and for support in relation to sexual and relationship issues associated with the patient’s health condition. Support is as essential for people with physical health problems as for those with mental health problems, and for carers as well as for patients.

*The provision of emotional and psychological support should be an integral part of a diabetes service. Emotional and psychological needs of a person with diabetes have to be properly assessed in partnership with the person as part of the care planning process. It is important that people are made aware of the support available, so that they are able to choose if and when they need to access it.*

*(Improving supported self-management for people with diabetes. Diabetes UK, 2003)*

Several organisations noted that depression could be associated with other health conditions, and that support is needed for people with depression. Unfortunately, we heard of some very poor experiences of getting support, particularly from mental health service users.

*I watched my daughter die, a few weeks later I was told by my psychiatrist to pull myself together, and that I had to just get on with my life. I still haven’t been offered any counselling.* (Crisis service user in What matters to mental health patients and their families and carers, Mental Health Foundation, 2010)

*I had to wait over a year for an advocate, it was horrible because I needed the support straight away. Access to support services straight away would have helped my mental health not to get as bad as it has done.*

*(Crisis service user in What matters to mental health patients and their families and carers, Mental Health Foundation, 2010).*

Appropriate involvement of family and friends
Families and friends have a major role in supporting patients, and need information and support themselves too.

*If my family had any suggestions to make it would be that there should be more, readily available advice and information for family and carers early on in the recovery process.* (Alwyn James age 55 in Survivors’ stories – strokes in adulthood, Different Strokes, 2010 [http://www.differentstrokes.co.uk/].)

1.7 Partnership with professionals
Many organisations told us about the importance of partnerships between patients/carers and professionals. There are several aspects to this, with information being by far the most frequently mentioned as without it neither patients nor their carers can be equal partners in decisions relating to their own treatment and care.
Access to information in appropriate media at the right times

Lack of information can lead to misconceptions, anxiety and fear. When information is provided, it is sometimes based on what health professionals think patients and carers want to know, rather than addressing patients’ actual concerns. (Nobody told me – highlighting the importance of information for stroke survivors when they leave hospital, Stroke Association, 2007).

There are shortcomings in both medical and non-medical aspects of information and these were mentioned by almost all the groups who provided material for this study. Sadly, in spite of some good practice, inadequate information is reported as a problem at all stages of the patient experience, and in both hospitals and community settings.

In particular, we heard that information is not offered at appropriate times, and that a one-off approach to information is seldom satisfactory as needs change according to the patient’s condition and their expertise in living with it.

.. it needs to be the right information at the right time. Often, patients are just given an information pack, but they can’t take it all in (Breakthrough Breast Cancer, interview).

Information at diagnosis is very important, but in a whole range of conditions, including neurological conditions, diabetes and rheumatoid arthritis, information at diagnosis is inadequate. Equally, information is sometimes inadequate later on, particularly when patients leave hospital and when treatment comes to an end. This has major consequences on patients’ abilities to manage their own conditions.

What matters to patients includes full and accurate information, planning for and provision of the next step. There are often significant gaps here.

(What matters to patients – members’ views, Encephalitis Society, 2010)

Patients want more information about services and treatment options and they want to know about possible side effects of treatments. Where this is not available, they feel insufficiently involved in their own care.

Personalised information

While leaflets, DVDs etc. are necessary and important, patients want information that is personalised to their own needs and circumstances. This can be done by complementing generic material with verbal information including telephone helplines, electronic media and by material tailored to individual needs and circumstances. For example, we heard of problems particularly for people who cannot easily read English, and for people with communication difficulties e.g. people who have had strokes and those who are dysphasic because of strokes or other conditions.

Getting personalised and specific information is also very important. Including information about what to do on discharge from hospital. People need to be given an opportunity to talk about what the information means for them. These are all common issues for all conditions, but with stroke there is also the particular communication difficulty.

(Stroke Association, interview)
Groups of older people emphasised their wish to stay healthy and therefore they needed information on diet, exercise etc., yet they did not always know how to get such information or who could provide it. The National Rheumatoid Arthritis Society suggested that people needed a ‘route map’, especially to steer people to reliable sources on the internet.

**Support for self-management**

We heard a great deal about self-management and how patients need the support of professionals to self-manage effectively. For example, people with COPD should be given advice about taking exercise as well as rehabilitation where appropriate.

Across a range of conditions, people encounter difficulties in getting support to self-manage in hospitals and care homes. Also, inappropriate assumptions are sometimes made about people’s ability to self-manage (e.g., for people with diabetes who also have mental health problems). In some instances, this reflects the lack of awareness and understanding of health professionals about the characteristics and consequences of particular health conditions.

**Signposting to support in the community**

Signposting to support and self-management is seen as very important, but it is offered patchily. We heard that there is significant value in health professionals signposting their patients to additional support from voluntary and community organisations, who are often well placed to offer advice, support, information in relation to a range of non-medical aspects of people’s lives. Partnership with professionals can be enhanced if professionals are more proactive about signposting to sources of support that they cannot reasonably be expected to offer. This might include signposting to both peer support and support from others with specialist knowledge of, for example, benefits and employment opportunities.

A large number of respondents rated the information and support they received from Arthritis Care very highly, suggesting that there is significant value in health professionals signposting their patients to additional support from charities such as Arthritis Care (Arthritis Hurts – the hidden pain of arthritis, Arthritis Care, 2010).

There isn’t always a match between what might be helpful and what people ask for. If you go to the doctor and say words like “depression” you get prescribed anti-depressants. But there might be other non-medical help you could get linked in to, e.g. to go for a walk (Together, interview).
2. To what extent are the themes generic?
Many of the findings from voluntary organisations show a remarkable consistency both across conditions and in relation to the various sectors (e.g. primary, secondary and specialised/tertiary care).

Awareness and understanding and access to appropriate and timely treatment
Insufficient awareness of a range of physical and mental health conditions, particularly in primary care, is common. This unfortunate situation is not limited to rare conditions, but applies also to conditions such as breast cancer and depression. As a result, diagnosis is often delayed and treatment is not started at the earliest opportunity.

When patients are in contact with specialised services and with specialist nurses they report a much more positive experience.

Continuity of care is a particular issue for people with long-term conditions.
People with mental health problems and their organisations express concerns about a lack of choice about treatment options, and, therefore, a lack of access to an appropriate range of staff.

Being treated as a person
Virtually all organisations emphasise that it is important for people with all kinds of health conditions to be treated as a person with dignity and respect. Older people have particular issues in relation to dignity and respect and this may reflect the persistence of ageist attitudes. Concerns about not being treated as a person are also particularly emphasised by organisations that work with people with communication difficulties, such as those who have had a stroke. We also noted particular concerns about impersonal or undignified interactions when people are afraid, or feel vulnerable and exposed – patients with breast cancer being a case in point.

Cultural sensitivity is particularly mentioned as an issue by older people and their organisations, in relation to the needs of BME elders. In mental health services, specifically, we heard that services are sometimes considered to be oriented towards women, particularly in primary care. A lack of understanding of issues for gay men in mental health services was also noted.

Partnerships with professionals
Concerns about partnerships with professionals are largely generic, with the need for personalised information, appropriate to individual needs, being a particular issue for people whose conditions change over time. Patients whose treatment comes to an end also report concerns about information at that stage.

The need for information and signposting towards self-management is commonly expressed across a range of conditions, but is particularly important where the ability to work or maintain relationships may be affected. This applies, for example, both to people with depression and to people with conditions as diverse as stroke and arthritis.
3. Measuring patient experience

Voluntary organisations representing patients identify a number of problems and acknowledge the challenges with the way that NHS organisations currently measure the aspects of patient experience that are considered important to them. They make suggestions about the general approach to measurement and the kind of questions that might be asked in order to better understand patient experience. On the whole, the organisations are keen for there to be greater involvement of service users and carers in patient experience measurement and make suggestions about how this could be achieved.

How the NHS currently measures patient experience

The difficulties of trying to capture the quality of inter-personal relationships through the standard NHS surveys are acknowledged:

_This is about people and relationships – this is not easy to count – it is too qualitative_ . . . _You need to have a conversation – I am not sure this can be done in a questionnaire_ (Diabetes UK, interview)

_It is very difficult e.g. you can’t measure kindness, though you can ask people about their experiences_ (BLF, interview).

The limitations of electronic patient experience trackers was specifically mentioned by some and alluded to by others and the importance of actually talking to people in order to understand their experience was stressed.

_It’s about capturing people’s stories. Story-telling works. It can take time and resources but the outcome is very rewarding. Technology has its place, but personal contact is very important in recording what matters to people, and their experiences_ (Age Concern Dorset, interview).

There are also concerns that this can be a “tick box” exercise and patient experience data is not used to improve services:

_Multi-disciplinary teams are required to undertake patient satisfaction surveys. …but these are not analysed in a meaningful way and may not be taken to the Trust or PCT, and especially not fed into commissioning_ (Breakthrough Breast Cancer, interview)

_Satisfaction surveys are usually difficult in that people appear satisfied but it doesn’t tell you anything. It gives no information about how to improve services_ (Carers UK, interview).

There are concerns that current measurement tools, particularly in primary care, do not ask about the aspects of care that concern patients:

_In the GP survey you are asked more about the surgery than you are asked about the things mentioned above [what matters to patients]_ (BLF, interview)

_Sometimes you get into the detail of measuring patient experience, so you get infinitesimal details about the receptionist, but not “did it help”?_ (Together, interview).

Some organisations suggested that complaints might be used more to capture patient experience.
Finally, it was pointed out that patient experience surveys rarely capture the experience of carers as they do not address issues important to carers themselves and do not ask them for their perspective as carers using the service, only as proxies for the service user.

**Suggestions for aspects to measure**

A number of suggestions were made about the kinds of questions that might be asked to better capture what matters to patients:

- **The GP survey is OK, but it does not really ask the questions our members are concerned about e.g. “Did the GP signpost you to the right source of expertise and support?”** (Diabetes UK, interview)

- **The GP survey questions don’t tease out about the process of diagnosis and whether diagnosis was made the first time the patient went; and was the patient given information about their condition?** (BLF, interview)

Other suggestions for improvement of the GP and other national surveys were:

- Measuring waiting times to see your preferred GP
- Asking about the content of information received and whether it was individualised to the person and whether it was timely and appropriate

A good question might be asking both the stroke survivor and carer whether they knew where to go for help and advice and further information once they left hospital (Stroke Association, interview).

It was also noted that there is a need to better track how people move between services and the experience of transition and joined up care. This is particularly important for older people who may have multiple conditions.

**How service users and voluntary organisations could be more involved**

It was suggested that service users could be involved in both framing the questions to be asked and in capturing the patient experience information:

- People could be involved in defining what they think is important and relevant in their area – if outcomes come from the people themselves then it is more relevant and quality could really improve (Diabetes UK, interview)

- Older people could be involved in designing the questions to be asked e.g. to ensure they are in language that people understand... We could use older people through the forums to capture that information, as trained volunteers (Age Concern Dorset, interview).

A number of organisations had experience of training service users to work as researchers and advocates to explore and capture the views of other service users. Some had experience of capturing the views of those who are often thought of as harder to reach, such as frail older people, people with dementia and people with mental health problems.

One organisation observed that user involvement was possibly better in larger NHS Trusts than in local GP practices.
ANNEX 1

List of organisations interviewed

Age Concern Dorset
Age UK
Alzheimer’s Society
Arthritis Care
Breakthrough Breast Cancer
British Lung Foundation
Carers UK
Cure Parkinson’s Trust
Depression Alliance
Diabetes UK
Dystonia Society
Lupus UK
Migraine Trust
Mind
National Rheumatoid Arthritis Society
The Stroke Association
Together
Trigeminal Neuralgia Association
Appendix 3: Patient/carer interviews

Aims
Our research activities seek to identify gaps in the evidence base for patient experience which has been identified as a priority area of delivery in the NHS. The study aims to provide evidence about what matters most to patients and carers, with a particular focus on non-acute care settings. Our study draws on the existing work undertaken in this area by The King’s Fund, the Department of Health, and others as well as the plethora of policy briefings, reviews and numerous other publications related to patient experience of which we already have a detailed knowledge.

Methods
The study included fifty narrative-based, tape-recorded interviews with NHS users (patients) and carers with one or more of the following conditions: Chronic obstructive pulmonary disease (COPD), elective hip replacement, depression, stroke and diabetes. The sample included 47 patients and 3 carers. The aim was to explore patients’ experiences along one or more care pathways, with a particular focus on the non-acute sector. Taking a pathway approach, the patient journey for any particular care episode, treatment or management requires the involvement of many agencies. Understanding the ‘touch points’ along the journey which are important from a point of view of a patient’s experience was key. These ‘touch points’ were translated from a patient perspective into what this means for an individual organisation, so that those with the responsibility and the means for service change (e.g. providers and commissioners) are able to act on the captured patient experience. The five conditions were selected in consultation with the NHS Institute and Department of Health. They were based on the following pathways:

- a long term condition in which effective self-management contributes to better clinical outcomes
- a simple elective procedure either requiring or not requiring an overnight stay in hospital
- very intensive use of primary, community and acute services by patients with complex needs and co-morbidities
- a condition for which conventional wisdom supports the transfer of significant aspects of care away from acute hospitals and into the community
- a mental health condition

Recruitment
In order to maintain confidentiality, patients were recruited via relevant voluntary organisations, patient groups or local health services. A purposive sampling approach was used. We provided the organisation/group with clear guidance for identifying potential participants in the research. This involved asking them to include patients who were relatively well and who were being cared for during a specified time period. Patients recruited to the study were over the age of 18 and had one or more of the selected five conditions.

Patients were recruited to the research using one of two approaches: We provided the organisation/group with a pack to send to patients’ home addresses on our behalf. The packs included a covering letter explaining how they had been selected, a patient information sheet providing details of what participation will involve, and an ‘opt in’ sheet for patients to return to the research team. The patient information sheet and covering letter both made clear that participation was entirely voluntary and that patients could withdraw at
any time without giving a reason. The researcher (VT) also attended organisation/group meetings and introduced the project, giving a brief overview of the project, what it would involve and providing the group with an information pack including a patient information sheet and an ‘opt in’ sheet that they could hand in or return by post (in a reply paid envelope). The ‘opt in’ sheet would permit the researcher to contact the patient directly.

Once a patient had opted in to the research, a member of the research team (VT) contacted them to further explain the project and invite them to take part in an interview, either face to face or by telephone. Before each interview the researcher (VT) clearly explained the project and gave the patient the opportunity to ask questions. Patients were then asked to sign a consent form or for telephone interviews, the consent form was read to the participant and recorded oral consent was obtained. The consent form confirmed that they understood the information sheet and that their participation was voluntary, that they were free to withdraw at any time, without necessarily giving a reason and that they agreed to take part in the study.

Twenty-four interviews were conducted face to face and 26 by telephone. Face to face interviews were conducted at an agreed meeting place either in the patient’s home or in a meeting room arranged at the patient’s convenience. Nineteen interviews were filmed for use on the Healthtalkonline website. It was agreed with Oxford University that all hip replacement and COPD interviews would be filmed as a trade-off for access to the Healthtalkonline library which holds transcripts of interviews with people with depression. Therefore, 20 interviews were also filmed - 10 COPD and 10 hip replacement. All 50 interviews lasted approximately one hour and was audio recorded to allow verbatim transcription of the data and subsequent analysis. A semi-structured interview schedule was used. Transcripts from all interviews with staff and patients were anonymised and stored on password protected computers, with hard copies stored in a locked filing cabinet, in a locked office at Kings College London.

Interview transcripts were analysed thematically. The aim was to capture the key ‘touchpoints’ for all patients throughout the patient journey; those moments that really shaped their overall experience of care. Initially the researcher looked for emerging themes and patterns that were specific to each of the conditions. Only themes that were mentioned more than three times for each condition were included in the final list of themes. The researcher then compared the themes across all conditions to determine whether themes were generic or condition-specific.

**Results**

An analysis of the interview transcripts revealed that there were twenty emerging themes about what is important to patients when receiving care (see Table one). These themes were categorised into ‘functional’ or ‘relational’ aspects of care. A functional aspect of care is defined as “care that meets the preferences of the patient as far as timings and locations of appointments are concerned... that meets needs diagnosed with accuracy for an individual using genetic and other data”. A relational aspect of care is defined as “care that forms part of an ongoing relationship with the patient and perhaps the family...in which someone gives a hoot about what experience is and the outcomes are” (pp14 Taking it to the limit). Our study results show that relational aspects of care are what mattered most to patients. Themes such as ‘being treated as a person, not a number and staff who listen and spend time with patients were considered important aspects of care among patients.
### TABLE ONE: Functional or relational themes

<table>
<thead>
<tr>
<th></th>
<th>Functional</th>
<th>Relational</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being treated as a person, not a number</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Staff who listen and spend time with patient</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Individualised treatment and no labelling</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Using language that is easy to understand</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Finding out about the latest technologies and innovations medications</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Feeling informed, receiving information and being given options</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Patient involvement in care and being able to ask questions</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>More public awareness about condition</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Efficient processes</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Knowledgeable health professionals</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Aftercare support</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Positive outcomes</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Continuity of care</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Good relationships and positive attitudes among staff</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>The value of support services</td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

An analysis of interview transcripts reveals that there were generic themes across all conditions but that there were also themes that were condition-specific (see Table two).

The most commonly reported themes across each condition were:

1. Feeling informed and being given options
2. Staff who listen and spend time with patient
3. Patient involvement in care and being able to ask questions
4. Being treated as a person, not a number
5. Efficient processes
6. The value of support services
7. Individualised treatment and no labelling
1. Feeling informed- receiving information and being given options
One of the most common themes across all five conditions related to what matters to patients was feeling informed and being given options about what is available. Patients with depression felt that staff had little understanding about their condition and as a result felt they were passed from one health professional to another. Patients with other conditions felt that they needed more information. For patients with diabetes, receiving information about their condition at diagnosis was important. Patients having hip replacement felt the most crucial times for receiving information were before and after surgery. COPD and stroke patients felt they needed to be kept up-to-date about their condition and carers needed more information about their role in patient care.

Well, nobody tells you about aphasia; you’ve had a stroke, but why is my speech like this? ‘Well, you’ve had a stroke.’ It was never mentioned, aphasia was never mentioned until I went to the speech therapist. So you just muddle your way through, really. As I say, your mind is in turmoil anyway. And it would be nice to be told, ‘You’ve got this,’ or, ‘You’ve got that,’ instead of, ‘Oh, you’ve had a stroke.’ (116-stroke)
Nobody visited me and talked to me about it, I was just given a lot of booklets and pamphlets. So I didn’t have any visit or a one-to-one with anybody when I was diagnosed. So maybe a one-to-one with somebody will have helped because I didn’t know anything about diabetes. (129-diabetes)

I think before an operation everybody needs a lot of explanation, and people need the truth. Why it took me so long to come to terms with it was simply because I had worries from what people said, not what the doctor said, and if I’d had it talked through a lot more with the GP or with the consultant I might have come to terms with it better. (Hip03)

2. Staff who listen and spend time with patient
Patients across four conditions (COPD, diabetes, depression, stroke) felt that it was important that staff take the time to listen to patients.

Time, and caring healthcare professionals is important. They need to take an interest so you don’t feel neglected. You need to feel secure. No one has got any time for you anymore, it’s just like, you know, they try and get you out of hospital as quick as they can anyway, don’t they? So it would be nice if they just took a step back sort of thing. (116-stroke)

I think not being patronising is important. I think listening to the patient. It’s having a sense of humour. It’s having a bit of empathy with the patient and the fact that it’s not always easy. And yeah, generally, you know, having a little bit of time. I think even though one of the things about DSNs, diabetes specialist nurses, is that whilst I know they’re always horrendously overworked, they always seem to be able to find a minute or two to just go, ‘Look, how is everything?’ Not on a kind of, ‘We’ve got to answer these questions and tick these boxes,’ way, but more on a kind of, ‘Right, are you okay?’ level, which is... just as simple as that can make the difference between really liking the team and having difficulties. (123-diabetes)

3. Patient involvement in care and being able to ask questions
Patients across four conditions (COPD, diabetes, Hip replacement, Depression) emphasised the importance of being involved in their own care and treatment decisions.

It certainly happened very quickly for me and I think for other people – your GP refers you to them, you get seen by a psychiatrist, and you get given some medication. I never sensed, you know, they talk about a care plan approach, and I never sensed that there was any kind of discussion with me, or I think with anybody else, about what treatments were suitable for me and what would help me to get through and recover. It really was just a case of, ‘We dish out pills, you can try these.’ (099 depression)

I do try and take a participatory standpoint, like I feel it’s a two-way thing with the doctor. I think it’s important that you know as much, that you work with them, and I do find that that really helps if you start a dialogue and discussion rather than going in and making demands, or going in there without any information, it really helps facilitate all the processes. I think it all makes a big difference. So I don’t expect them to cure everything. I expect that I need to be engaged and involved, and do all the right things as well. (Hip02)
4. Being treated as a person, not a number
Patients across four conditions (COPD, Hip replacement, Depression, diabetes) felt it was important to receive personalised care, to be treated as a person, not a number. Many felt that satisfied when they thought the doctor was concerned for their wellbeing.

*It’s the small things that matter really. A lot of the time, the frustration is the people who man the reception. Too often you feel as though you’re in the way. The X clinic, there’s always a lady, be at the other side of the receptionists, ‘Hello, Mr X, how are you today? Now you’re going to see Dr So-and-So and Dr So-and-So. We want to take some bloods from you. Will you sit down over here?’ It’s being treated nicely as opposed to, ‘No, we haven’t got your name. We don’t know which clinic you’re going to. Wait here.’ Sorry, I sound bitter and twisted, but it’s the way it comes across.* (038-diabetes)

*I feel like they’re trying to treat too many people at once, so everyone becomes a low priority. And their priority is getting people off their waiting list. And you just feel like a statistic rather than a person with problems.* (096-depression)

5. Efficient processes
Patients across four conditions (COPD, depression, hip replacement, diabetes) emphasised the importance of efficient processes, related to administrative processes as well as speed and efficiency of appointments and referrals.

*That whole process which I think is more of a sort of sausage machine of having your bloods taken six-monthly and getting your results back and seeing the GP...seems to work very efficiently. So just little things like the appointments seem to run on time, when you go in to see the nurse to take the blood, you’re in and out quite quickly, it’s not a big drama. And the service just seems to be very well-tailored for what it’s supposed to do. And it’s very efficient, or it seems to be very efficient.* (104-diabetes)

*I was impressed by the way in which the NHS responded to the initial diagnosis, sorted out the operation, and then sorted it out again when I had to cancel it. I felt the arrangements that were made were very supportive and helpful, and clear, and so that at every stage you knew what was coming next and the likely timescale so that you could sort out arrangements.* (Hip06)

6. The value of support services
Patients across three conditions (Depression, diabetes, COPD) spoke about the value of support services in relation to emotional and psychological support.

*The Depression Alliance have a whole lot of things going on there. They have a support group, but they also have lots of other events and things going on, I’ve only sort of recently joined them, but they do lots and I find it quite helpful because you don’t just feel alone in the depression.* (097 depression)

*Diabetes UK have been really good, they have a monthly magazine, or bi-monthly, called Balance which has lot of good information, which I always used to have. And I used to attend a few of their Living with Diabetes days, which I really enjoyed and enjoyed meeting other people. You get a lot of information from other people with diabetes actually, which you probably don’t get through healthcare professionals, which is really helpful.* (119-diabetes)
7. Individualised treatment- no labelling
A lack of awareness and understanding about mental health conditions meant that patients were often labelled and not given individualised treatment and care. Patients across three conditions (COPD, Hip replacement, Depression) talked about such experiences.

I suppose it’s natural, but young health professionals do sometimes tend to stereotype you. They see an old woman with a Zimmer frame in the hospital and they, they kind of think that you go around all the time like that. One young woman said to me, ‘What do you usually use to get about?’ and I was puzzled for a minute, and then I said, ‘My legs.’ So she said, ‘Oh, you don’t use a stick or anything?’ and I said, ‘No.’ And, and I think that is something that they [laughs] could be careful about. Just because you’re in hospital and you’ve had an accident, it doesn’t mean that you’re always dodderly and going around like that. (08-Hip)

Themes that were condition-specific included:
1. Positive outcomes (Hip replacement)
2. Using language that is easy to understand (COPD)

1. Positive outcomes (Hip replacement)
Hip replacement patients spoke about the impact of a positive outcome on their lives. This is one of the aspects of care that mattered the most to them. This differs to all other patients in this study who are dealing with long-term conditions.

It saved my life. I mean if I’d had to go on in the pain I was in… I have a friend and both of his hips started to go and he said, ‘If I can’t do anything about it I’m going to kill myself because I just can’t stand it.’ People who have arthritis know how painful it is… if you have it in your fingers first just imagine that in your hip…it’s life affirming. (Hip09)

2. Using language that is easy to understand (COPD)
Using language that was easy to understand mattered to COPD patients who often were trying to come to terms with their condition:

The way doctors used to speak to you… they spoke to you like a human being and they spoke in everyday language, they didn’t use medical jargon, they spoke to you so you could understand what was going on, and that made a big difference. (COPD02)
Appendix 4: Analysis of NHS choices ‘postings’

In order to inform WP1 (‘what matters to patients’) we undertook a series of secondary analyses of postings made to the NHS Choices website. The postings from patients comprised of responses to a series of rating-scale questions and open comments. We analysed postings relating to (a) GP and (b) hospital care.

Tables 1 and 2 below details the frequency of postings per practice and hospital for the periods we studied. The GP dataset comprised 3,008 postings made during the period 14th April to 4th July 2010 whilst the hospital dataset comprised 454 acute postings (one week from each of the four previous quarters).

In the GP dataset (table 1) the majority of practices (66%) had received only one posting in this period; 38 practices nationally had received six or more postings:

**TABLE 1**  
GP postings (3,008 postings during 14th April - 4th July 2010)

<table>
<thead>
<tr>
<th>Response per practice</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1328</td>
<td>66.07</td>
<td>1328</td>
<td>66.07</td>
</tr>
<tr>
<td>2</td>
<td>426</td>
<td>21.19</td>
<td>1754</td>
<td>87.26</td>
</tr>
<tr>
<td>3</td>
<td>149</td>
<td>7.41</td>
<td>1903</td>
<td>94.68</td>
</tr>
<tr>
<td>4</td>
<td>46</td>
<td>2.29</td>
<td>1949</td>
<td>96.97</td>
</tr>
<tr>
<td>5</td>
<td>23</td>
<td>1.14</td>
<td>1972</td>
<td>98.11</td>
</tr>
<tr>
<td>6</td>
<td>20</td>
<td>1.00</td>
<td>1992</td>
<td>99.10</td>
</tr>
<tr>
<td>7</td>
<td>6</td>
<td>0.30</td>
<td>1998</td>
<td>99.40</td>
</tr>
<tr>
<td>8</td>
<td>6</td>
<td>0.30</td>
<td>2004</td>
<td>99.70</td>
</tr>
<tr>
<td>9</td>
<td>3</td>
<td>0.15</td>
<td>2007</td>
<td>99.85</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>0.05</td>
<td>2008</td>
<td>99.90</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>0.05</td>
<td>2009</td>
<td>99.95</td>
</tr>
<tr>
<td>43</td>
<td>1</td>
<td>0.05</td>
<td>2010</td>
<td>100.00</td>
</tr>
</tbody>
</table>
In the hospital dataset (table 2) the majority of hospitals (62%) had received only one posting during the stated period; 9 hospitals nationally had received six or more postings:

**TABLE 2** Hospital postings (454 acute postings (one week from each of four previous quarters, September 2010))

<table>
<thead>
<tr>
<th>Frequency Count Response per hospital</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>208</td>
<td>62.09</td>
<td>208</td>
<td>62.09</td>
</tr>
<tr>
<td>2</td>
<td>63</td>
<td>18.81</td>
<td>271</td>
<td>80.9</td>
</tr>
<tr>
<td>3</td>
<td>33</td>
<td>9.85</td>
<td>304</td>
<td>90.75</td>
</tr>
<tr>
<td>4</td>
<td>14</td>
<td>4.18</td>
<td>318</td>
<td>94.93</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
<td>2.39</td>
<td>326</td>
<td>97.31</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>0.9</td>
<td>329</td>
<td>98.21</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
<td>0.6</td>
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</tr>
<tr>
<td>11</td>
<td>1</td>
<td>0.3</td>
<td>335</td>
<td>100</td>
</tr>
</tbody>
</table>

We also included 550 GP and 550 hospital ‘open’ comments in our analysis; these were coded based on emerging themes using NVIVO qualitative analysis software.

We undertook four separate analyses (two relating to the GP dataset and two relating to the hospital dataset), the results of which are each described in turn below:

- Quantitative analysis of GP ratings
- Qualitative analysis of GP comments
- Quantitative analysis of hospital ratings
- Qualitative analysis of hospital comments

1. **Quantitative analysis of GP ratings – NHS choices**

On the NHS Choices website at the time of our study patients were asked to rate their experiences of GP care in terms of five specific questions and an overall ‘would you recommend’ question. The five specific questions were:

- Q1: I am able to get through to the practice by telephone
- Q2: I am able to get an appointment when I want one
- Q3: I am treated with dignity and respect by the staff
- Q4: This GP practice involves me in decisions about my care and treatment
- Q5: This GP practice provides accurate and up to date information on services and opening hours
Tables 3-8 below a descriptive analysis of the ratings as posted:

**TABLE 3**  I am able to get through to the practice by telephone

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>1192</td>
<td>39.26</td>
<td>1192</td>
<td>39.26</td>
</tr>
<tr>
<td>Usually</td>
<td>843</td>
<td>27.77</td>
<td>2035</td>
<td>67.03</td>
</tr>
<tr>
<td>Sometimes</td>
<td>498</td>
<td>16.40</td>
<td>2533</td>
<td>83.43</td>
</tr>
<tr>
<td>Rarely</td>
<td>415</td>
<td>13.67</td>
<td>2948</td>
<td>97.10</td>
</tr>
<tr>
<td>Never</td>
<td>88</td>
<td>2.90</td>
<td>3036</td>
<td>100.00</td>
</tr>
</tbody>
</table>

**TABLE 4**  I am able to get an appointment when I want one

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>651</td>
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<td>21.48</td>
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<tr>
<td>Usually</td>
<td>872</td>
<td>28.77</td>
<td>1523</td>
<td>50.25</td>
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<tr>
<td>Sometimes</td>
<td>438</td>
<td>14.45</td>
<td>1961</td>
<td>64.70</td>
</tr>
<tr>
<td>Rarely</td>
<td>573</td>
<td>18.90</td>
<td>2534</td>
<td>83.60</td>
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<tr>
<td>Never</td>
<td>497</td>
<td>16.40</td>
<td>3031</td>
<td>100.00</td>
</tr>
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</table>
### TABLE 5  
I am treated with dignity and respect by the staff

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>1408</td>
<td>46.38</td>
<td>1408</td>
<td>46.38</td>
</tr>
<tr>
<td>Usually</td>
<td>481</td>
<td>15.84</td>
<td>1889</td>
<td>62.22</td>
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<tr>
<td>Sometimes</td>
<td>494</td>
<td>16.27</td>
<td>2383</td>
<td>78.49</td>
</tr>
<tr>
<td>Rarely</td>
<td>421</td>
<td>13.87</td>
<td>2804</td>
<td>92.36</td>
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<tr>
<td>Never</td>
<td>232</td>
<td>7.64</td>
<td>3036</td>
<td>100.00</td>
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</tbody>
</table>

### TABLE 6  
This GP practice involves me in decisions about my care and treatment

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>1461</td>
<td>49.26</td>
<td>1461</td>
<td>49.26</td>
</tr>
<tr>
<td>Usually</td>
<td>486</td>
<td>16.39</td>
<td>1947</td>
<td>65.64</td>
</tr>
<tr>
<td>Sometimes</td>
<td>380</td>
<td>12.81</td>
<td>2327</td>
<td>78.46</td>
</tr>
<tr>
<td>Rarely</td>
<td>325</td>
<td>10.96</td>
<td>2652</td>
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<tr>
<td>Never</td>
<td>314</td>
<td>10.59</td>
<td>2966</td>
<td>100.00</td>
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</tbody>
</table>
TABLE 7  This GP practice provides accurate and up to date information on services and opening hours

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1698</td>
<td>52.60</td>
<td>1698</td>
<td>52.60</td>
</tr>
<tr>
<td>I have no view</td>
<td>940</td>
<td>29.12</td>
<td>2638</td>
<td>81.72</td>
</tr>
<tr>
<td>No</td>
<td>590</td>
<td>18.28</td>
<td>3228</td>
<td>100.00</td>
</tr>
</tbody>
</table>

TABLE 8  Overall rating for this GP practice

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recommend</td>
<td>1239</td>
<td>38.38</td>
<td>1239</td>
<td>38.38</td>
</tr>
<tr>
<td>I have no view</td>
<td>819</td>
<td>25.37</td>
<td>2058</td>
<td>63.75</td>
</tr>
<tr>
<td>I would not recommend it</td>
<td>1170</td>
<td>36.25</td>
<td>3228</td>
<td>100.00</td>
</tr>
</tbody>
</table>

Figure 1 shows the correlations between each of the five rating questions, and between the five questions and the ‘overall rating’ question. The highest correlation (0.81) was between Q3 (dignity and respect) and Q4 (involves me) but all correlations are 0.60 or higher and statistically significant. Q3 (0.9555) and Q4 (0.9280) have the strongest correlation with the ‘overall rating’ question.

FIGURE 1  CORRELATIONS BETWEEN RATING QUESTIONS – GP POSTINGS

<table>
<thead>
<tr>
<th></th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
<th>Q5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q2</td>
<td>0.7385</td>
<td>1.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q3</td>
<td>0.6631</td>
<td>0.7227</td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q4</td>
<td>0.6059</td>
<td>0.6658</td>
<td>0.8163</td>
<td>1.000</td>
<td></td>
</tr>
<tr>
<td>Q5</td>
<td>0.7205</td>
<td>0.7627</td>
<td>0.7825</td>
<td>0.7867</td>
<td>1</td>
</tr>
<tr>
<td>Recommend</td>
<td>0.8240</td>
<td>0.8878</td>
<td>0.9555</td>
<td>0.9280</td>
<td>0.9151*</td>
</tr>
</tbody>
</table>
2. Qualitative analysis of GP comments

Table 9 below summarises, by theme, the analysis of 550 ‘open’ comments posted on the NHS Choices website in relation to patient experiences of GP care.

**TABLE 9  NHS choices – GP comments by theme (in order of times mentioned)**

<table>
<thead>
<tr>
<th>Theme</th>
<th>No. times mentioned</th>
<th>Positive Comment</th>
<th>Negative Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Efficient appointment systems</td>
<td>147</td>
<td>You are able to make an appointment with a specific member of staff, or take the quickest appointment which is really useful.</td>
<td>This surgery is absolutely useless, I’m never able to get an appointment when i need one it’s a three week wait by that time I’m usually better and don’t need the appointment, you have to explain what’s the matter with you to the receptionist, if you manage to get an appointment on occasions they ring half an hour before and ask you to go to the other surgery which for me a can’t do as I don’t drive and they end up cancelling the appointment because the doctor won’t be turning up, in my opinion complete waste of time I won’t be recommending this surgery to anybody!</td>
</tr>
<tr>
<td>Friendly and supportive staff (particularly receptionists)</td>
<td>109</td>
<td>Everyone is so friendly as well as professional - I really feel that my health and welfare matter to them and that I am not just another patient on a long list to be dealt with. I love the fact that people remember me, always smile and greet me (and everyone else, for that matter) as a valued client</td>
<td>Reception staff are often rude &amp; obstructive leaving me feeling upset and frustrated by their attitude.</td>
</tr>
<tr>
<td>Feeling 'listened to', included in care</td>
<td>66</td>
<td>My doctor even remembers things that I have said during previous appointments, that haven't been written in my records - how's that for personalised, individual treatment?! They hear and listen, and take on board your concerns, and then discuss those concerns with you. They don't just pay 'lip service' to you, give you a prescription and send you on your way.</td>
<td>I am sorry but this is my worst doctor’s experience ever. I am sick, have a chesty cough and coughing up blood. I was in and out of the doctor’s surgery in less than a minute and told to take paracetamol. I haven't visited for over 3 years and was obviously concerned about my health to go this time. I am still feeling very ill and need to consider my options. Do I need to pay private to have my health taken seriously? Might as well close this surgery down. Waste of money!</td>
</tr>
<tr>
<td>Theme</td>
<td>No. times mentioned</td>
<td>Positive Comment</td>
<td>Negative Comment</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>---------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Caring staff, patients’ best interest</strong></td>
<td>61</td>
<td>First and foremost, the doctors strike me as being quite exceptional: they are clued-up and wise, willing to give time even when running late and emphatically on the side of the patient. One of the GPs came to visit me in hospital when I was in hospital earlier this year, which was enormously welcome but no surprise considering the dedicated style of the doctor concerned.</td>
<td>Nurse I saw went through the motions, hilariously not explaining acronyms for diseases in health questionnaire (good job I work in health) and couldn’t be bothered to say goodbye on leaving, seemed more interesting in putting some stuff away.</td>
</tr>
<tr>
<td><strong>Time spent with GPs and feeling informed</strong></td>
<td>54</td>
<td>The doctors are very caring and give you the time you need rather than rushing you, and I don’t mind the doctors running late since having the time in the consultation with the doctor is the most important factor for me.</td>
<td>Some of the GPs are particularly bad at explaining conditions and treatments; for example, when I was told that a particular drug could harm my liver and I asked whether this would mean having my liver functions tested regularly, the GP simply sniggered and told me it wasn’t that kind of problem. I still don't know why. When I asked what side effects could affect my liver I was told to read the drug’s leaflet. This was outrageous given that I needed the information to decide whether I wanted to take the drug in the first place.</td>
</tr>
<tr>
<td><strong>Innovations in care</strong></td>
<td>26</td>
<td>The thing I like most about this surgery is that you can book doctor appointments online and it has some really good services like a mobile texting service for reminders. I logged in at a little past 8 am online to book appointments for my two children and was able to get an appointment that same morning with my preferred doctor and when I got there I was seen within 5 mins. You can’t argue with that.</td>
<td>I am happy with the doctors care that I am given, but the improvement that could be made is the telephone services. It is very hard to get through to the surgery. Maybe they could install a queuing system, where you a placed in a queue instead of always getting an answer machine and then hanging up, and having to call back time after time. Then you have to go in to the surgery to get an appointment instead.</td>
</tr>
<tr>
<td><strong>Open convenient hours</strong></td>
<td>18</td>
<td>I always manage to get through on the phone and get an appointment convenient to fit around my working hours (fantastic having a late night surgery).</td>
<td>This practice runs hours and a telephone reception system that are decidedly unhelpful to anyone who happens to have to work. I would NOT recommend this practice to anyone.</td>
</tr>
</tbody>
</table>
3. Quantitative analysis of hospital comments

On the NHS Choices website at the time of our study patients were asked to rate their experiences of hospital care in terms of four specific questions and an overall 'would you recommend' question. The four questions related to:

- Q1: cleanliness of hospital
- Q2: how well doctors and nurses worked together
- Q3: treated with dignity and respect by the staff
- Q4: involved in decisions about care and treatment

Tables 10-14 below a descriptive analysis of the ratings as posted:

TABLE 10  The area of the hospitals where I was treated was …

<table>
<thead>
<tr>
<th>Cleanliness</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exceptionally clean</td>
<td>124</td>
<td>24.41</td>
<td>124</td>
<td>24.41</td>
</tr>
<tr>
<td>Very clean</td>
<td>180</td>
<td>35.43</td>
<td>304</td>
<td>59.84</td>
</tr>
<tr>
<td>Clean</td>
<td>146</td>
<td>28.74</td>
<td>450</td>
<td>88.58</td>
</tr>
<tr>
<td>Not very clean</td>
<td>44</td>
<td>8.66</td>
<td>494</td>
<td>97.24</td>
</tr>
<tr>
<td>Dirty</td>
<td>14</td>
<td>2.76</td>
<td>508</td>
<td>100.00</td>
</tr>
</tbody>
</table>

TABLE 11  Doctors and nurses worked well together …

<table>
<thead>
<tr>
<th>Co-operation</th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>All of the time</td>
<td>275</td>
<td>58.14</td>
<td>275</td>
<td>58.14</td>
</tr>
<tr>
<td>Most of time</td>
<td>72</td>
<td>15.22</td>
<td>347</td>
<td>73.36</td>
</tr>
<tr>
<td>Some of the time</td>
<td>57</td>
<td>12.05</td>
<td>404</td>
<td>85.41</td>
</tr>
<tr>
<td>Hardly at all</td>
<td>49</td>
<td>10.36</td>
<td>453</td>
<td>95.77</td>
</tr>
<tr>
<td>Never</td>
<td>20</td>
<td>4.23</td>
<td>473</td>
<td>100.00</td>
</tr>
</tbody>
</table>
### TABLE 12  I was treated with dignity and respect by hospital staff ...

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All of the time</strong></td>
<td>323</td>
<td>63.33</td>
<td>323</td>
</tr>
<tr>
<td><strong>Most of time</strong></td>
<td>45</td>
<td>8.82</td>
<td>368</td>
</tr>
<tr>
<td><strong>Some of the time</strong></td>
<td>52</td>
<td>10.20</td>
<td>420</td>
</tr>
<tr>
<td><strong>Hardly at all</strong></td>
<td>27</td>
<td>5.29</td>
<td>447</td>
</tr>
<tr>
<td><strong>Never</strong></td>
<td>63</td>
<td>12.35</td>
<td>510</td>
</tr>
</tbody>
</table>

### TABLE 13  I was involved with decisions about my care ...

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All of the time</strong></td>
<td>261</td>
<td>56.86</td>
<td>261</td>
</tr>
<tr>
<td><strong>Most of the time</strong></td>
<td>68</td>
<td>14.81</td>
<td>329</td>
</tr>
<tr>
<td><strong>Some of the time</strong></td>
<td>35</td>
<td>7.63</td>
<td>364</td>
</tr>
<tr>
<td><strong>Hardly at all</strong></td>
<td>40</td>
<td>8.71</td>
<td>404</td>
</tr>
<tr>
<td><strong>Not at all</strong></td>
<td>55</td>
<td>11.98</td>
<td>459</td>
</tr>
</tbody>
</table>
TABLE 14  Overall rating of hospital

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Cumulative Frequency</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would recommend it</td>
<td>380</td>
<td>63.55</td>
<td>380</td>
<td>63.55</td>
</tr>
<tr>
<td>I have no view</td>
<td>58</td>
<td>9.70</td>
<td>438</td>
<td>73.24</td>
</tr>
<tr>
<td>I would not recommend it</td>
<td>160</td>
<td>26.76</td>
<td>598</td>
<td>100.00</td>
</tr>
</tbody>
</table>

Figure 2 shows the correlations between each of the four rating questions, and between the four questions and the ‘overall rating’ question. Whether ‘doctors & nurses work well together’ (0.90) and ‘dignity & respect’ (0.90) have the strongest correlation with the ‘overall rating’.

FIGURE 2  Correlations between rating questions – hospital postings

<table>
<thead>
<tr>
<th></th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>1.0000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q2</td>
<td>0.7232</td>
<td>1.0000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q3</td>
<td>0.7960</td>
<td>0.9112</td>
<td>1.0000</td>
<td></td>
</tr>
<tr>
<td>Q4</td>
<td>0.6841</td>
<td>0.8951</td>
<td>0.9073</td>
<td>1.0000</td>
</tr>
<tr>
<td>Rec</td>
<td>0.7725</td>
<td>0.9040</td>
<td>0.9014</td>
<td>0.8752</td>
</tr>
</tbody>
</table>
4. Qualitative analysis of GP comments

Table 15 below summarises, by theme, the analysis of 550 ‘open’ comments posted on the NHS Choices website in relation to patient experiences of hospital care.

**TABLE 15  NHS choices – hospital comments by theme (in order of times mentioned)**

<table>
<thead>
<tr>
<th>Theme</th>
<th>No. times mentioned</th>
<th>Positive comment</th>
<th>Negative comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring, dedicated, respectful care</td>
<td>116</td>
<td>The nurse in EGU explained our miscarriage to us in a most sympathetic manner, giving us both comfort and hope during our most desperately devastating time.</td>
<td>I have noticed personally that some of the younger nurses could do with a course in manners and politer treatment of patients. My husband was admitted to the ward at just after midnight, and I was amazed at the amount of chatter amongst the nurses at the desk. The nurse who had come up from A&amp;E with us had to ask these chatting ladies to help get my husband of the trolley and into bed. They were so busy chatting, they didn’t realise help was needed. They then carried on in quite loud voices about their private lives all the time I was there. I can only say I am glad I was not a patient in that ward.</td>
</tr>
<tr>
<td>Friendly, kind staff</td>
<td>85</td>
<td>The key to the success of that place is the manner in which everyone - patients, nurses, staff work together to make it run smoothly by creating such a happy, cheerful atmosphere, pulling together to make, each other feel “happy to be there”!” Could not be better in a hospital environment. I’ve had a really good experience here, every single midwife I have met have been really nice to me. Even over the phone they’re very polite and always help you. I would recommend this hospital to anybody.</td>
<td>I was referred to clinic and the nurses and doctors were great, the problem came when I explained to the doctor when I’d be on holiday and he sent me an appointment for while I was away, then I came into contact with the appointments line staff. The person I dealt with was rude, unhelpful, obstructive and insisted that because it wasn’t written in my notes that I was on holiday, I was clearly lying and had just not turned up for my appointment. For this mortal sin, which I hadn’t actually committed, I was relegated to the back of the queue and couldn’t be seen for a further month. Nothing was budging this member of staff from their position that suddenly there were no appointments for a whole month. It seems a shame really to have such quality frontline staff and yet have patients left with the impression that the eye hospital is no good because of treatment they’ve received from admin staff that don’t realise manners and courtesy cost nothing.</td>
</tr>
<tr>
<td>Efficient processes</td>
<td>73</td>
<td>I was admitted to A&amp;E late at night following an appointment with the local out of hours GP. I was so impressed with the speed of treatment and the fact that the hospital was expecting my arrival. I could not have spent more than 10 minutes in A&amp;E (where the staff were very helpful and friendly) when I was transferred to Ward 2 CDU.</td>
<td>I accept that emergencies take priority, but can’t understand how after sitting in the minor injuries unit from 8.40pm until 10pm only TWO people were seen, i feel it beggars belief.</td>
</tr>
<tr>
<td>Cleanliness, modern, well presented</td>
<td>69</td>
<td>The cleanliness of the hospital has vastly improved since 2005. I noticed all staff wash their hands after each patient and use the alcohol hand wash, and after each patient leaves they perform a complete wash down of the bed and the area.</td>
<td>The hospital is filthy with windows that are grey with grime, I commented to a member of staff and was told that’s how it is all over.</td>
</tr>
<tr>
<td>Care on ward</td>
<td>68</td>
<td>Over the next six days I received excellent care and consideration from everyone involved with my case and could only look on in frank admiration at the tremendous dedication and work rate of this fine team of nurses and auxiliaries. It was simply outstanding!</td>
<td>Do not answer buzzer calls... my granddad has had two falls in that place and both times they have tried to blame him for their blatant lack of care. They need more nurses and to start taking responsibility before it seriously injures someone.</td>
</tr>
<tr>
<td>Being informed, clear explanations, reassured</td>
<td>67</td>
<td>I was very nervous about having my procedure done, but the staff were fantastic and the consultant took lots of time to explain what was going to happen. I would thoroughly recommend this hospital to anyone.</td>
<td>A lack of communication is a problem. The patient would just like to know what is going on. My husband had a scan, and was waiting for some-one to see him the next day. When no-one had been by 3pm he complained and a doctor chased up the notes. It would appear the consultant who should have spoken to my husband was away that day - nobody bothered to tell my husband.</td>
</tr>
<tr>
<td>Being informed, clear explanations, reassured</td>
<td>67</td>
<td>I was very nervous about having my procedure done, but the staff were fantastic and the consultant took lots of time to explain what was going to happen. I would thoroughly recommend this hospital to anyone.</td>
<td>A lack of communication is a problem. The patient would just like to know what is going on. My husband had a scan, and was waiting for some-one to see him the next day. When no-one had been by 3pm he complained and a doctor chased up the notes. It would appear the consultant who should have spoken to my husband was away that day - nobody bothered to tell my husband.</td>
</tr>
<tr>
<td>Clinical care</td>
<td>31</td>
<td>The skill and ability of the surgical team that operated on my father.</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td>----</td>
<td>---------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>i was sent home from day surgery when it was obvious that i was in no fit state to do so the pain relief was minimal and subsequently needed the emergency doctor 2 days later to prescribe stronger pain killers and antibiotics for infection surely prompt after care and another day with trained staff could have prevented this.</td>
<td></td>
</tr>
<tr>
<td>Good food choice</td>
<td>13</td>
<td>Thanks to catering especially the soup, every meal delivered hot to your bed and tasty, most enjoyable. Glad that I able to enjoy each mealtime</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The food was terrible</td>
<td></td>
</tr>
<tr>
<td>Patient involvement in care</td>
<td>13</td>
<td>On the first occasion, the Dr went out of their way to call obstetrics to ensure that the drugs that they were prescribing me would not do my baby any harm. I felt that decisions were shared with me, and that the staff really knew what they were doing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nothing really went to see surgeon re a gastric by-pass and the main consultant and their team were so unapproachable and not easy to talk to... it was their way or no way. As a patient I had no say or choice in my treatment</td>
<td></td>
</tr>
<tr>
<td>Team working</td>
<td>11</td>
<td>Teamwork was very evident and the relaxed, professional atmosphere staff created, gave us all much comfort and confidence.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>nursing staff did not seem familiar with my case, the reason i was being treated, the medication I was on &amp; why and there was obviously no communication between the medical and nursing staff. The situation did not inspire me with confidence at all.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5: Quantitative analysis of patient opinion ratings

In order to inform WP1 (‘what matters to patients’) we undertook a series of secondary analyses of approximately 7,000 postings made to the Patient Opinion website. The postings from patients comprised of responses to a series of rating-scale questions and open comments relating to their experiences of five service types:

- Ambulance
- Community
- Hospital
- Mental health
- Residential (excluded from analyses due to low numbers of ratings posted)

The vast majority of postings related to patient experiences of hospital care.

Slightly different sets of rating questions are used for the four different services as shown in figure 1 below (questions common to all services are shown in bold type):

**FIGURE 1  Patient opinion dataset**

<table>
<thead>
<tr>
<th>ACUTE</th>
<th>COMMUNITY</th>
<th>MENTAL HEALTH</th>
<th>MENTAL HEALTH</th>
</tr>
</thead>
<tbody>
<tr>
<td>treated with respect and dignity</td>
<td>treated with respect and dignity</td>
<td>treated with respect and dignity</td>
<td>treated with respect and dignity</td>
</tr>
<tr>
<td>standard of medical care</td>
<td>standard of medical care</td>
<td>standard of medical care</td>
<td>standard of medical care</td>
</tr>
<tr>
<td>standard of nursing care</td>
<td>standard of nursing care</td>
<td>standard of nursing care</td>
<td>standard of nursing care</td>
</tr>
<tr>
<td>cleanliness</td>
<td>cleanliness</td>
<td>cleanliness</td>
<td>cleanliness</td>
</tr>
<tr>
<td>parking</td>
<td>parking</td>
<td>parking</td>
<td>parking</td>
</tr>
<tr>
<td>service punctuality/timeliness</td>
<td>service punctuality/timeliness</td>
<td>service punctuality/timeliness</td>
<td>service punctuality/timeliness</td>
</tr>
<tr>
<td>information and decision making shared appropriately</td>
<td>information and decision making shared appropriately</td>
<td>information and decision making shared appropriately</td>
<td>information and decision making shared appropriately</td>
</tr>
<tr>
<td>getting there</td>
<td>getting there</td>
<td>getting there</td>
<td>getting there</td>
</tr>
<tr>
<td>being listened to</td>
<td>being listened to</td>
<td>being listened to</td>
<td>being listened to</td>
</tr>
<tr>
<td>clear information</td>
<td>clear information</td>
<td>clear information</td>
<td>clear information</td>
</tr>
<tr>
<td>clean, safe, friendly place</td>
<td>clean, safe, friendly place</td>
<td>clean, safe, friendly place</td>
<td>clean, safe, friendly place</td>
</tr>
<tr>
<td>family/friends could be involved</td>
<td>family/friends could be involved</td>
<td>family/friends could be involved</td>
<td>family/friends could be involved</td>
</tr>
</tbody>
</table>

Tables 1-3 below show the ratings (from 1 ‘low’ to 5 ‘high’) by organisation for the three questions common to the four service types:
**TABLE 1**  Ratings for ‘treated with respect and dignity’ by service

<table>
<thead>
<tr>
<th>ratingtype (ratingtype)</th>
<th>r05 (Treatment with respect and dignity)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulance</td>
<td></td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>Community</td>
<td></td>
<td>31</td>
<td>26</td>
<td>44</td>
<td>89</td>
<td>294</td>
<td>484</td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td>440</td>
<td>405</td>
<td>709</td>
<td>1511</td>
<td>3667</td>
<td>6732</td>
</tr>
<tr>
<td>Mental health</td>
<td></td>
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**TABLE 2**  Ratings for ‘service punctuality/timeliness’ by service

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Ratings for ‘information and decision making shared appropriately’
by service

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Frequency Missing = 121
Appendix 6: Organisational case studies

Key messages: lessons from case study sites

Focusing on patient experience should be empowering for staff and service users. Organisations that were effectively capturing patient experience and using it to drive service change demonstrated some or all of the following features.

1. Patient experience is seen as valuable, providing new insights and leading to change that is welcomed by staff and service users.
2. Patient experience can be understood from the perspective of service users; patients’ stories are heard and used to inform patient experience activity.
3. Service users are actively engaged in capturing and feeding back experience.
4. Patient experiences are captured across pathways in addition to particular episodes of care.
5. The process of collecting and reporting patient experience is regular and on-going in order that a focus is maintained.
6. Staff, from the frontline to the boardroom, are engaged with patient experience and recognise the value of it.
7. Staff are able to own feedback about their service and act on it. They can hear and respond positively to difficult feedback.
8. The link between staff experience and patient experience is recognised; staff experience is also captured and used.
9. Strong leadership is evident throughout a period of cultural change.
10. Patient experience is an integral and equal part of the organisation's quality framework alongside clinical governance, safety and outcomes data.
11. Patient experience work is properly resourced and supported. This may include:
   • Dedicated posts to oversee and coordinate the work and provide expertise
   • A budget for training, survey materials, external expertise
   • Protected time for staff to review feedback and learn from patient experience.
12. Trends in patient experience can be compared over time and, where appropriate, with other similar organisations.
13. Patient experience informs commissioning decisions and strategic planning.
14. Patient experience underpins effective relationships between commissioners and providers.
Methods
The information on which this report is based was gathered between October 2010 and January 2011.

We interviewed 62 people across 12 case study sites (see templates in appendices), with each researcher conducting interviews at 6 case study sites. 54 of the interviewees were staff, working at various levels, from the front line up to Chief Executive. Eight of the interviewees were service users or carers, involved in some way with patient experience activity or a relevant project at a case study site. Most of the interviewees were seen individually, but a few interviews were conducted with pairs or small groups. Eight of the interviews took place by telephone and the remainder were face to face.

The interviews were semi-structured, using a prepared interview schedule (see Appendix 1). The interview schedule was used flexibly to allow contributions from interviewees in a range of different roles in the case study sites. Interview questions were, in part, informed by previous work for the project, e.g. interviews with patients and voluntary organisations, conducted in the summer of 2010, together with material submitted by voluntary organisations on what is important to patients and how such data are collected.

Full contemporaneous notes of interviews were taken by hand, and the majority of face-to-face interviews were digitally recorded. All of the recorded interviews were transcribed. Typed notes and transcriptions were all looked at by both researchers, who collaborated to extract the key themes.

Short vignettes were prepared to illustrate the report, and the text of these vignettes was checked and approved by the case study sites.

Some interviewees provided additional background material, such as copies of surveys and survey results, reports to committees and annual reports etc. These were drawn on to give a fuller understanding of local activities and they provided context, where appropriate, to the interviews.

In addition, three meetings related to user and carer experience were observed at two case study sites. The number of attendees at these meetings has not been included in the total number of people seen in interviews.

1. Capturing patient experience
A wide range of methods for collecting, analysing and reporting patient experience data were observed across the 12 case study sites. These included:

- Surveys in a range of formats and administered using different means.
- The collection of patient stories, involving in-depth qualitative methods and opportunistic methods
- The development and use of on-going fora to listen to patients / service users.
Surveys
Surveys, where the aim is to record the responses of a number of people to the same or similar questions, were conducted in all the case study sites. All of the sites, of course, were conducting surveys as part of the National Patient Survey Programme, and, in addition, all were supplementing these with local surveys of patient experience in some, or all, of their services.

A wide range of methods were used for administering questions in local surveys including:

- Postal or email questionnaires
- Questionnaires in clinics, waiting rooms or patient’s homes
- Dr Foster mobile patient experience tracker devices (PETs) or Picker Frequent Feedback on hand-held electronic devices (often referred to as PDAs).

In addition, a range of means were used to gather the responses, through questionnaires and PETs / PDAs including:

- Self-completion by patients reading questions and recording answers
- Self-completion with support and explanation
- Assistance provided through face to face interview with volunteer, audit nurse or link worker asking the questions and recording the answers.

Capturing quality data
Decisions about the administration of surveys were usually dictated by pragmatism and the desire to ensure that the views of as many patients as possible were included. Issues taken into consideration were:

- The desire for patient respondents to be anonymous in order to encourage responses and the belief that patients will give more honest responses if they are not identifiable
- The importance of clinical teams owning the responses in order to take action, but having to trust that anonymous data relates to their patients / service
- The need to keep question sets short and simple in order to encourage more responses, versus the desire to ask more in-depth questions or cover a wider range of issues
- The desirability of feeding back results quickly versus the collection of a comprehensive data set.

It is worth noting that different methods of administration were sometimes used within the same survey. For instance, support might be given to respondents in order to ensure that the survey included those who were not comfortable with, or able to use, electronic devices or those who could not read English well, or those who had difficulty writing, but this would be balanced with the undesirability of having clinical staff involved in helping a patient comment on the care they were providing.

You have to read it to some people as they have come for treatment and they have not come prepared to read with their glasses. But if it is to be anonymous, we shouldn't be involved as it can influence the person although we don't mean to, and they may not be totally honest. If the receptionist could help them, they'd be more likely to be totally honest but the machines are in the clinic.
Using volunteers to support surveys
One case study site, who were using Frequent Feedback devices throughout the Trust, routinely used volunteers who were not involved in patient care to capture responses.

_Involving sixth-form students as volunteers in patient experience data collection_
Throughout University College London Hospitals NHS Foundation Trust (UCLH) volunteers are used to collect patient experience data recording answers to a set of questions on Frequent Feedback hand held electronic (Picker) devices. At the Heart Hospital a mixture of audit staff and volunteers ask the questions and collect data, including prospective medical students (currently in sixth-form) who are seeking work experience to support their medical school applications. The students work with the audit nurses doing patient surveys for a while and then the hospital will arrange a week’s work experience for them. This has been quite successful and, as Clinical Director Dr Dollery points out, can have far reaching benefits as the students spend time with patients instead of spending time with doctors, “which I actually think is probably a better place to start for somebody who’s going to go into medicine”.

Support through a help-line
Essex County Council have a help-line to support their survey programme which provides explanation and clarification to questionnaire respondents. This helps to improve the response rate and the accuracy of the data and allows them to get feedback on the questions people find difficult to understand or answer.

Improving accessibility for “seldom heard” groups
In some cases, it was seen as necessary to produce an “easy read” version of a survey in order to make it possible for people with learning disabilities, and others who may have difficulties with comprehension, to participate. In other cases, the format of a questionnaire survey was considered an unsuitable method for people with comprehension difficulties, requiring too much support to complete, and so alternative means would be used to seek their views, such as face to face interviews.

_Getting the views of people with learning disabilities_
Hertfordshire Partnership NHS Foundation Trust is committed to seeking the views of all its users. It recognises that flexibility and creativity are necessary and that different approaches may be necessary in order to be inclusive of certain groups of people, such as people with learning disabilities.

One of the practical innovations that the trust has implemented is the production of Easy Read versions of its Having Your Say questionnaires about hospital services and community services. These Easy Read versions are attractive and brightly coloured, with illustrations. The questions are easy to understand and there are just three options for responses. There is a smiley face, an unhappy face and a neutral face symbol to signify “yes”, “no” and “don’t know”.

However, the trust has also found that just having accessible material is not enough. Some people with learning disabilities also need extra time to complete a survey, and some need assistance from an advocate or a member of staff to do so. The resources to support this can be significant, and must be factored in if people with learning disabilities are to be empowered to make their views known. It is also important to seek the views of carers, recognising that these may not be identical to those of service users.
Service-specific or patient-centred?

On the whole, surveys were conducted within a service or team and sought the views of respondents only about that service. An exception was in Essex County Council where the Evidence team in the Adults, Health and Community Wellbeing Directorate have developed surveys focused on the service user with personalised questionnaires that seek responses about a range of different services across a pathway.

*Individualised questionnaires to capture experiences along the whole pathway*

In Essex County Council the Evidence Team in the Adults, Health and Community Wellbeing Directorate have transformed the way they gather information, based on feedback from workshops run with citizens and service users which highlighted the importance of understanding experience along the whole pathway. In the past they conducted single service surveys on, for example, homecare, meals on wheels, assessment and review. The new approach is to generate a tailored survey for each individual person which aims to understand people’s experience from the time they contact social care right through to gaining services, managing a personal budget and the transitions in between. Each of the surveys matches an individual’s pathway; “so instead of getting a large survey that covers everything, they get the questions that are appropriate to them and that’s proved a successful approach”. The Evidence Team have developed a large database using the responses to these surveys which can be interrogated to answer new questions. They are also able to contrast new customers’ experience with existing customers’ experiences.

Service specific surveys, particularly if they are generated by those working in the service and conducted whilst patients are actually using the service (or as they are leaving), are generally seen as useful for engaging staff with the patient experience activity. The data from these surveys seems more likely to be owned by the staff and can lead to small but significant changes quite quickly. A survey conducted by the practices in the Croydon Federation of GPs is an example.

**The Croydon Federation Survey**

Twelve GP practices in the Croydon Federation of GP Practices, including Parchmore and Keston House, conducted a patient experience survey as part of a project to improve access. A series of questions was developed to address:

- The effectiveness of information available to patients on how to access the GP Practice through different routes and portals
- The preferences of Patients for accessing the GP Practice
- Ease of access of Patients to the GP Practice via the telephone
- How patients rated the effectiveness of reception staff
- How patients rated the effectiveness of the GP Practice system to allow them access to a Doctor if they had a problem they considered to be urgent
- How patients rated the effectiveness of the GP Practice system to allow them access to a Doctor or Nurse more than two days in advance
- How patients rated the attitude of the Doctor or Nurse they last consulted with
- How patients rated the clinical effectiveness of the doctor or Nurse they last consulted with in dealing with their urgent problems or on-going conditions
- How patients rated the responsiveness overall of the GP Practice in addressing their needs if they had an urgent problem or any on-going conditions.
To ensure that feedback was obtained from patients with current knowledge and real time experience of the GP Practice, those attending the surgery were selected as the target group as opposed to a randomised postal survey using traditional methodology. The questions were limited to one page of A4 to ensure ease of completion by patients and to maximise survey returns. No patient details or identifiers were marked on the survey forms to encourage honest responses. Survey forms were e-mailed to each of the twelve participating GP Practices who printed sufficient copies to ensure a return of 100 completed survey forms per practice. The survey was conducted simultaneously in the twelve participating GP Practices in one week in February 2009. Patients presenting to the GP Practices reception desk were randomly given a survey form and asked to complete and return it to a box on the reception desk. Survey forms were centrally collected and collated and analysed independently by staff in various practices.

Teresa Chapman, Chief Executive of the Parchmore Partnership which took a lead in devising the survey, said “We wanted to administer a questionnaire to people who were actually accessing the service. We felt this was more accurate than the feedback we get from the National Survey”. Dr Fernandes from Parchmore added “We wanted to benchmark and compare with other practices and to set some standards to aspire to. We did a baseline of what needed to be done as a result of the survey and we shared this across the practices”.

The practices involved found that it was useful to collaborate and share resources to administer the survey and collate the data, though the solutions to the findings will often need to be devised at an individual practice level, depending on the responses of their patient population and the size, organisation and capacity of the practice. They continue to work together to discuss solutions and learn from each other.

Examples of changes implemented following local surveys included:

- Changes to the timings of admissions to avoid problems identified
- Improved information on notice boards
- Development of posters to raise awareness of the different ways of accessing a GP surgery
- An audit of call bells and replacement of those not working
- Improvements to the format of information about a 24 hour care centre.

However, it was observed by a number of respondents, in different sites, that surveys can tend to confirm what is already known rather than providing a lot of new information. More than one commentator talked about using data, especially that gathered by the electronic PETs, as “ammunition” in making a case for further resources to address problems staff were already aware of. Examples were:

- Using patients’ dissatisfaction with waiting times in a walk-in centre to get funding for posts unfrozen
- Addressing problems with poor telephone systems in a number of sites.
PETs

Patient Experience Trackers (PETs) were being used, or had been used, at most of the provider case study sites (except in primary care). The most comprehensive use was in Camden Provider Services where PETs are used in almost all of its services and patients are asked about the care they received each time they use a service, except in inpatient care where the PETs are used weekly.

We noted mixed views about the value and suitability of PETs across the case study sites.

The value of the data generated

Services use PETs principally for their ability to generate easy to read data, captured from a potentially large cohort of people, quickly. This can be helpful in enabling them to address problems without delay. PETs have often been introduced to supplement the data from large scale surveys, such as those in the National Patient Survey Programme which take a long time to report. At the Heart Hospital they have also found that Frequent Feedback systems keep people interested and give staff something regular to focus on

I think it's quite difficult to motivate people to change their behaviour if all they get is a report once a year that comes out six months after the sample size was actually taken.

On the whole, services using PETs find that staff are more likely to “own” the data, than that derived from National Patient Surveys, but we also heard of frustrations amongst staff that, as the data are non-identifiable, it is not possible to address some of the concerns highlighted. Others noted that the generality of the questions also meant that it was not always clear what patients were actually commenting on. The limitations of the (Dr Foster) PETs had led one Trust (UCLH) to move to using Picker Frequent Feedback devices with a much larger set of core questions and some additional service specific questions.

In Camden, where PETs are used widely, they had found that they were most useful in the larger services, such as sexual health, health visiting and podiatry, but it is not so clear whether it is the most appropriate method for seeking patient experience data in a small service, where there may be only four or five patients a day.

It was noted that data from PETs often show a high level of satisfaction, but it is not always clear why. It has been suggested that this may be due to staff proximity to patients using the device and also that patients often are satisfied with a clinical interaction, particularly after it has just occurred, but that does not necessarily pick up issues about the organisation of care, continuity and follow up.

There was some concern that, in spite of reassurance about anonymity, patients may worry about the consequences of giving their views.

Benefits

PETs were seen as valuable for providing opportunities to check the consistency of service quality across the organisation and also the quality of services across time. One benefit identified in Bristol Community Health was that the reports generated can also be fed back easily to commissioners.

It was noted that frequent feedback mechanisms, and the regular data they generate, can help to promote a culture of dialogue between patients and staff and serve to keep patient experience high on the agenda and maintain a focus within staff teams.
Accessibility and inclusiveness

Experience and views varied about the accessibility of PETs to people who did not read English well. Some interviewees noted that, if they required it, people would always have interpreters, link workers or relatives with them to assist in a consultation and these could then assist with their PET response. Others thought that this might be a problem. The acceptability of PETs was also noted as a problem in relation to older people and some socially deprived populations.

*We see a large proportion of elderly patients and you can’t underestimate the extent to which any kind of technology stuns them. Some just don’t understand what it is we are trying to do.*

One respondent contrasted response rates from similar walk-in services in different parts of the town:

*In [name], a big commercial and banking area, there is a high response rate – people there are very good at pressing electronic buttons . . . In the other centre in [name] there is a high rate of deprivation - teenage pregnancy, drug users, high unemployment and they don’t like computer thingys so it is difficult to get people to use the trackers.*

Other considerations

It was generally found that it can take time to convince staff of the benefits of PETs, particularly as they are so busy. However, it is essential for staff to be committed to using PETS as they need to be proactive in encouraging patients to use them, which can add time to a consultation.

PET machines and reporting systems were also considered quite expensive and, as the technology was becoming out-dated, needed upgrading and replacing. In a number of instances they had also gone missing. In some cases, there was not necessarily a commitment to continuing with PETs in the future, with some commentators indicating a desire to focus efforts on developing other survey methods. In the Heart Hospital (and other UCLH hospitals), where they had moved on to using devices with a larger set of questions and the responses were recorded by dedicated audit staff or volunteers, there were extra cost implications and they had experienced difficulties finding sufficient volunteers to administer the surveys.

Stories

We were told about the value of listening to patients’ stories in all the case study sites. Throughout the sites there were various ways described of capturing patients’ stories ranging from formal qualitative methods to opportunistic listening activities. These included:

- Talking to people on wards, in clinics, waiting rooms and in residential care settings (Camden Provider Services, Essex County Council, Hertfordshire Partnership NHS Foundation Trust, South Street Surgery)
- Comments, complaints, obituaries, letters, emails, NHS Choices (most)
- Free text comments on surveys (Essex County Council, Healthcare at Home)
- Shadowing - observing and talking to - individual clients through the care pathway (Essex County Council)
- Calls to helpline (Healthcare at Home, Essex County Council)
• Recording calls to a surgery (Parchmore Partnership)
• “Problem book” where GP receptionists note patient comments (Parchmore Partnership)
• Focus groups (Bristol Community)
• One to one interviews (Bristol Community, Essex County Council)
• Experience based design (Bristol Community, Northumbria Healthcare NHS Foundation Trust)
• Service users speaking about experiences at service planning groups (Essex County Council, NHS South Birmingham, Hertfordshire Partnership NHS Foundation Trust).

A range of people were involved in collecting patient stories including:

• Staff
• Service users / peers
• Researchers or interviewers who are independent from the service.

Different approaches to capturing stories

It was observed that there was value in all these approaches. For example, at one site an assistant director talked about the value of just walking along the corridor and talking to people; “it gives you a different perspective”. A modern matron in Hertfordshire Partnership NHS Foundation Trust holds a weekly surgery:

  I talk with patients about a range of issues and I ask if they feel safe and if not, why not, and I action that if necessary. I ask about the environment, meals, cleanliness, cultural needs, problems with communication/language barrier, have they received a copy of the care plan, are nurses spending adequate time with them etc.

At South Street Surgery a number of staff, including managers, were involved in interviewing patients in the waiting room.

**Waiting room interviews**

In South Street Surgery in Bishops Stortford, GPs and other practice staff were well aware that previous levels of patient satisfaction about access to their services had not been high. All the staff wanted to listen carefully to patients about their experience and what could be improved.

Non-clinical staff at the surgery conducted 153 waiting room interviews with patients over a three month period. Staff approached patients randomly in the waiting room, using a standard format to ask about their experience about accessing services. For example, patients were asked about their experience of getting through on the phone, whether they got an appointment with the doctor they wanted to see, the friendliness and helpfulness of reception staff, views on online booking, telephone consultations etc. Staff were also able to learn that information that was available to patients – for example, about extended hours – was not getting through to patients.

Patients’ names were not recorded, unless they wished to be put in touch with the Patient Participation Group. Patients were generally very willing to talk openly to staff in the waiting room, although staff were clear that this would not be appropriate if clinical or patient safety issues were under discussion.
There was a huge benefit for the practice in staff hearing patients’ stories directly. It also gave a clear message to patients that the practice really wanted to know their views. Staff at the practice commented “It was the best thing we ever did. Just sitting down and talking to them was really good. The process of doing it was useful as well as the outcome. It was an eye opener.”

There is considerable value in staff hearing patients’ stories directly. It can sensitise them to patient experience, helps them to “own” the data and acts as a motivator to do something about it. This, of course, has to be balanced with concerns that patients and carers may not always want to share their views and experiences with those actually working in the service they are commenting on, particularly the practitioner or care-giver.

It was observed that patients might be more open about their experience when talking to peers or other service users. Amongst the case study sites there were examples of this. In Essex County Council lay visitors, including older people, mental health service users and people with learning disabilities, go out to talk to people in residential care homes to capture their experience. The visitors are trained and supported by the Council and work alongside the Council’s Quality Monitoring Teams. The Council have also supported older people to conduct more formal research methods to capture the experiences of their peers.

“WhyNot!” Older People’s Research Group

In Essex, during the past three years, over 60 older people have been trained as researchers and provide a service conducting research with older people. “WhyNot!”- the Older People’s Research Group was set up by the County Council’s Adult Social Care Directorate in partnership with Anglia Ruskin University (funded by Skills for Care), who provide a programme of training and on-going support to the researchers. The Group conduct research for the Council and others, for example they recently carried out a piece of work on Telecare, exploring why the uptake was not as high as expected. They often interview older people in their own homes. “This age group finds it easier to talk to others in their peer group; we have patience and listening skills and the ability to relate to older people as we are older people ourselves”. All the work is voluntary – they get travel expenses only, but they have identified a need for some other expenses to be paid, such as printing costs.

www.essexinfo.net/whynot

In an HIV service patient representatives act as conduits for patient experience information.

The work of the Patient Representatives and Patients Network at the Bloomsbury Clinic, Mortimer Market Centre (Camden Provider Services)

The HIV service, provided by Camden Provider Services, includes out-patient services at the Bloomsbury Clinic, which has 4000 patients. Understanding patient experience has always been extremely important to the service. It reflects the way in which service users with HIV have always worked in partnership with health professionals – particularly important now in the light of recent developments: effective treatments, fewer hospitalisations and normal life expectancy.

One of the distinctive features of the service is the employment of two salaried, part-time, Patient Representatives. The Patient Representatives provide a five day a week drop-in and appointment service, offering peer support, advice and advocacy, with particular emphasis on psycho-social needs. As they see about a quarter of the
patients using the service, they are also effective conduits for patient experience information. A particular strength of this approach is that patient experience is seen as an integral part of the service and not as an add-on, nor as a sporadic activity.

The Patient Representatives also administer the Patients Network, take part in facilitating and attending workshops, forums, focus groups and courses for newly diagnosed patients. Many of these have a multiple purpose: to inform and support service users and to gather their stories, personal experiences and views about the service and how it could be improved. Patient Representatives are also involved in seeking the views of patients in more formal ways e.g. through evaluation forms and patient satisfaction surveys.

The Patient Representatives have first-hand knowledge of many of the issues faced by their fellow patients, so they have all-round credibility. They also have a close working relationship with consultants, nurses, health advisers and staff in the psychology department. They regularly attend management meetings and have positive on-going informal relationships with clinical colleagues, all of which enable them to ensure that patients’ views are considered at all levels and by all staff.

Staff who are independent of a service or team can also be used in a research role to capture stories. In Bristol Community Health the chronic obstructive pulmonary disease (COPD) service conducted semi-structured interviews using an interviewer from NHS Bristol, the local commissioning organisation. This had dual benefits; the team were not directly involved in getting feedback from their patients allowing them to speak more freely, and the commissioners were sensitised to issues of patient experience. The Patient and Public Involvement (PPI) Manager in Bristol has also been involved as a researcher, piloting innovative methods to engage staff and patients.

**Obtaining information on patient experience of the District Nursing service, using experience based design**

The District Nursing service in Bristol Community Health had previously carried out a patient experience survey which indicated high levels of satisfaction with the service. In 2009, when the service was approached about carrying out another patient experience survey, staff expressed dissatisfaction with this method as it didn’t give them enough qualitative information to make improvements. This was also a view being expressed by other domiciliary services.

It was agreed to pilot a more qualitative approach and Experience Based Design (EBD) was chosen as a framework for piloting this approach with District Nursing. The Patient and Public Involvement (PPI) Manager spent two mornings shadowing a District Nurse in two different localities. A photographer was hired to shadow two or three district nurses and take photographs of whatever he observed as they went about their duties and a selection of fifteen photographs was made by the PPI Manager and the team leaders. A total of five in-depth interviews with were carried out with district nurse patients by the PPI Manager, using the photographs as prompts for discussion. The results were discussed with staff from the District Nursing Team who were invited to suggest some recommendations for action. Some significant areas for service improvement were identified and a number of actions are planned as a result.
The advantage of this method of data collection is that whilst the numbers of people interviewed are small, it provides enough material for reflection and discussion and highlighted a variety of individual experiences of the service. This approach also values the input and views of staff and includes their concerns. It has generated useful discussion and is regarded as the beginning of further qualitative work that the District Nursing service will carry out on patient experience.

The value of patient stories
A number of observations were made about the importance of listening to patients, and the value of the stories told, throughout the case study sites.

Raising important issues from patient point of view
It was observed that patient stories could raise issues that the organisation or team were not already aware of. Patients were not always concerned about the issues that staff thought they would be. In one organisation, using volunteers to capture patient experience feedback on PDAs, it was observed that the volunteers often find it difficult to get patients to just give answers to the questions, but want to chat and tell their stories. Others remarked that free text replies on questionnaires often reveal much more than answers to the pre-worded questions:

the numbers are not really important – it is what Mrs so and so says about the service – the key, the really good bits, are the stories.

Conveys experience effectively
Hearing patient stories sensitises staff and managers to the value of patients’ experience and makes it real for them. This is particularly powerful if they are actually doing the listening, but even hearing stories captured by others can be effective. Patient stories have a different quality to numbers and graphs and are the most effective way of actually conveying an experience, if not measuring it. In Hertfordshire Partnership NHS Trust the Service User and Carer Experience Committee meetings include service users and carers who are able to talk about their care. This acts to focus the committee’s discussions on patient experience.

Captures issues of continuity of care
Patient stories will often cross organisational and service boundaries and so can pick up on issues of accessing services, transition and continuity of care. Data from service-specific surveys usually do not capture issues of continuity of care, coordination or transition.

Therapeutic value of involving patients in making their views known
In Hertfordshire Partnership NHS Foundation Trust a commitment to engaging patients in collecting and understanding patients’ experience was seen as part of the process of recovery, as well as a means of enabling the organisation to perform at the best possible level.
The process of gathering patient experience data, particularly by involving and empowering service users to make their views known, fits well with a commitment to the key principles of recovery in the mental health field\(^\text{10}\). One of the recovery principles is that the mental health system must be aware of its tendency to promote service user dependency and that service users need to be aware of the negative aspects of co-dependency. It follows from this that active engagement of mental health service users in communicating their views and trying to improve their treatment can be therapeutic.

**On-going engagement through groups and forums**

Service user groups and forums can be a good source of patient experience data and can support the collection of data through other methods such as surveys. Patient participation groups (PPGs) in primary care are a good example of this.

**Patient Participation Groups**

Parchmore Partnership and South Street Surgery both have active patient participation groups (PPGs) set up in the past three years. They find that these Groups work really well as sounding boards to take issues and proposals for discussion and they get really useful feedback.

The PPGs have discussed issues taken to them by the practice staff such as appointments systems, how they handle test results and proposals to change the telephone systems. They have made many useful suggestions which have been taken up by the practices. For example, a suggestion to have pictures of all the staff in the waiting room with their names and roles came through the PPG.

The PPGs have also helped to communicate and explain changes to other patients. The PPG at Parchmore helps to produce a newsletter for patients to pick up in the waiting room and an annual open evening was instigated by the PPG and is largely organised by them. One member of the Parchmore PPG – an older African Caribbean man with long term conditions - was initially reluctant to use a computer to access the practice online, but now he does demonstrations at the practice, and the open evening, for other older patients showing them how to book online.

Both PPGs have a core group of members, though the groups are open to anyone using the practice. At South Street the group was initially chaired by an external facilitator and in Parchmore the group was brought together by a nurse practitioner originally, though this is now chaired by a patient member. In South Street the Group is now chaired by a member of staff, as they have found that the patients prefer the structure of that, though both practices are working towards getting the patients to set the agenda more. At Parchmore there are plans to put up photos of PPG members so that other patients can recognise them and talk to them. At South Street there are also plans to encourage members of the PPG to take part in interviews with other patients in the waiting room in order to find out more about the views and experiences of patients.

Both practices find that, although the PPG generally attracts a mixture of people, it is harder to get young people involved, although at South Street proposals to hold some meetings in the evening may help to change that and they now have some younger people interested.

\(^\text{10} \text{NIMHE Guiding Statement on Recovery, National Institute for Mental Health in England, January 2005}\)
In Hertfordshire Partnership NHS Foundation Trust there is a well-developed Service User and Carer Committee.

**Service User and Carer Experience Committee**

The Service User and Carer Experience Committee at Hertfordshire Partnership NHS Trust is a good example of how an effective decision-making committee that includes service users and carers, fits into an integrated governance system. The Committee meets every two months and oversees the work of the Involvement Steering Group and ensures that involvement developments are in line with and complimentary to wider Trust objectives. It receives minutes of the Service User Council, the Carer Council and the Involvement Steering Group. The committee is chaired by an executive director and attended by a wide range of senior staff, who report on relevant aspects of their work, and bring information to the committee in response to matters raised, as appropriate. The quorum for the committee includes service user and carer representatives, and if they are absent, no decisions can be made.

At a meeting in December 2010, the first item was a presentation by a current user of the trust’s mental health services, who involved all those present in an exercise to help them understand the problems caused when care is uncoordinated. The powerful effect of this presentation resonated throughout the meeting and ensured that even relatively formal and mundane items of business were well grounded in people’s actual experiences.

In Essex County Council’s Adults, Health and Community Wellbeing Directorate there are well organised and supported planning groups for a number of services including older people, people with learning disabilities and people with physical disability. These groups act as mechanisms for feedback and consultation and are structured so that they are not just talking shops, but action-oriented. For example, everyone on the Learning Disability Partnership Board has a specific role and job description. The groups have very engaged service users involved who actually undertake pieces of work alongside Council officers and they are all co-chaired by a service user / citizen and a council officer. Most have good structures for feeding in views from various constituent communities and from all parts of Essex.

**Value of on-going involvement**

There are a number of benefits of having structures for engaging patients / service users in an on-going way. These include:

- Ensuring that services are listening to patients all the time and are more likely to ask the right questions in surveys etc. if they aware of the patient agenda
- Acting as a sounding board for planned patient experience work
- Leads to more informed service users who can also inform others and support patient experience work
- Can provide input into service redesign – not just commenting on services as they are now
- Empowering and therapeutic for service users.
Supporting on-going involvement

Service users need practical and financial support to maintain their involvement. In two case study sites the issue of Department of Health “red tape” with regards to payment to service users was raised as a problem. One commentator described this as a “minefield”. It was noted that concerns about the effect on pensions and benefits could restrict the involvement of some people and the bureaucracy involved sometimes discouraged staff from getting new people involved.

LINks

Local Involvement Networks (LINks) are established in every area and could potentially be a useful forum as both a source of patient experience information and a support for patient experience work. There appeared, however, to be little involvement in, or awareness of, patient experience activities by LINks in the case study sites we observed.

2. Acting on patient experience information

Importance of using information collected

Collecting patient experience information is only part of the work involved in valuing patient experience, though we observed that it was often the main focus in some organisations. Using the information collected is at least as important as collecting good quality data. Some informants in the case study sites stressed the importance of analysing and using the information collected. It was suggested that if information could not be used, then it should not be collected. One interviewee pointed out that it was unethical to collect data (in this case free text replies) if they were not analysed and used.

Using patient experience information requires that organisations have the capacity to collate and analyse data. It is also important to have good systems for managing and tracking the data collected. The most important issue is how patient experience information leads to change.

Importance of feeding back to service users

Feeding back the results of patient experience surveys and conversations is a key part of demonstrating the value of patient experience, though, as one commentator in a commissioning organisation pointed out, it is not always done.

What they miss a trick on is telling patients how they have improved as a result of what they have learned. Providers don’t finish off that sort of cycle, giving feedback.

It is important to let service users know what was done with the feedback they provided and what might be changed as result. This is essential for supporting and sustaining patient experience work and avoiding survey fatigue. It can also lead to improved relationships between staff and patients. In Bristol Community Health it was observed that feeding back survey results has promoted a culture of dialogue between patients and staff. Through well designed posters the system encourages staff to explain how they have listened to what patients are saying and what they have done about it. The Hertfordshire Partnership NHS Foundation Trust and the Heart Hospital also use posters to feedback to patients and staff.
Feeding back results and actions to patients

Two years ago the Heart Hospital started gathering frequent feedback using patient tracker devices which use core questions drawn from the wider in-patient survey (23 questions) plus 5 questions specific to the Hospital. The analysis is done within the Trust by the information department who produce monthly reports broken down to ward area and which are sent direct to the ward sisters. The ward sisters, in consultation with the divisional senior nurse, choose which aspect of the patient experience results they want to focus on for that month. The results and changes made or planned are displayed on patient experience notice boards which are on every floor of the Hospital.

In Hertfordshire Partnership NHS Foundation Trust (and other sites) it has been observed that a range of methods are required to effectively feedback to patients how their views and experiences have been used. One way is to go to user and carer organisations and report, although they noted that you sometimes have to “over feedback”:

people didn’t pick up that we had used what they told us in the first round events when we went back to them. They didn’t see HOW we had used the information.

It was also noted that people with learning disabilities sometimes feel they miss out on feedback, so, accessible feedback is necessary too.

In Essex County Council people with learning disabilities are involved in producing material to feedback the results of consultations and other reports to people with learning disabilities. One person has developed a reputation for his expertise in selecting which messages will be of interest to others with learning disability and the best means of communicating these.

Importance of staff being involved in discussing and acting on data

Patient experience work is sustained by staff owning and acting on the data. We observed that it is important for staff teams to have opportunities to consider and discuss the findings of surveys, complaints and comments.

At the Parchmore Partnership a range of patient experience data are discussed at least once a year by the whole team, including receptionists and administrative staff. Proposals to address problems and improve patient experience are developed by the staff working in groups across disciplines to come up with ideas, so that doctors do not always take the lead in action planning.

In Bristol Community Health the district nursing team leaders discussed the findings of the Experience Based Design research at two meetings drawing out the issues they could do something about and devising an action plan to address these issues.

At the Heart Hospital the results of frequent feedback surveys are discussed in the quality and risk meeting for the nursing staff. They had recently spent a lot of time focusing on how teams share information in an appropriate way, and how they document what has been said to the patient to minimise contradictory information, which had been picked up as a problem. A summary of the patient experience data are also presented at the governance meeting - held nine times a year and usually attended by about 200 staff. It was noted that here the patient experience report is presented alongside finance, clinical and innovation reports.
So I think we’ve moved to a place where patient experience has a much higher perceived value - we talk about it next to our financial bottom line, who’s introducing a new procedure, etc.

The Healthcare at Home Family Liaison Service discusses monthly patient experience reports as a team. Recent feedback suggested that clients did not always know who the health and social care professionals coming into the house were and what their roles were. They have now introduced a multidisciplinary form which is left in the house for all professionals going in to write when they have been, what they did, and when they are due back. This reduces duplication and the need for the patient to keep repeating their history to everyone who comes in.

Hertfordshire Partnership NHS Foundation Trust have set up a meeting to look at patient experience data from the in-patients survey. It is led by the joint head of acute services, and attended by matrons, ward managers, therapists, service users’ representatives and nurses on the ward.

It is really useful. It feels like the voices of patients are finally being heard. Prior to the survey, we had some attitude problems and we had to come on strong. Now it is better.

It was noted that it is important to ensure that patient experience information is fed back to ward managers directly “on an immediate loop” and that this is then communicated to everyone in the team face to face. This has led to a number of changes, in addition to the effect on staff attitudes, particularly in relation to the environment on the ward, including food, and improvements in privacy and safety.

The Hertfordshire Partnership NHS Foundation Trust supplement face to face communication with items in staff newsletters to feedback patient experience results and action plans. In Essex County Council the intranet is used to communicate findings of surveys to staff.

Service redesign
In a number of the case study organisations patient experience has had an impact on the design of services. For example, when they were considering the development of new premises, South Street Surgery sought the views of their patients through questionnaires and discussions with the PPG. When the plans were drawn up they then had an online questionnaire and used SMS messaging to invite patients to respond. They also held two open days for patients to talk to the practice staff and the developers. The consultation changed their plans – they had been planning to move into one site from the current two, but the survey highlighted the preferences of some patients to retain the two sites.

The strength of feeling was a surprise. Most of us thought that patients would like brand new premises, but a third said they might register elsewhere if we were not located where they wanted.
Hertfordshire Partnership NHS Foundation Trust have an on-going programme of involving service users alongside staff and other stakeholders in their four year service redesign programme. They often talk to mixed groups, for instance, GPs, staff and service users and they have found benefits of this approach:

- the views of staff can be changed by having to express them in ways that resonate with service users
- hearing people’s experiences can provide a challenge to the practices of staff teams that can be built around their needs – it breaks down boundaries
- It makes it easier to look at the whole service
- The organisation is now driven by a recovery oriented philosophy.

**Triangulation**

Case study sites tended to agree that it was valuable to triangulate patient experience data from different sources in order to get a more complete picture. However, the ways in which they did this, the level at which they collated and considered information and the use they made of such intelligence varied.

Community trusts were in agreement that the data they set out to capture from surveys should be understood alongside other feedback such as complaints, suggestions for improvements and incident reports.

*We operate an integrated governance system and each service then monitors a range of metrics, and it’s expected to triangulate them. So clinical outcomes, patient satisfaction, complaints, incidents are all analysed up to service line level and presented to the service line themselves, … each service line knows where it stands on all of those areas, so you see a pattern coming up through the complaints, incidents, and patient surveys.* (Camden Provider Services)

In an acute trust, triangulation was seen as important, and in particular, there was some interest in tracking “hotspots”, where relatively poor experience had been an issue in the past. The idea of “hotspots” was in current use in understanding staff experience and there was thought to be further potential for applying this approach to scrutinising information about patient experience from various sources.

In some organisations (e.g. Hertfordshire Partnership NHS Foundation Trust), there was a particularly integrated approach, regularly putting together patient experience data with PALS data.

In primary care settings, there appeared to be further potential for making greater use of collated patient experience data at some of the case study sites, but at one (Parchmore Partnership), a half-day meeting was held at least once a year with all staff to look at all sources including the QOF data, public health data, other survey data, official complaints and the problem book.

**Benchmarking**

There was a range of opinion and practice on the potential value of making comparisons about patient experience between different services, wards or departments within an organisation.
Comparisons within organisations

Sometimes, comparison and benchmarking of services within organisations was encouraged, but was seen as hard to achieve. A member of staff in one organisation explained:

*When I go to speak at team meetings I do always mention that they can look on our trust space[on the intranet] to have a look and compare the different service streams, and I do sometimes get some negativity towards the sort of competitiveness, ‘Well our unit is very different to somebody else’s …’*

In one site there was a deliberate non-comparison between services within the organisation as they were all seen to be different and comparison was “a very unfair thing to do”. However, this did not preclude identification of shared issues across the majority of its services.

Also, within the same organisation, the potential benefits of some comparisons between services were seen differently by different people. While acknowledging the potential impact of negative comparison between services that could not reasonably be compared, one person in a community trust noted the potential incentive to improve when comparisons were made. This had “a congratulatory effect”, leading to more efforts by staff to collect compliments (although we cannot be sure that this was matched by actual improvements in patients’ experiences).

At the Heart Hospital, it was observed that benchmarking across the organisation (in this case the various hospitals and directorates of University College London Hospitals NHS Foundation Trust) could act as a source of pride and motivation for staff.

In one provider of community services (Bristol Community Health), questionnaires were being standardised to some extent in order that services could be benchmarked internally.

Comparisons between organisations

National surveys were sometimes seen as a useful basis for comparison, but this was limited by delays in receiving results, amongst other factors.

Other than that, there were relatively few examples of making systematic comparisons between patient experience in the case study organisation and other organisations. In one organisation (Hertfordshire Partnership NHS Foundation Trust), all mental health trusts within a region were working together on quality measures, which was seen as making benchmarking more feasible. However, this was at an early stage of development.

Comparisons over time

For the most part, organisations regarded trends over time within their own organisation as more important than comparing themselves to others. Most, but not all, organisations had or were developing, reports that showed trends in patient experience. In Bristol Community Health, for example, monthly reports were given to show trends.
One Chief Executive observed:

“I’m not that bothered about anybody else because there is virtually nothing to look at, so what I’m bothered about is improving over time. And as long as we can show ourselves that we’re improving over time eventually it will become clearer to compare with others, but let’s not get distracted with that, and exactly the same approach on safety and quality as well…… And we’re peeling an onion, we’ll be doing it differently next year, and differently the year after.

In conclusion, we found that the scope and frequency of benchmarking was fairly limited. There would seem to be more potential for benchmarking even where the characteristics of organisations vary to some extent.

**Leadership and Organisational Culture**

We observed that there were two main features in organisations that were collecting and using patient experience information to make changes. These were:

- Strong leadership for patient experience
- An organisational culture where it was generally understood that patient experience was a priority.

**Leadership**

A strong finding from the case study sites is that a comprehensive approach to understanding and applying patient experience can best be achieved when it is underpinned by effective leadership and a commitment to seeking and applying patient experience is communicated throughout the organisation. Effective leadership with regard to patient experience can manifest itself at several levels.

**Leadership at Board level**

There was general agreement that conspicuous leadership at Board level was necessary in order to communicate the seriousness with which the organisation addressed patient experience. Both executive and non-executive leadership were seen as important. Boards showed their interest by requiring, receiving and properly discussing regular quality and safety reports, in which patient experience was intrinsic. In a local authority context, the involvement of Council members, as well as the most senior officers who were available to be involved in Partnership Boards etc, was seen as important to engaging service users and learning from their experiences.

**Reporting mechanisms**

Reporting mechanisms from front line to Board level varied, although it is not easy to determine how much the apparent variations reflect actual differences in structures, or simply the ways in which committees and sub committees are known. In essence, organisations typically reported upwards to Board level through a number of intermediate committees, as part of an integrated governance system. The extent to which such committees included service users and carers varied. In Essex County Council, service users sit on the senior management board of the Adults, Health and Community Wellbeing Directorate; in some NHS organisations, (for instance, Hertfordshire Partnership NHS Foundation Trust), patients are involved in committees at all levels of the reporting structure and are able to be part of the corporate leadership on patient experience. General practice case study sites did not appear to have followed that route, preferring, so far, to report within the practices and without significant external input.
For provider organisations, the issue of how to report to commissioners was an issue where leadership could make a big difference. It was seen as potentially easier to report shortcomings in patient experience internally than it was to a commissioning organisation, which could potentially “punish” a provider for poor performance. However, strong leadership and an organisational commitment to cultural change were sources of courage:

... I'm confident that at a management level I think we’re embracing a culture of learning so it’s OK to say, ‘We’re not doing terribly well, but we’re going to improve because I think we’ve got the culture right’...

The impact of becoming a foundation trust
Some organisations noted that the experience of becoming a foundation trust had focused minds on patient experience. The expense of becoming, and being, a foundation trust also impacted on the leadership of the patient experience agenda, and particularly how it was reported on and owned by the top of the organisation. For example, at one hospital (the Heart Hospital) there was a strong awareness of being held to account by the Governors. Also, Patient Governors sat on the Quality and Safety Committee. Similarly, in Northumbria Healthcare NHS Foundation Trust the Chief Executive was very much aware of needing to engage with Governors and to carry them with the organisation as it progressed and made changes. He also saw further potential to engage with Governors who could reach out into the community to bring in additional sources of patient experience.

Individual leadership
Having a champion or lead on patient experience – either someone dedicated to that role or someone who had a personal conviction about the importance and centrality of patient experience – was quite a significant driver to the quality of patient experience work and, particularly, to ensuring that patient experience information was acted on. Individual leadership and enthusiasm was also a key factor. This was possibly not sufficient to ensure a thorough organisation-wide approach to patient experience, however – and this was most evident in general practice – leadership and commitment by individuals was often the factor that kick-started a commitment to gathering and heeding data from patients.

Individual leadership was also a useful complement to corporate leadership. Where there were dedicated posts to oversee and/or support patient experience work, individual leadership provided both practical and symbolic support. In view of all the competing pressures on busy staff, such support should not be under-estimated. For example, in one trust (Hertfordshire Partnership NHS Foundation Trust) the Service User and Carer Experience Coordinator plays a key role in encouraging ward clerks etc. to submit survey results, and also takes a lead in ensuring that feedback is given at a ward level. The PPI Manager in Bristol Community Health and the Director of Patient Experience in Northumbria Healthcare Trust have a number of roles including motivating staff and providing expertise on methods of obtaining patient feedback. In Northumbria the Director of Patient Experience plays a key role overseeing the change process that ensued as a result of patient experience.
Support for staff in making changes based on patient experience

Robust and appropriate methods for gathering patient experience data are clearly essential. However, organisations sometimes find it challenging to apply what they have learned in order to improve services. In particular, it is often necessary to provide support for staff in using various methods and in considering what patients say about their services so that they can make appropriate changes in the light of patient feedback.

Northumbria Healthcare Foundation Trust explicitly attempts to meet these challenges, and it does so in a number of ways. First, the trust has appointed a Director of Patient Experience. The post holder maintains some involvement in clinical practice, but is mainly responsible for overseeing patient experience work within the trust. Close contact is maintained with executive directors and with front-line staff and their managers. While patient experience is everyone’s business, it is very useful to have a named person, working with a small team, with responsibility for developing and applying the various methods of gathering patient experience that are used across the trust.

Some changes require significant efforts on part of front-line staff, particularly if patient experience has highlighted the need for attitudinal changes. It is not easy for busy staff to sit down together to plan for change, but the trust is committed to giving opportunities for staff in wards and departments to take time out to plan together for change, wherever possible.

Work with identified teams follows three specific steps in each engagement:-

1. Challenge the team: Following the collection of baseline data for that service, ward or clinical area - the team is challenged with making improvements across priority areas. The metrics chosen are themselves meaningful to both staff and patients with data generated as close to the level of each clinical team as possible (e.g. ward by ward). Sponsorship for their work will be secured from the appropriate managerial lead and a timeline for their work will be agreed upon.

2. Apply QI Process: The team will then be facilitated through a systematic quality improvement process which is frontline led but which directly involves patients and families. The team may draw upon FOCUS PDSA\(^{11}\) or a LEAN\(^{12}\) approach to process improvement which emphasise value as seen through patients’ eyes and involve rapid cycles of testing change. Team away days also bring the opportunity to explore why Patient Experience matters & enhance compassionate behaviours through Communicating Caring workshops.

3. Spread good practice: Once successful change strategies have been identified they are implemented at a team level, supported by the teams’ sponsors and then these good practices for positive patient experience will be celebrated by, and shared across, the broader organisation.

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\(^{11}\) Waiting for reference from Annie Laverty - to be added

\(^{12}\) Waiting for reference from Annie Laverty - to be added
The impact of personal leadership (as well as the prevailing culture) was also evidenced by differences within organisations. For example, in one community trust, although corporate leadership ensured that the whole organisation participated fully in collecting real-time feedback, one particular service – the HIV service – went far beyond that in using a wide range of qualitative and quantitative methods to understand their patients’ experience in a deeper way.

Individual leaders can make a significant impact in enabling services that have not been in the forefront of gathering patient experience data to embrace a more modern approach to doing so. Some commentators implied that there have been issues for staff in some of the more traditional wards and domiciliary services, where individual staff may feel that they simply know what their patients feel about the services they receive, or they may, without foundation, believe that staff concerns and patient concerns are the same.

**Leadership and coordination**

In addition to Board level leadership and individuals playing their part, there is a value in having a co-ordinating group. This can undertake a variety of tasks, such as ensuring some consistency in relation to surveys that are being administered, avoiding duplication and possible survey fatigue, and coordinating how results from surveys and other methods of enquiry are communicated in a consistent and comparable manner throughout an organisation.

**The QIS Group**

All services in Bristol Community Health are expected to conduct at least one patient experience survey a year. The PPI Manager facilitates this activity and convenes the Questionnaire, Interview and Survey (QIS) Group. This Group meets monthly to coordinate and assure the quality and consistency of the various patient experience surveys being conducted across the organisation. Services present a proposed piece of survey work for discussion by the Group who comment on issues such as the process to be used to administer survey and ensure responses, how patients would be accessed and the appropriateness of letters and survey questions for the audience.

The Group is also used to ensure that various survey work is not cutting across other work going on and so avoids duplication of effort or over researching of one patient group. A mixture of people attend the Group including service managers involved in conducting surveys, staff with expertise in audit and evaluation and two lay members who make useful comments on the proposed survey materials.

One service manager described it as a “fantastic learning forum . . . one of the few of the many meetings I have to go to that I find valuable”.

**Cultural change**

Organisations that were most advanced in collecting and using patient experience data systematically saw themselves as being on a journey of cultural change. The use of patient experience in a systematic way was, in itself, a key to transforming the organisation and how patients experienced its services. One organisation referred to “a culture of dialogue” that had resulted from the systematic collection of real-time patient experience data.
Several organisations viewed a culture of “box ticking” with distaste, and were aware that a mechanistic approach to methods, without a corresponding understanding of purpose and potential impact, could be counter-productive. One senior manager explained that “just having a nice big action plan” was not enough. There was a need for staff to believe in what they were doing and to demonstrate it:

> It's addressing staff attitude and values head on, and as quickly as you can, through prompt feedback from managers. ‘Hang on a minute, I didn't like the way you talked to that pensioner a minute ago.’ That's what we try and model and encourage.

An interviewee in Essex County Council, who had previously worked in a primary care setting in the NHS, observed

> the whole concept of service user and carer participation was quite alien to me. . So it was quite different for me coming into local government, a whole change of mind-set. . . You don’t have to be in local government for very long before you learn that actually service user participation is very important, and that actually they’re central to the provision of services. The whole culture is different.

We also heard that it can be quite challenging to achieve the necessary cultural change particularly when a robust approach to valuing patient experience can threaten traditional ways of working. Investment in understanding patient experience and support for staff at all levels were necessary if real cultural change was to be achieved.

Further, it was observed that there was frequently a link between staff experience and patient experience. Stressful work conditions can impact negatively on patient experience so it is important for organisations to capture and act on staff experience in addition to patient experience. It was observed in one organisation (Bristol Community Health) that working together to focus on patient experience could improve the morale of teams.

### 3. Budget for patient experience work

Interviews at all case study sites attempted to tease out what budget was allocated to patient experience work in all its aspects, including data collection, analysis and dissemination of findings. The amount of the budget, if it were known, could give an indication of the extent to which organisations invested in this kind of activity and the importance that was attributed to it. It might also be possible to assess whether any savings could be directly attributed to patient experience activity. Potentially, questions about the budget could also lead to discussions about who held responsibility within an organisation for ensuring that work on patient experience was properly resourced and managed. However, in fact, it was commonplace for interviewees to be rather vague about what their organisations spent on patient experience work and so these questions were not able to be adequately addressed.

The reasons for the lack of precision about budgets generally were complex. First, it must be acknowledged that interviewees were not all budget holders and not all of them could reasonably be expected to know about the budget for patient experience. Second, even for those with a more detailed knowledge of their organisation’s finances, it was not always clear what they might consider to be included as relevant to patient experience. It was understandably difficult for many people to disentangle what monies might come from service-specific budgets, what might be explicitly identified as “patient experience” money and what might be part of another cost-centre, such as patient and public involvement. As a
result, it was easier for interviewees to put a figure on disbursements for such items as Patient Experience Trackers, specific surveys and external consultants, or for the costs of specific dedicated posts, rather than for the quantum of patient experience spending.

Finally, in some cases, patient experience was seen as wholly interwoven with the quality and safety agenda, so the costs could not be separated. Culturally, this may be a considerable strength, but it is not without possible adverse consequences in terms of being able to make and defend decisions about increasing or decreasing the volume of activities to seek out patient experience. It is certainly understandable that initial forays into gathering patient experience are funded ad hoc, or costs are absorbed into existing budgets.

All of this was compounded by the tendency in some organisations for some of the analysis of data to be done by administrative and clinical staff in time carved out of their substantive roles. This applied in most of the primary care case settings, and to some extent to other kinds of organisation too. This may turn out to be a problem in the ensuing months and years when public service budgets are under particular pressure, particularly if organisations increase their patient-experience-related activities and can no longer carry out the work without expert staff in dedicated roles.

The relationship between patient experience and PPI

The question of how patient experience and patient and public involvement (or engagement) fit together is discussed here under the heading of Budgets, as some of the issues are about who pays for what kinds of activity, but in fact, it is a wider question about how different pieces of the jigsaw fit together.

We noted that the structural and financial relationship between “patient experience” and “PPI” varied across the case study sites. In some organisations, the two strands are led by different people and their budgets and reporting lines are separate too. In other organisations, the PPI lead oversees the patient experience agenda and little or no distinction is drawn between the concept of PPI and the concept of patient experience – the former being a means of understanding the latter.

In a commissioning organisation one person commented that her post was focused on redesign, so PPI was seen as part of that. In the same organisation, another person made explicit links between PPI and patient experience:

> PPI is really important, especially for a commissioning organisation. You could commission in isolation, but you need to commission in response to what the public tells us. If you are getting it right, you won’t get constant complaints about the level of service.

The key to successful working does not appear to lie in any one organisational solution. Where the two strands are managerially and financially integrated, the risk of fragmentation is reduced, but the time and budget available for either aspect of the work may be under pressure. Conversely, where different people are responsible for patient experience and PPI, and particularly where these functions sit in different directorates, those involved may need to work harder at integrating their work but they may have more resources to do so.
What matters is that close cooperation takes place between people who are involved in engaging patients, whether for discrete and tightly focussed methods of soliciting patients’ views, or for broader and on-going aspects of working in partnership with patients, carers and other stakeholders.

Training
In all of the case studies, we enquired whether interviewees or their immediate colleagues had had training in developing measures of patient experience or of analysing or interpreting them. In the case of those who had not had training, we asked whether there was any help available from elsewhere in their organisation. Overall, we were interested not only in formal training, but also in other ways which people could be better equipped and supported to gather, analyse and apply patient experience.

Responses to questions about training can be grouped under a number of headings – although respondents sometimes gave multiple answers that straddle these categories:

Those who had found training helpful
Some people had attended useful courses or sessions. For example:

- One person had been part of the NHS Institute’s Patient Experience Learning Programme, and had found this very helpful.
- In Bristol Community Health we heard about the Questionnaire Interview and Survey (QIS) Group which was described as “a fantastic learning forum”, where people learn from each other (see vignette above).
- One person had been doing a session on patient experience measurement at “preceptorship” training for newly qualified staff. However, it is interesting to note that this kind of directly relevant training was rarely mentioned, either as something that people had undertaken, or as an identified training need.
- In a primary care practice reception and managerial staff had been on courses run by the PCT on Improving Patient Experience.
- In a mental health trust, recovery training was seen as fundamental to understanding patients’ experience.

Those who referred to pre-existing expertise/training
Some people referred to training or experience that they had had in previous roles. This was usually mentioned in order to make the case for why they did not necessarily require patient experience training at this stage.

[I have not had training on patient experience but] the point is… I used to teach interpersonal skills, I have several degrees, I’ve got a post graduate educational qualification, I’ve got a PGCE, I’ve got an MA….

One interviewee mentioned her degree in social policy and social research and another referred to having studied an online course from the Market Research Society. Another person referred to her training in Six Sigma methodology, which she described as helping her to understand the patient voice.
Those who identified areas of training need
Some people would welcome further training and were able to identify possible topics or areas for such training. One senior clinician/manager who would not expect to be involved in data collection identified a personal need for training on the interpretation of results and “satisfaction thresholds”. In another organisation, one person wanted training on statistical significance and how to weight different evidence. Elsewhere, it was suggested that there was such excitement at getting good data that excessive significance might be attached to good results.

One of the few people who would have welcomed more training on actual methods – incidentally someone who had a degree in social research – wanted specific training on what was research and what was “just having a chat with somebody”.

Elsewhere, a PPI lead wanted to run training for colleagues on in-depth interview technique, but felt constrained by budgetary considerations and by the difficulties in getting people to attend training. She wondered if “on the job” training might be preferable. She also reported that plans to run training on patient experience for staff in conjunction with local universities had been deprioritised during a period of organisational change.

Sometimes senior staff mentioned the possible need for the organisation to understand the basic approach to patient experience – for example, the importance of recovery principles in mental health in one trust, and patients’ motivations in being open about their experience in another trust.

In the local authority setting, a service user mentioned the need for training in the social model of disability to create a climate for equal participation. It was also suggested that GP consortia will need training to help them understand what patient experience is about.

Some people would welcome training on patient experience in relation to groups whom they saw as relatively hard to reach e.g. people with dementia.

 Those who felt training was not necessary in their role
There were, however, some who did not identify any training needs or felt that training was not necessary, either in their role or more widely. In one organisation, training was not thought to be necessary at Board level, not least since patient experience was strongly led and supported by a Director of Patient Experience.

One senior manager was wary of patient experience training to some extent, for as he explained:

  I don’t want to make this a really big complicated thing, so if you’re a nurse, a physio, an OT, ward manager, why isn’t this the thing that you do?

In a similar vein, a GP looked back at how the practices’ work on patient experience had commenced without prior training and noted that the work started gradually and the cost of training might have meant that it would never have got going.

  We needed to get on with it and see results.

In one organisation only, a member of staff was fairly negative about training because of a perception that it was not particularly informative and it relied on participants to feed ideas in.
General training in customer care and quality

Some people found it difficult to conceptually differentiate between general training on customer care and more specific training focusing on the quality of patient experience and how to measure and improve it within an organisation. So, when asked about training on patient experience, it was sometimes general customer care training that came to mind:

*The training we value most is on staff attitude. We have training on customer care for admin and reception staff.*

Training for patients and volunteers

When patients or volunteers were involved in gathering views on patient experience there seemed to be an expectation that they needed and would receive training – perhaps rather more than was the case for their professional colleagues.

Examples of such training include:

- Training volunteers on the use of hand held devices (Heart Hospital)
- Training service users to visit facilities (Essex County Council)
- Training for patients involved in procurement (NHS Leicester City)
- Training for peer support workers (Hertfordshire Partnership NHS Foundation Trust).

Training by patients /service users

Patients, carers and service users were sometimes involved in the delivery of training related to patient experience, usually to raise the awareness of staff on issues such as the needs of people with learning disabilities, people with dementia and people with mental health problems.

*Patients are involved in training staff. We encourage patients (if they are well) to train student nurses by telling them about their experiences. The patients enjoy it and it helps the nurses too.*

Support from a range of sources

Some interviewees referred to advice and support from a variety of sources other than training courses.

*We’re linked in with a lot of local, regional networks. And there are national conferences about this sort of thing. So we’ve got ways of learning, but that’s not the same as training.*

One person, working in a dedicated PPI / patient experience role had made links with a colleague in another organisation in the region in order to share learning.

One person referred to having had a toolkit, from their Communications and Public Engagement Team, on methods of consulting with patients, such as focus groups and surveys.

One person felt that there may be expertise in his trust that was not fully used e.g. expertise from psychiatrists and psychologists on devising surveys.
In conclusion
Although some relevant training and support was available, in many of the organisations it was striking how little training was available to assist and support people to gather and understand patient experience data, and it appeared that there was a particular lack of training in collating and analysing data for those staff who came to assume such duties as part of their role. Even more striking was that staff, in general, sometimes did not perceive a need for training. This may be because they were already well equipped for their roles, but it raises the possibility that some people did not appreciate the limitations on their knowledge and skills and therefore did not appreciate that they might, in fact, benefit from training in this area.

4. Role of commissioners
Case study sites included both provider organisations and commissioning organisations, with providers being in a clear majority. This mix enabled us to gather a range of views about patient experience in relation to commissioning from different perspectives. It is worth noting that interviewees in provider organisations held a range of views about how commissioners could drive and/or be involved with patient experience.

What commissioners can do
The observation made by our one local authority case study site - that commissioners tend to drive strategic change and change which involves planning across service sectors so awareness of patient experience is important and necessary at this level – resonated with some NHS providers as well as with other commissioners.

In NHS South Birmingham, commissioners were particularly concerned to address patient experience across the whole of the pathway, particularly for people who were approaching the end of life, where patient experience could encompass many different services. In that context, a commissioning organisation could try to bring together patient experience across all stages of the pathway, potentially bringing together patient experience data from many different providers.

Patient experience data at the end of life – how commissioners can find out about the views of patients
It can be particularly difficult to get a good understanding of the views of people who are approaching the end of life. In addition to taking care not to burden patients who may have significant symptoms of pain, discomfort and fatigue, staff are often rightly aware of the sensitivity of the situation, and may feel very reticent about asking patients about their experiences. There is also the obvious issue that with many other patients it is possible to ask them to reflect on care they have received some time ago, but once a patient has died, no-one can know what their views were unless they were asked at the time. For all these reasons, there is often a tendency to ask carers and bereaved relatives instead of patients, but that may not give the whole picture.

As a commissioning organisation, NHS South Birmingham is thinking hard about how it can find out more about the whole picture from the patient’s point of view. While providers of services are required to understand patient experience, their traditional focus has been on what patients feel about their own services.
In view of the limitations of standard methods of data collection such as postal surveys and questionnaires for people at the end of life, consideration has been given to the use of key workers to ask such patients for their views. This could be done in ways that are acceptable and sensitive to patients’ and carers’ needs. For example, key workers could leave questionnaires for patients, or could discuss what patients and carers felt about their care as part of their visit. As part of the multi-disciplinary integrated teams in community services, key workers are well placed to look across the whole patient pathway – a particular concern for commissioners (as well as for patients and carers).

There may be other useful approaches too and NHS South Birmingham is looking at how to address the challenge of asking providers to be involved in the collection of data that may extend beyond the remit of their own service. This will require a high level of trust between organisations.

NHS South Birmingham is at an early stage of working in partnership with providers of the whole range of services involved in end of life care in order to better understand patient experience across the entire pathway. They have also had some meetings with forums at local hospices, as well as a stakeholder workshop with local groups with an interest in health to inform their work. An end of life care steering group has been established with a remit to define and deliver a local health economy End of Life Care work plan for the next 12 months in line with the outcomes of the stakeholder workshop.

Although there is a long way to go, the prospect of working in partnership offers a realistic prospect of developing a holistic approach to understanding patient experience in a particularly sensitive area.

**Relationships between commissioners and providers**

Generally, provider organisations felt that the impetus for change is both commissioner and provider-driven, and effective partnership work with commissioners was therefore necessary, although the candid (and outlying) views of a senior manager in one provider organisation suggested that commissioners are largely seen as irrelevant to the process of obtaining and using patient experience information:

> I’ve never had a conversation with a commissioner that has said, ‘I’m really worried about your patient experience in a particular service,’ they’re completely blind in that respect. …. I bet you would struggle to find a provider that said they had a proper conversation with a commissioner about satisfaction or outcomes.

This same person saw CQUINs as a system that had started out well but had become a “punishment process”. Elsewhere, more positively, there were some indications that CQUINs were seen as focussing minds of providers, although a manager in a provider organisation who made the following statement was at pains to emphasise that his Board was interested in patient experience in any case:

> And of course, with CQUIN, it brings money with it, and in these days of financial pressures, anything that brings money in automatically is important to us.
Although the requirement to produce Quality Accounts is a requirement of the Department of Health and not of commissioners, it is worth mentioning here as providers sometimes spoke of the two in tandem as potential drivers for understanding patient experience. As the person who referred to CQUINs (above) explained:

.. actually there’s a rather complicated relationship between CQUIN and Quality Accounts, because Quality Accounts is meant to be about us as a Trust deciding what’s most important in terms of quality. CQUIN ultimately is imposed by commissioners. But it’s hard for us to ignore the importance of CQUIN when there’s the money attached.

Both commissioners and providers noted the need for a mature relationship between the two kinds of organisation. From commissioners, this might require an understanding of what different providers could achieve, and when:

While we set the context and contracts, it is for providers to make the improvements. The final detail has to be done through collaboration. You have to have dialogue on a realistic pace for improvement, especially if they are smaller providers and don’t have a big infrastructure. You have to align your intentions to how providers can get there, i.e. the pace may vary.

From providers, honesty was required about what patients said about their experience, together with other sources of quality information. This required trust and collaboration, although in the context of a recognition that poor performance needed to be addressed and not merely explained.

The following vignette provides an example of partnership working between a commissioner and a provider:

**Systematic and frequent feedback to commissioners**

During 2009 a proposal was put forward for NHS Birmingham East & North PCT to work in partnership with Healthcare at Home Ltd, (HAH) to provide a coordination service – Family Liaison Service (FLS) for end of life care to support people to stay in their own homes. The service systematically collects data from service users including:

- A questionnaire completed by service users typically after the third visit from a coordinator, including free text comments
- A record of concerns raised to the 24 hour helpline support service provided by the FLS
- Letters and emails from families
- Comments made in obituaries
- Patient scenarios / stories.

Healthcare at Home combine this information to make monthly reports which are discussed at a meeting with the commissioners. The commissioners particularly value the patients’ stories and the free text comments, and the fact that feedback is gathered from the clients themselves whilst in receipt of service rather than bereaved relatives or carers.
How commissioners can learn about patient experience and use to redesign services

Clearly, in order for commissioners to be in touch with patient experience, they had to explore various ways of accessing the views of patients. An example is the MIME service in Essex.

**Service User and Carer Involvement in Mental Health Commissioning**

Making Involvement Matter in Essex (MIME) is a service commissioned jointly by Essex County Council, the unitary authorities of Thurrock and Southend and the five PCTs in Essex to feed the views of service users and carers into mental health service commissioning. The service is based at Anglia Ruskin University and so is independent of the commissioners and the local mental health services. The MIME service has been commissioned for three years and has been running for about a year.

The team, which includes academic researchers and a coordinator who has experience of using mental health services, employ a range of methods to gather views and experiences. They have held broad consultation events, conduct discrete pieces of research, and conduct service evaluation. They also have a newsletter which is used to engage people in their events and through which people can feed in views. They have built up large mailing list for this by going out to where mental health service users are and talking to them and inviting them to become involved in their events and activities. The service also links with community development workers to widen involvement particularly with Black and Minority Ethnic (BME) communities.

The MIME service feedbacks to commissioners in a number of ways including:

- Regular meetings with commissioners
- Reports with the evidence from the research and survey and consultation work
- The Coordinator sits on the Partnership Board for the County Council and the two mental health trusts
- Organising meetings between service users and commissioners in order that they can feed back directly and ask questions of the commissioners.

The service has provided feedback to commissioners on a range of issues such as:

- Commissioning priorities and the joint strategic needs assessment (JSNA)
- Personalisation and day services
- Views of seldom heard groups.

The MIME service aims to promote good practice amongst commissioners and has produced standards for user and carer involvement. The service also provides training for service users to enhance their skills and support their involvement in commissioning.

NHS Leicester City, have produced guidance based on their experience of involving service users in commissioning.
**Guidance to encourage and facilitate user involvement in commissioning**

The engagement team in NHS Leicester City have produced guidance on involving patients in procurement for those commissioning services. This incorporates lessons learnt from various approaches to involving patients in procurement panels, including a ground-breaking initiative where patients were involved in the procurement of a diabetes service a year ago.

The guidance focuses on the involvement of service users in mixed procurement panels, making decisions alongside PCT officers. It is stressed that the best practice is to involve service users as early as possible in the process so they can influence the questions asked of those tendering for a service. The guidance takes commissioning managers through the process involved in selecting, training and preparing service users for sitting on a procurement panel, including taking them through a mock panel exercise and highlights key issues such as confidentiality, understanding of bias, devising questions and evaluation criteria.

**What the future holds**

Finally, we noted a range of views about how the relationship between commissioners and providers may evolve once GPs are more fully involved in commissioning through the consortia that are being formed. Some felt that work currently being undertaken with GPs would lead to a robust framework for new consortia in taking patient experience into account, while others were less certain about how the situation might pan out. Either way, lessons learned from the current phase of working collaboratively on patient experience will need to be adapted and applied to commissioning in a context where people are acquiring new skills in new roles and within a challenging financial situation.
Annex one

Interview Schedule for Staff in Case Study Sites

1. Introduction
Introduce self, King’s Fund, NNru

- Introduce research (funding, research design, outputs)
- Explain: confidentiality, tape recording, length of interview, nature of discussion (specific topics to address, but conversational in style, in your own words, no right or wrong answers), reporting and data storage/archiving (this should supplement written information given before or at beginning of interviews)
- Any questions
- Obtain written consent

2. Background
- Role, years in the organisation

3. Measuring patient experience
- How do you/does your organisation gather information about patient experience?
  - Across a range of services or for specific patient groups, services or pathways?
  - From large groups of service users through, for example, surveys and / or more in-depth experiences and stories?
  - What weight do you give to each? Do you use the different types of data in different ways?
- What do you measure in relation to patient experience in this organisation? What questions do you ask?
- Do you use ‘real time’ feedback?
- Do you collect information down to individual ward level / department /service/directorate?
- How long have you been doing this?
- What do you do with the data you collect?
  - In terms of process (i.e. how are the results summarised and presented to board/senior managers/staff/external stakeholders?) – can we see any documents / reports that summarise results?
  - In terms of acting on what you find – i.e. how you make use of the data to improve patient experiences? What mechanisms are available to improve areas where patient experience appears poor?
- Do you attempt to triangulate the information you obtain in measures with information about the same services from other sources: complaints? comment cards?
- Can you provide any examples of where collection and feedback of patient experience data has directly led to service improvement?
  - Three things that have changed?
  - Three things you tried to change – what were the obstacles?
- Are you comparing patient experience data between services within the organisation or with other organisations and / or over time within your organisation?
• In which topics/clinical areas is it a priority for this organisation to gather information on patient experience? Why?

• Have you measured the experiences of service users who may find it harder to give feedback (e.g. due to language barriers, low literacy levels, communication difficulties linked to their condition)? How?

• What budget is available for the work on gathering relevant data and improving patient experience?

• Who is involved in collecting the data?

Prompts:
Staff in the organisation? (if so, what kinds of staff and at what levels?)

External contractors (if so, academic? Private sector? Third sector?)

• Are the public / service users involved e.g. Local Involvement Networks (LINks) – and if so, how?

• Are there any ethical/confidentiality/data protection issues that you have had to consider?

• Have you experienced any other barriers to collecting patient experience data?

• What are the main lessons you have learnt from using patient experience data to improve services? Any organisational changes made that have helped? What advice would you give to others?

• Training: have you personally, or any of your immediate colleagues, had training in developing measures of patients’ experience, analysing or interpreting them? If not, is there any help available from elsewhere in the organisation?
# Annex Two: Organisation templates

<table>
<thead>
<tr>
<th>Name of organisation:</th>
<th>Bristol Community Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope of the case study in one sentence:</td>
<td>A coordinated approach to collecting and using patient experience data across a community health provider organisation.</td>
</tr>
</tbody>
</table>

**What main areas/issues of patient experience does this case study illustrate?**

- The use of various methods to collect and feedback data
- The importance of a good supportive coordinator for the activity
- The use of a coordinating group of people (through the Questionnaire, Interview and Survey (QIS) group) and standard tools to facilitate and support patient experience data collection
- Innovative work to engage district nurses with patient experience
- Patient experience focus can help to bring teams together when going through organisational changes.

**What is the focus of the data collection e.g.**

<table>
<thead>
<tr>
<th>Organisation-wide</th>
<th>All services are required to do at least one patient experience survey / activity a year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across certain directorates</td>
<td></td>
</tr>
<tr>
<td>Specific departments/services</td>
<td></td>
</tr>
<tr>
<td>Patient Population</td>
<td></td>
</tr>
<tr>
<td>Clinical Speciality</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
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</tbody>
</table>

**Measures:**

**What data is collected about patient experience?**

- Quantitative data from Dr Foster hand held devices
- Quantitative data from questionnaire based surveys
- Qualitative data from semi-structured, in-depth interviews
- Observational data

**What methods are used to collect data about patient experience?**

- Electronic hand-held electric patient response devices (Dr Foster)
- Postal and face to face questionnaires
- In-depth, semi-structured interviews
- Focus groups
- Experience based design
- Community outreach
## How is feedback translated into improvement?

- Service teams discuss results of survey work and agree action to take.
- Outcomes of survey work and actions are reported to PPI Coordinator and the QIS working group and progress is charted (plans for a database to manage this).

## What has changed as a result of the activities and approaches outlined above?

- Cultural change – staff more aware of patient experience focus and value what patients are saying.
- In the Podiatry service improvements have been made in the way information was provided to patients.
- The Walk-In clinic service has used patient feedback obtained through Dr Foster in support of an application to fill vacant posts.
- Changes have been made to the way the pulmonary rehab service is administered due to feedback from patients. For example, times when the phones are open have been changed and volunteers are being used to help staff chase patients who have not made appointments and to obtain patient feedback.
- Patient feedback has provided the District Nursing service with a tool to discuss and develop greater consistency amongst staff in dealing with patient expectations of the service.

### Lead person/contact for further information:

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Contact Information</th>
</tr>
</thead>
</table>
| Hildegard Dumper | Public Involvement Manager | Tel: 0117 984 1547  
Hildegard.Dumper@briscomhealth.nhs.uk |
<table>
<thead>
<tr>
<th>Name of organisation:</th>
<th>NHS Camden Provider Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scope of the case study in one sentence:</td>
<td>Understanding patient experience in an NHS provider of community services</td>
</tr>
</tbody>
</table>

**What main areas/issues of patient experience does this case study illustrate?**

- Gathering information on the experience of using community services in a wide range of settings
- Role of patient representatives and the patient network in the HIV service

**What is the focus of the data collection e.g.?**

<table>
<thead>
<tr>
<th>Organisation-wide</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across certain directorates</td>
<td>All</td>
</tr>
<tr>
<td>Specific departments/services</td>
<td>Case study also looked at how patient experience is collected and applied in the service for people with HIV</td>
</tr>
<tr>
<td>Patient Population</td>
<td>Residents of Camden and some of neighbouring Boroughs</td>
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<tr>
<td>Clinical Speciality</td>
<td>Sexual &amp; Reproductive Health &amp; GP and Hospital Support services</td>
</tr>
<tr>
<td>Other (please specify)</td>
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</table>

**Measures:**

**What data is collected about patient experience?**

Real time feedback across almost all services, supplemented by more detailed feedback in a number of services.

**What methods are used to collect data about patient experience?**

- Patient Experience Trackers used for real-time feedback across the organisation
- Surveys conducted by external consultants in most services
- Workshops, focus groups and other events in HIV service
- Exit questionnaires in the in-patient rehabilitation service and one community service
- Formal and Informal feedback from patients e.g. the Patient Support Service proactively solicits comments, concerns, complaints and compliments

**How is feedback translated into improvement?**

- Each service receives reports on feedback and addresses issues through action plans
- Reports of patient experience are made monthly to a committee chaired by a NED
- Reports to Board
What has changed as a result of the activities and approaches outlined above?

- Work on redesign of telephone access
- Revised appointments system in Contraceptive Services
- Continual refinement of HIV services e.g. on-site pharmacy, late night clinics.
- Patients are being surveyed about their interpretation support needs and whether this is being met

| Lead person/contact for further information: | Brid Hehir  
|                                           | Head of Engagement and Patient Involvement  
<p>|                                           | <a href="mailto:Brid.Hehir@camdenpct.nhs.uk">Brid.Hehir@camdenpct.nhs.uk</a> |</p>
<table>
<thead>
<tr>
<th>Name of organisation:</th>
<th>Essex County Council (Adults, Health and Community Wellbeing Directorate)</th>
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<tbody>
<tr>
<td>Scope of the case study in one sentence:</td>
<td>User engagement and feedback in commissioning a range of adult social services.</td>
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</table>

**What main areas/issues of patient experience does this case study illustrate?**

- Development of individualised questionnaire surveys to capture experiences along a person’s whole pathway
- Comprehensive survey programme and database of experiences
- Very strong culture of service user, carer and citizen engagement
- Service planning groups with good engagement of service users / citizens
- Service users involved as lay visitors and researchers to capture experiences
- Commissioning of independent mental health service user involvement service.

**What is the focus of the data collection e.g.**

- Organisation-wide
- Across certain directorates
- **Specific departments/services** Focus on older people, people with learning disabilities, people with physical disabilities, mental health services and carers
- Patient Population
- Clinical Speciality
- Other (please specify)

**Measures:**

**What data is collected about patient experience?**

- Responses to surveys of existing service users and new service users
- Feedback also fed up through various mechanisms to planning groups
- Reports of lay visits to residential care and other facilities
- Reports from consultation events and other involvement activities
- Reports from Older People’s Research Group.

**What methods are used to collect data about patient experience?**

- Surveys of existing service users and new service users
- Structures in place to ensure that planning groups hear from a wide constituency
- Lay visiting
- Consultation events
- Specific research around service developments – interviews, focus groups (MIME – mental health service user involvement service, “WhyNot!” Older People’s Research Group)
- Strategic commissioning officers listening to service users.
**How is feedback translated into improvement?**

- Through service planning groups – action plans are made and followed up
- Issues raised at Senior Management Board (which includes two service user representatives)
- Strategic commissioning officers using data and feedback to plan services.

**What has changed as a result of the activities and approaches outlined above?**

- On-going service improvement through strategic commissioning
- Relatives and Residents Association set up and signposting DVD produced
- Improved approach to people with dementia in acute hospital settings
- Better focus on issues that matter to people with learning difficulties
- Development of a Carers’ Participation Board.

<table>
<thead>
<tr>
<th>Lead person/contact for further information:</th>
<th>Jennifer Maude</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>01245 435567 ext. 55567</td>
</tr>
<tr>
<td></td>
<td><a href="mailto:jennifer.maude@essex.gov.uk">jennifer.maude@essex.gov.uk</a></td>
</tr>
</tbody>
</table>
### Name of organisation:
Healthcare at Home - Family Liaison Service for NHS Birmingham East and North

### Scope of the case study in one sentence:
The collection, analysis and presentation of patient experience data by a private sector organisation commissioned by the NHS to provide an end of life care and coordination service.

### What main areas/issues of patient experience does this case study illustrate?
- Systematic and comprehensive patient experience data collection and regular reporting to commissioners
- That it is possible to get meaningful feedback from people who are at the end of life and use this to improve the service
- That small changes can make a big difference
- The value of patient stories to inform experience.

### What is the focus of the data collection e.g.
- **Organisation-wide**
- **Across certain directorates**
- **Specific departments/services** Data is collected about client experience of the Family Liaison Service (FLS) providing end of life coordination and care
- **Patient Population**
- **Clinical Speciality**
- **Other (please specify)**

### Measures:

#### What data is collected about patient experience?
- Responses to questionnaire which asks about 10 questions relating to patient experience
- Free text data
- Feedback captured from patients / clients through the 24/7 helpline provided by the FLS service
- Letters and emails from families
- Comments made in obituaries
- Patient scenarios / stories
- Focus group feedback.

#### What methods are used to collect data about patient experience?
- Questionnaire completed by clients (typically after third visit from coordinator)
- Feedback captured from patients through the 24/7 helpline that the service provides access to
- Letters and emails from families
- Comments made in obituaries
- Focus groups
- Stakeholder review with clinicians referring to the service.

### How is feedback translated into improvement?

- Monthly team meeting (including senior management in Healthcare at Home Ltd) and the project manager from the NHS to discuss all the data and performance indicators and the patient experience measures.
- Learning from scenarios – patient stories.

### What has changed as a result of the activities and approaches outlined above?

- Changes in length and timing of visits
- Increased sensitivity of the need to check with clients how much they want to involve relatives in information and decisions about care
- Introduction of multi-disciplinary form to allow for sharing of information, avoid duplication and coordinate visits from the various professionals providing care in the home.

### Lead person/contact for further information:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steve Davis</td>
<td>Head of Marketing, Healthcare at Home Ltd</td>
<td>07818 016160</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:steve.davis@hah.co.uk">steve.davis@hah.co.uk</a></td>
</tr>
<tr>
<td>Karen Coles</td>
<td>Manager, Family Liaison Service, HAH Ltd</td>
<td><a href="mailto:karen.coles@hah.co.uk">karen.coles@hah.co.uk</a></td>
</tr>
</tbody>
</table>

144
**Name of organisation:** The Heart Hospital

**Scope of the case study in one sentence:** Collection and dissemination of patient experience data in a specialist / tertiary service setting

**What main areas/issues of patient experience does this case study illustrate?**

- Very strong culture of safety and quality with sustained focus on the importance of patient experience
- The use of Picker Frequent Feedback surveys throughout all services
- Routine reporting of patient experience data displayed on wards
- Innovative involvement of prospective medical students as volunteers to collect data.

**What is the focus of the data collection e.g.?**

- **Organisation-wide**
- **Across certain directorates**
- **Specific departments/services** Across all services at the Heart Hospital (a tertiary hospital within UCLH Trust)
- **Patient Population**
- **Clinical Speciality**
- **Other (please specify)**

**Measures:**

**What data is collected about patient experience?**

- Patient responses to Picker Frequent Feedback survey (approx. 30 questions)
- Other survey data.

**What methods are used to collect data about patient experience?**

- Picker Frequent Feedback devices (administered by audit nurses or trained volunteers)
- Audits conducted by individual teams include patient experience questions
- Other surveys (sometimes in conjunction with patient groups)
- NHS Choices site (including a pilot where patients texted comments to the site).

**How is feedback translated into improvement?**

- Monthly reports are discussed at ward level and action agreed
- The monthly results and action planned are displayed on the ward noticeboards (using a standard poster)
- The results are also regularly discussed by nursing staff at the quality and risk meeting
- The results are also taken to a multidisciplinary meeting by the Clinical Director and discussed there.
What has changed as a result of the activities and approaches outlined above?

- It has made a big difference to the culture in the hospital and awareness of patient focus.
- Admissions are now staggered to avoid an issue that was picked up about delayed discharge and people having to get up at 6am when they had had a procedure the night before.

| Lead person/contact for further information: | Dr Clare Dollery  
Clinical Director  
The Heart Hospital  
clare.dolley@uclh.nhs.uk |
**Name of organisation:** Hertfordshire Partnership NHS Foundation Trust  
**Scope of the case study in one sentence:** Experience of gathering and using patient experience in a partnership trust dealing with mental health and specialist learning disability services.

**What main areas/issues of patient experience does this case study illustrate?**

- Relationship between user and carer engagement and user and carer experience
- Value of patient experience to service transformation as well as day-to-day service issues
- Dedicated staff support to encourage data collection and utilisation
- Robust links between patient experience agenda and quality and safety agenda
- Importance of recovery principles of mental health to empowering and involving patients (users)
- Methods adapted for different needs (e.g. material accessible for people with learning disabilities)
- Importance of leadership

**What is the focus of the data collection e.g.**

<table>
<thead>
<tr>
<th>Focus</th>
<th>Focus Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisation-wide</td>
<td>Yes</td>
</tr>
<tr>
<td>Across certain directorates</td>
<td></td>
</tr>
<tr>
<td>Specific departments/services</td>
<td>Some methods used in particular departments/services</td>
</tr>
<tr>
<td>Patient Population</td>
<td></td>
</tr>
<tr>
<td>Clinical Speciality</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

**Measures:**

**What data is collected about patient experience?**

Combination of systematic data collection through surveys etc. are complemented by hearing users’ and carers’ stories in a range of ways

**What methods are used to collect data about patient experience?**

- National Patient Survey
- Patent Experience Trackers (real-time electronic feedback) on a movable basis in selected services
- Having Your Say questionnaires - also in easy read form
- Modern matrons’ surgeries
- Involvement of users and carers in various meetings
How is feedback translated into improvement?

- Integrated governance structure in terms of assurance to the board. Four committees report into the integrated governance committee, including the service user and carer experience committee
- PET results systematically collated and regularly fed back to wards
- Action plans developed and implemented as a result of patient experience data

What has changed as a result of the activities and approaches outlined above?

- Patients feel safer in in-patient services
- Improvements to the environment in which care is delivered
- Changes to catering for in-patients

<table>
<thead>
<tr>
<th>Lead person/contact for further information:</th>
<th>Lara Harwood, service user and carer experience coordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><a href="mailto:Lara.harwood@hertsparts.nhs.uk">Lara.harwood@hertsparts.nhs.uk</a></td>
</tr>
</tbody>
</table>
**Name of organisation:** Keston House Medical Practice

**Scope of the case study in one sentence:** Focusing on patient experience in a medium-size general practice.

**What main areas/issues of patient experience does this case study illustrate?**
- Early stages of developing an in-house survey of patients
- Use of survey by local federation of practices
- The benefits of using several different approaches to collecting patient experience data
- Use of informal feedback

**What is the focus of the data collection e.g.**
- Organisation-wide
- Across certain directorates
- Specific departments/services
- Patient Population
  - Surveys of those using the practice
  - Website and newsletter as means of inviting patients’ views
- Clinical Speciality
- Other (please specify)
  - Some data collected across the Croydon Federation of practices.

**Measures:**

**What data is collected about patient experience?**
- Survey responses (National survey and local / practice based)
- Complaints
- Comments and suggestions

**What methods are used to collect data about patient experience?**
- National survey
- Local Federation survey
- In house survey planned
- Complaints and suggestions
- Comments via website
- Comments invited through newsletter
- Feedback via Federation-wide Patient Participation Group (early stages)
- Occasional feedback through NHS Choices
<table>
<thead>
<tr>
<th>How is feedback translated into improvement?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Discussions at practice meetings and meetings for clinical and non-clinical staff</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What has changed as a result of the activities and approaches outlined above?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Changes such as telephone triage for same-day appointments came in because of national survey results, which highlighted concerns about access</td>
</tr>
<tr>
<td>• Other technological innovations are attempts to make services more accessible.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lead person/contact for further information:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Kate Hopkins-Jones</td>
</tr>
<tr>
<td><a href="mailto:Kate.Hopkins-Jones@gp-H83016.nhs.uk">Kate.Hopkins-Jones@gp-H83016.nhs.uk</a></td>
</tr>
<tr>
<td>Name of organisation:</td>
</tr>
<tr>
<td>----------------------</td>
</tr>
<tr>
<td>Scope of the case study in one sentence:</td>
</tr>
</tbody>
</table>
| What main areas/issues of patient experience does this case study illustrate? | • Involvement of service users in actual procurement activity  
• The development of tools, templates and guidance to encourage and support user involvement in commissioning throughout the process  
• Engagement of commissioning staff with patient experience and service user involvement. |
| What is the focus of the data collection e.g. |  
| • Organisation-wide |  
• Across certain directorates |  
• Specific departments/services | Specific example of involvement of people with diabetes  
• Patient Population |  
• Clinical Speciality |  
• Other (please specify) | Learning from various involvement activities has been brought together in guidance for commissioners. |
| Measures: |  
| What data is collected about patient experience? |  
| • Patient experience is fed into the commissioning process through consultation events, workshops, one to one interviews etc. |
| What methods are used to collect data about patient experience? |  
| • Feedback through consultation events  
• One to one interviews,  
• Workshops  
• Surveys. |
### How is feedback translated into improvement?

- Service users are involved in devising the questions to be asked of bidders (potential service providers)
- Service users involved in assessing the tenders and potential bidders.

### What has changed as a result of the activities and approaches outlined above?

- More community based patient-focused services (in diabetes and some other services)
- Patients and members of the public are now involved systematically in the procurement of services.

### Lead person/contact for further information:

<table>
<thead>
<tr>
<th>Joanne Tyler</th>
</tr>
</thead>
<tbody>
<tr>
<td>0116 295 4182</td>
</tr>
<tr>
<td><a href="mailto:Joanne.tyler@leicestercity.nhs.uk">Joanne.tyler@leicestercity.nhs.uk</a></td>
</tr>
<tr>
<td><strong>Name of organisation:</strong></td>
</tr>
<tr>
<td>---------------------------</td>
</tr>
<tr>
<td><strong>Scope of the case study in one sentence:</strong></td>
</tr>
</tbody>
</table>

**What main areas/issues of patient experience does this case study illustrate?**

- Role of the commissioner in gathering and applying data on patient experience in partnership with providers
- Relationship between PPI and patient experience
- Use of workshop events for healthcare professionals and the public
- Possible role of key workers in gathering information about patient experience
- Importance of patients’ and carers’ stories
- Particular challenges about gathering patient experience data at the end of life – involving patients and carers
- Focus on how organisations can work together to streamline and coordinate the pathway to improve patient and carer experience

<table>
<thead>
<tr>
<th><strong>What is the focus of the data collection e.g.</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Organisation-wide</td>
</tr>
<tr>
<td>• Across certain directorates</td>
</tr>
<tr>
<td>• Specific departments/services</td>
</tr>
<tr>
<td>• Patient Population</td>
</tr>
<tr>
<td>• Clinical Speciality</td>
</tr>
<tr>
<td>• Other (please specify)</td>
</tr>
</tbody>
</table>

**Measures:**

**What data is collected about patient experience?**

- Work is underway to decide what data to collect and how it can best be collected, but use is made of national and local surveys, local workshop events and information gathered from key workers.
### What methods are used to collect data about patient experience?

- Workshops
- Patient stories
- Potential use of VOICEs questionnaire (Views of information carers – evaluation of services)
- Liaison with local public groups and networks

### How is feedback translated into improvement?

Review of patient experience data and stories will give an understanding of patient and carer experience across the pathway. This will result in identifying areas for improvement for different services providers which will be included in service specifications and contracts.

### What has changed as a result of the activities and approaches outlined above?

- Clearer requirements about quality from providers
- Generally too early in the process to see specific changes.

### Lead person/contact for further information:

<table>
<thead>
<tr>
<th>Name</th>
<th>Alice Twitchin</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position</td>
<td>Patient Experience Manager</td>
</tr>
<tr>
<td>Organization</td>
<td>NHS South Birmingham</td>
</tr>
<tr>
<td>Email</td>
<td><a href="mailto:alice.twitchin@nhs.net">alice.twitchin@nhs.net</a></td>
</tr>
<tr>
<td>Name of organisation:</td>
<td>Northumbria Healthcare NHS Foundation Trust</td>
</tr>
<tr>
<td>-----------------------</td>
<td>---------------------------------------------</td>
</tr>
<tr>
<td>Scope of the case study in one sentence:</td>
<td>The use of patient experience data across a large multi-site acute trust</td>
</tr>
</tbody>
</table>

What main areas/issues of patient experience does this case study illustrate?

- Systematic approach to patient experience across a whole organisation
- No “silver bullet” – a range of methods is needed
- Impact of becoming a foundation trust
- Staff and patient experience are linked
- Importance of development and support to staff in implementing changes

What is the focus of the data collection e.g.

<table>
<thead>
<tr>
<th>Organisation-wide</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across certain directorates</td>
<td></td>
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<tr>
<td>Specific departments/services</td>
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<tr>
<td>Patient Population</td>
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</tr>
<tr>
<td>Clinical Speciality</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
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</tr>
</tbody>
</table>

Measures:

What data is collected about patient experience?

Range of data about patient experience across the whole organisation, with rolling programme of more intense work in areas where there are indications that patient experience is less good.

What methods are used to collect data about patient experience?

- National patient survey
- Patient Perspectives (survey)
- Real-time data (electronic questionnaire)
- Two minutes of your time (card to send back in sealed envelope)
### How is feedback translated into improvement?

- For each business unit there is a business unit governance group, which looks at incidents, complaints, external visits and patient and staff experience.
- There is a trust-wide Assurance Group with all the business units reporting in, which reports to Board.
- Support from Director of patient Experience to implement changes

### What has changed as a result of the activities and approaches outlined above?

- Improvements to staff attitudes, resulting in improved communication, privacy and dignity and better patient care
- Improved information for patients
- Improved relationships between clinicians and patients
- Improved nutrition for a particular client group.

| Lead person/contact for further information: | Anne-Marie Laverty, Director of Patient Experience  
<p>|                                           | <a href="mailto:Anne-Marie.Laverty@nhct.nhs.uk">Anne-Marie.Laverty@nhct.nhs.uk</a> |</p>
<table>
<thead>
<tr>
<th><strong>Name of organisation:</strong></th>
<th>Parchmore Partnership</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Scope of the case study in one sentence:</strong></td>
<td>A multidisciplinary approach to focussing on patient experience in a large primary care provider organisation</td>
</tr>
</tbody>
</table>

**What main areas/issues of patient experience does this case study illustrate?**

- The development and administration of a large survey to users of the practice
- An active patient participation group (PPG)
- A multidisciplinary approach to developing action plans based on patient experience feedback.

**What is the focus of the data collection e.g.**

- Organisation-wide
- Across certain directorates
- Specific departments/services
- Patient Population: Survey of those using the practice about access
- Clinical Speciality
- Other (please specify): Feedback from PPG

**Measures:**

**What data is collected about patient experience?**

- Survey responses (National survey and local / practice based)
- Complaints
- Comments and suggestions

**What methods are used to collect data about patient experience?**

- Questionnaire surveys (National survey and local / practice based)
- “Problem book” for receptionists to record comments
- Recording telephone calls
- Listening to individual patients
- Feedback from PPG

**How is feedback translated into improvement?**

- All data is discussed at full team training events and action plans developed.
What has changed as a result of the activities and approaches outlined above?

<table>
<thead>
<tr>
<th>Changes to telephone system</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publicity to raise awareness of the various ways to access the practice</td>
</tr>
<tr>
<td>Information produced to explain roles of the various practitioners and team members</td>
</tr>
<tr>
<td>Changes in appointment systems</td>
</tr>
<tr>
<td>Increase in availability of telephone consultations</td>
</tr>
<tr>
<td>Annual open evening introduced to promote awareness of services and how to access.</td>
</tr>
</tbody>
</table>

Lead person/contact for further information:

Karen Nash  
Karen.Nash@gp-H83053.nhs.uk or k.nash@nhs.net

OR

Teresa Chapman  
Chief Executive Officer  
teresa.chapman@gp-h83053.nhs.uk
Name of organisation: South Street Surgery, Bishop’s Stortford

Scope of the case study in one sentence: Gathering and applying patient experience data in a large GP practice

What main areas/issues of patient experience does this case study illustrate?

- Experience of gathering and applying patient experience data in a large GP practice
- Particular experience of gathering information on patients’ views on access to primary care and views on redevelopment of premises.
- Importance of listening to patients
- "Just do it" – the value of learning by planned doing and how the team has developed knowledge of patient experience over time.

What is the focus of the data collection e.g.

<table>
<thead>
<tr>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisation-wide</td>
</tr>
<tr>
<td>Across certain directorates</td>
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<tr>
<td>Specific departments/services</td>
</tr>
<tr>
<td>Patient Population</td>
</tr>
<tr>
<td>Clinical Speciality</td>
</tr>
<tr>
<td>Other (please specify)</td>
</tr>
</tbody>
</table>

Measures:

What data is collected about patient experience?

Patients’ personal experiences and views of using services at the practice.

What methods are used to collect data about patient experience?

- *GPAQ survey* (General Practice Assessment Questionnaire) and other bespoke surveys
- *Patient Participation Group* - Has existed for past 3 years. Initially chaired by an external facilitator, but now chaired by the Business Excellence Director. The PPG has about 24 members.
- *Waiting room interviews* - Particularly focussing on access, using a standard format for interview questionnaires. Questions were asked about patients’ experience of getting through on the phone, whether they got an appointment with the doctor they wanted to see etc.
- *Specific consultations* E.g. about premises.
- *Two way text messages* - Has potential for the future. Not done yet for the purpose of engagement, though patients are contacted for other purposes in this way.
- *Suggestions boxes* - Online and actual in the surgery – rarely used.
How is feedback translated into improvement?

There is a business excellence committee, involved in process monitoring and developing products and services, although the practice also places an emphasis on systems rather than structures. Therefore, potential changes are discussed where they best fit e.g. access survey discussed in the Patient Access group.

The practice uses the EFQM excellence model\(^\text{13}\) and aligns its patient experience work with that.

<table>
<thead>
<tr>
<th>What has changed as a result of the activities and approaches outlined above?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Changes to appointments system and telephony</td>
</tr>
<tr>
<td>• Impact on plans for premises redevelopment (including location)</td>
</tr>
<tr>
<td>• Involvement of patients in drafting of information</td>
</tr>
<tr>
<td>• Cultural change – patients’ views now seen as integral to service improvement</td>
</tr>
</tbody>
</table>

Lead person/contact for further information: Dr Paresh Dawda

[paresh.dawda@nhs.net](mailto:paresh.dawda@nhs.net)

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Annex 7: National training survey

Summary
The importance of the patient experience is widely recognised by national bodies including the education regulators, and by those providing education and training courses that took part in our survey.

- But not all courses currently cover the different aspects of the patient experience. Generally speaking, courses provided within NHS trusts cover fewer aspects and do not include patients as much in planning, delivering and evaluating whether courses lead to improvement.
- The majority plan to develop the patient experience aspects of their courses over the coming year but, worryingly, NHS trusts are least likely to report such plans even though they currently perform less well.

Background

Remit
This report forms part of the Patient experience: evidence base development study, commissioned by the NHS Institute for Innovation and Improvement and sponsored by the Patient and Public Experience and Engagement team within the Department of Health. The study, carried out by a team from King’s College London and the King’s Fund, aimed to provide a robust evidence base to inform the future direction of travel, and help shape the support needed to implement this priority area of NHS delivery.

As part of the study we reviewed what is important to patients, and how education and training help staff to understand, measure and make improvements. This arm of the study included surveys of English:

- Higher Education sector providers of medical, nursing and allied health professions pre-qualification professional training (and any post-registration or other forms of relevant training provided for the NHS).
- NHS trusts, to identify post-registration, specialist and in-service training, and continuing professional development (CPD).

The aim of the surveys was to assess what relevant training and education support packages are currently made available, and where there needs to be further development and improvement. What education and training do future and working clinicians and managers receive in how to deliver a good patient experience (i.e. how to understand, measure or monitor the experience, preferences and priorities of patients and use that knowledge to improve their experience)? This aspect of the study was based on the premises that:

- There is a need to develop the capacity and capability to understand, measure and monitor on an ongoing basis the experience, preferences and priorities of patients, service users, carers and the wider local population across all tiers of the health and social care system.
- One way in which such capacity and capability could be developed is via professional education and training. Information was lacking on whether pre-qualification or in-service, continuing professional development includes any such focus on patient experience.
Patient experience education and training

What is ‘the patient experience’, and how can we evaluate whether it is included in the education and training available to NHS staff? Answering this question is not completely straightforward. Doctors talk of the ‘therapeutic relationship’ as at the heart of each interaction with a patient; nurses and allied health professionals often talk about person-centred care as at the heart of how they go about their daily work. These phrases are used in publications by professional bodies that try to define the clinical role, and the standards of behaviour that a clinician should maintain (this is taken up in more detail in the final chapter below). It almost goes without saying, therefore, that ALL pre-registration/qualification courses will teach these concepts, and that once they join the NHS all clinicians are judged by their peers and managers on how well they meet such standards. If this is what ‘the patient experience’ means, then there would surely be no need for a special study to see whether such education and training was available?

To provide useful new information our survey needed to look beyond these fundamental concepts. We believe that the phrase ‘the patient experience’ means much more than the fundamental standards that underpin this ‘mainstream’ professional understanding. The King’s Fund Point of Care project highlights the Institute of Medicine’s definition of patient-centred care:

“Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”

(Institute of Medicine 2001), encompassing these facets:

- compassion, empathy and responsiveness to needs, values and expressed preferences
- co-ordination and integration
- information, communication and education
- physical comfort
- emotional support, relieving fear and anxiety
- involvement of family and friends.

The definition of the patient experience in relation to education and training that we adopted was:

**How to understand, measure or monitor the experience, preferences and priorities of patients and use that knowledge to improve their experience.**

This wider understanding of what the patient experience means includes such concepts as shared decision-making; considering the full context and not just the immediate clinical condition; considering quality of life and not just whether the immediate clinical ‘problem’ is solved; hearing from patients what is important to them rather than clinicians assuming they know; etc.

Using this wider definition as our starting point, we constructed a questionnaire that could form the basis of the survey we were commissioned to undertake. We attempted to define specific wording that contained as little ambiguity as possible. The section below (Box 2 in ‘What is important and what is covered now’) and Annex 2 (the questionnaire) lists nine different aspects that make up what we thought could be measured as ‘the patient experience’ via a questionnaire. These were extracted from the sources just cited.

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It is important to stress that we did not set out to identify courses that are solely focussed on providing training about the patient experience. Rather, we wanted to investigate to what extent patient experience is included in ‘mainstream’ NHS education and training.

Types of course and who they are designed for

Sectors and professions

Before commencing our survey we identified 180 higher education (HE) organisations offering courses for NHS professions. In addition courses are provided by or within NHS trusts (including acute, mental health, ambulance, primary care trust, etc). A smaller number of other types of NHS organisations also reported courses, including SHAs, NHS Direct and networks. Courses may also be commissioned by NHS trusts from ‘external’ providers linked to the NHS, such as professional bodies. Some courses were reported as commissioned from specialist private sector organisations. We received replies to the questionnaire from a wide range of these different types of provider (Table 1) – however, no responses were returned from university medical schools.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Number we identified from other sources</th>
<th>Number from which one or more response was received</th>
<th>Total number of individual respondents from each type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical schools</td>
<td>23</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Nursing &amp; Midwifery schools</td>
<td>57</td>
<td>13</td>
<td>25</td>
</tr>
<tr>
<td>Allied Health Professions in HE</td>
<td>100</td>
<td>14</td>
<td>31</td>
</tr>
<tr>
<td>Deaneries</td>
<td>19</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>NHS trusts</td>
<td>390</td>
<td>99</td>
<td>153</td>
</tr>
<tr>
<td>Other course providers</td>
<td>Not possible</td>
<td>27</td>
<td>27</td>
</tr>
</tbody>
</table>

Source: Search of ACAS, NHS Careers and DH websites, and replies to King’s Fund/King’s College survey of patient experience in education & training winter 2010.

NB: although 250 respondents entered the survey and clicked on their sector (final column of the table), not all described full details about a course – see methodological annex for more details on the response.

15 Our main sources were the Universities & Colleges Admissions Service (UCAS) and NHS Careers.

16 We cannot report on the total number of courses, only the number of course providers. There is no readily available source on the number of courses across different provider types. When we attempted to collate such information, it became clear that the definition of what is a single ‘course’ differs between providers. For example, some providers list as separate courses those for BA or BSc; whether 2, 3 or 4 years in duration; and whether full or part-time (and within the latter whether associated with a work placement). Others do not separate these out in their information on websites or in their prospectus.
Education and training for NHS staff is thus provided by a mix of different providers, and is of the following main types (Table 2 and Annex 5):

- The HE sector provides almost all of the basic pre registration/qualification courses.
- HE organisations also provide some post-registration and other types of training commissioned by NHS organisations.
- A few pre-registration courses were described as provided by professional bodies.
- NHS trusts in partnership with the deaneries provide Foundation and ‘run through’, specialist training for doctors.
- NHS trusts also provide some post-registration training in nursing/midwifery and allied health professions, in partnership with HE providers.
- NHS trusts provide induction, in-service and continuing professional development (CPD) courses.
- NHS trusts commission some induction, in-service and CPD from HE providers, other trusts or specialist private sector providers.

<table>
<thead>
<tr>
<th>% across rows</th>
<th>Pre-registration</th>
<th>Post-registration</th>
<th>Foundation</th>
<th>Run-through, specialist</th>
<th>Induction</th>
<th>In-service, CPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>0%</td>
<td>0%</td>
<td>14%</td>
<td>20%</td>
<td>24%</td>
<td>41%</td>
</tr>
<tr>
<td>Dentist</td>
<td>0%</td>
<td>0%</td>
<td>13%</td>
<td>17%</td>
<td>29%</td>
<td>42%</td>
</tr>
<tr>
<td>Nursing &amp; Midwifery</td>
<td>24%</td>
<td>29%</td>
<td>0%</td>
<td>16%</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>Allied Health Professions</td>
<td>17%</td>
<td>27%</td>
<td>0%</td>
<td>0%</td>
<td>22%</td>
<td>34%</td>
</tr>
<tr>
<td>Managerial/Office</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>45%</td>
<td>38%</td>
</tr>
<tr>
<td>ALL</td>
<td>13%</td>
<td>19%</td>
<td>1%</td>
<td>2%</td>
<td>26%</td>
<td>38%</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 151 courses described.

The majority of the courses described within NHS Trusts were multidisciplinary (Table 3). ‘Office’ staff were included in many of the induction and CPD courses described and most included all levels from senior management right through to receptionist and other ‘front-line’, non-clinical, staff. Most of the single-profession courses described within the NHS were for Foundation and specialist medical training, or post-registration Nursing & Midwifery and Allied Health Profession courses.
Table 3: Professions covered by courses described by survey respondents

<table>
<thead>
<tr>
<th>% down columns</th>
<th>Higher Education</th>
<th>NHS trusts</th>
<th>Other</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>0%</td>
<td>15%</td>
<td>0%</td>
<td>7%</td>
</tr>
<tr>
<td>Nurses and/or midwives</td>
<td>35%</td>
<td>10%</td>
<td>11%</td>
<td>22%</td>
</tr>
<tr>
<td>Allied health professions</td>
<td>44%</td>
<td>4%</td>
<td>11%</td>
<td>23%</td>
</tr>
<tr>
<td>Managerial staff</td>
<td>0%</td>
<td>8%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Other17</td>
<td>1%</td>
<td>3%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Two or more groups</td>
<td>20%</td>
<td>59%</td>
<td>78%</td>
<td>42%</td>
</tr>
<tr>
<td>Number</td>
<td>71</td>
<td>71</td>
<td>9</td>
<td>151</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

By contrast HE sector courses were mainly single-profession. However, there were examples of multidisciplinary education, including:

“…interprofessional modules one of which brings together undergraduate health and social care students … and medical students…” (Faculty Lead for User and Carer Involvement, HE sector)

A good number of courses were reported to cover primary care staff, or both primary and secondary care – even within NHS trusts, some of which will only have been directly responsible for either primary or secondary care staff (Table 4).

Table 4: Health care sectors covered by courses described by respondents

<table>
<thead>
<tr>
<th>% down columns</th>
<th>Higher Education</th>
<th>NHS trusts</th>
<th>Other</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td>11%</td>
<td>19%</td>
<td>13%</td>
<td>15%</td>
</tr>
<tr>
<td>Secondary care</td>
<td>9%</td>
<td>52%</td>
<td>0%</td>
<td>29%</td>
</tr>
<tr>
<td>Both</td>
<td>80%</td>
<td>28%</td>
<td>88%</td>
<td>56%</td>
</tr>
<tr>
<td>Number</td>
<td>65</td>
<td>67</td>
<td>8</td>
<td>140</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

17 ‘Other’ staff described included commissioners, heads of service/functions, support workers, healthcare assistants, social workers and social care staff and “patient facing staff”. ‘Other’ sectors included SHAs, professional bodies, social enterprise and private sector training providers.
Externally-provided courses
A total of 27 externally-provided courses were described (19 by NHS trust respondents, two by HE respondents, and a further six by others). Examples are given in Box 1, and a more detailed series of case studies in Annex 6.

Box 1: Private sector courses

Some of these courses were described in use by respondents to our survey, and some were identified via other sources. See more detailed case studies in Annex 6.

- MHMTS specialises in the use of theatre techniques, including improvisation, forum-theatre and scripted role-play, delivered by professional actor-facilitators. Training and service development is for front-line staff and managers (http://www.mhmts.com). (Case study in Annex 6)
- The Patient Experience Network offers online customer service training (see annex) (http://www.patientexperiencenetwork.com).
- Simulated Patients UK delivers patient experience training to the NHS, using actors (simulated patients) and training facilitators (http://www.simulatedpatients.co.uk).
- Medicology offers a short CPD course, Core Skills in Patient Experience Excellence (http://www.medicology.co.uk).
- Personal Best Ltd provided a PCT’s community staff with training in ‘creating the best experience for patients’ (http://www.personalbestltd.co.uk).
- Picker offers training and toolkits in measuring patient experiences (http://www.pickereurope.org/improvingpatientexperience).

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010, internet searches and personal correspondence.

Who actually receives training
It was not within our study scope to try to identify how many NHS staff received patient experience training. However, we negotiated for a line asking about such training to be added to the National NHS Staff Survey 2010. The findings are due for publication at the end of March 2011. This major survey, managed by the Care Quality Commission (CQC), included the question “Have you had any training, learning or development (paid for or provided by your Trust) in the following areas? ...”. At our request one of the areas included was: “How to deliver good patient experience (e.g. monitor the patient experience and use the feedback to make improvements).” (Note; ‘service user’ replaced ‘patient’ in questionnaires sent to staff working in mental health settings.)
**Taking a lead**

A minority reported that there was a designated lead with overall responsibility for education/training in the patient experience (Figure 1). Their job titles varied widely, but the specific terms most frequently cited were ‘patient experience’ or ‘service user’ lead, head or manager.

<table>
<thead>
<tr>
<th>Designated Lead?</th>
<th>Yes (33%)</th>
<th>Neither clearly ‘yes’ or ‘no’ (27%)</th>
<th>No (41%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher education</td>
<td>33%</td>
<td>27%</td>
<td>41%</td>
</tr>
<tr>
<td>NHS Trusts</td>
<td>53%</td>
<td>23%</td>
<td>24%</td>
</tr>
<tr>
<td>SHAs</td>
<td>50%</td>
<td>33%</td>
<td>17%</td>
</tr>
<tr>
<td>Other</td>
<td>33%</td>
<td>67%</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 1: Is there a designated lead or coordinator within your organisation with overall responsibility for education/training in the aspects of understanding, gathering, measuring and improving the patient experience?*

The majority of respondents reported no clearly designated lead. However, such a lead was reported by half of those in NHS Trusts and SHAs.

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 79 HE, 140 NHS Trust, 6 SHA and 6 ‘other’ respondents.
Within NHS trusts these two responsibilities are often split. There is often one or more posts with overall responsibility for training (director of human resources, head of training, learning, development, etc.; directors of nursing, AHP or medical education). Then there is often a separate post with overall responsibility for involving patients (head of patient and public involvement; engagement; etc) who might also lead on aspects of the patient experience.

For example:

“…there are 2 separate roles, one for gathering, measuring and improving patient experience and another for education and training” (Clinical Effectiveness lead, NHS trust)

Sometimes responsibilities are even more diffused than just described, across large and complex trusts with many different services and department. For example:

“There is a vaguely articulated strategic lead role for patient experience, but the emphasis is more on feeding into strategy rather than the specifics of education/training. We have no specific courses for example but try to disseminate ‘soft intelligence’ and patient stories through briefings/reports to key meetings. NB Not making reference here to our successful Expert Patient Programmes which are focused modules on specific conditions rather than broader organisational learning.” (Head of Community Engagement, NHS trust)

A designated lead for patient experience is less common in the HE sector. Some commented, however, that expertise was available from some with a special interest, for example:

“There are lecturers with a key interest/experience in this area and they would be consulted on curriculum content.” (Course leader, HE sector)

In some cases there is a designated lead given the responsibility, but that responsibility is incorporate within a more generalised post (eg, Associate Dean). However, there are some HE sector examples where the job title does reflect this specific responsibility, for example:

“In my role I support all the current Health and Social Care Courses … including those leading to registration as nurse, midwife, social work, physiotherapy, occupation therapy. This is as a resource, link to networks and chair of a Faculty group which develops resources and support systems and offers advice.” (Faculty Lead for User and Carer Involvement, HE sector)

Some of those choosing to click on “neither clearly ‘yes’ or ‘no’” added a comment that the patient experience was the responsibility of every course tutor, for example saying that:

[The responsibility is that of] “Course Directors for all courses - major focus of the courses is the patient experience” (Course Director Pre-registration Mental Health, HE sector).

“Everyone employed has a responsibility for this” (Course Director, HE sector).

This split is reflected in the documents that many trusts publish on their websites. Most have a separate patient experience (or patient involvement) strategy, and a separate learning and development strategy. These are usually written by different people as reflecting the two posts just described above. A third related strand is that NHS trusts are now required to publish Quality Accounts. These will usually have a patient experience emphasis, reporting on for example the NHS Patient Surveys, but again do not often relate the findings to staff education and training requirements.
The two main sectors differed in terms of who actually completed our questionnaire (the reasons for these differences are discussed further in the ‘methodology’ annex):

- The majority of respondents from Higher Education described themselves either as tutors on the course about which they answered questions, or as the course leader.
- By contrast the majority of NHS trust respondents described themselves as designated leads for patient experience training, working at a level above a single course, or having some other relevant role.

1) Each organisation should identify a designated lead with overall responsibility for education and training in the aspects of understanding, gathering, measuring and improving the patient experience. (This does not counteract the individual responsibility that every member of staff has to improve the patient experience.)

2) The patient experience lead should work together with the learning and development lead to ensure that their separate strategies are joined up. Other relevant work – such as NHS trust quality accounts – should also reflect the education and training needed to improve the patient experience.
Do courses address the patient experience?

What is important and what is covered now

We asked respondents to rate nine different aspects of the patient experience according to whether each was covered by their course, and how important they thought it to cover each aspect. The full wording of the aspects and the survey questions is given in Box 2.

Box 2: Different aspects of the patient experience

<table>
<thead>
<tr>
<th>The two questions:</th>
<th>Responses available to choose:</th>
</tr>
</thead>
</table>
| Which of the following aspects of the patient experience are covered in your course? | • Covered extensively  
• To some extent  
• Not at all |
| How important do you think each aspect is in education/training in the patient experience? | • Essential  
• Of some importance  
• Not at all |

The aspects rated:

<table>
<thead>
<tr>
<th>Label</th>
<th>Full question text given with the label</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Relationship:</td>
<td>Aspects of seeing each patient as an individual; treating with respect, compassion, empathy, and dignity; responsive to needs, values and expressed preferences.</td>
</tr>
<tr>
<td>2. Support:</td>
<td>Emotional support; relieving fear and anxiety.</td>
</tr>
<tr>
<td>3. Involvement:</td>
<td>…in decisions about treatment; of family and friends.</td>
</tr>
<tr>
<td>5. Context:</td>
<td>Family context, the totality of events and interactions that occur in the course of an episode of care, including consideration of ethnicity and diversity.</td>
</tr>
<tr>
<td>6. Communication:</td>
<td>Provision of written information, breaking bad news, how shared decisions are documented with the patient, coordination and integration between services.</td>
</tr>
<tr>
<td>7. Physical:</td>
<td>Needs and comfort (eg, food, drink, pain control).</td>
</tr>
<tr>
<td>8. Measurement:</td>
<td>How patients’ experiences can be gathered, analysed and acted on.</td>
</tr>
<tr>
<td>9. Customer care</td>
<td>(Not further described in our question.)</td>
</tr>
<tr>
<td>10. Other</td>
<td>(Respondents could describe other aspects if they wished.)</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.
Taking only the ‘top’ answers (ie, the percentage of respondents deeming aspects as ‘essential’, and those ‘covered extensively’ by the course being rated), there are important gaps between what is considered essential and what is in fact covered now. For the most part both sectors’ respondents thought similarly about what is ‘essential’. However, there are much bigger differences between sectors in what is covered extensively now, with NHS trusts much less likely to be covering most aspects (Figure 2).

In more detail, the main trends are:

- In both sectors the aspect considered essential by the most respondents, and most covered now, is “relationships”.
- Both sectors think ‘measurement’ important, but neither sector covers this aspect extensively.
- NHS trusts are users of customer care training, sometimes providing the training themselves and sometimes commissioning it from private sector providers. Customer care training is often – but not exclusively - provided for frontline receptionist staff. Customer care training tends to emphasise how staff should respond to patients and the public including, for example, how to greet people, treat them with courtesy, provide useful information, portray a caring and useful attitude, etc. Customer care training is rarely provided by the HE sector, and is less likely to be considered essential:

  “I’m not sure that I like the notion that customer care is somehow discrete from other aspects of care that relate to the involvement of the patient/client/carer in decisions about care or issues around empowerment and self-care or the need to respect rights, dignity or individuality. What is customer care training? … introducing oneself and making sure that the patient/carier has all of their needs met (not just the clinical ones) is part of the package and not distinct in some way from it.” (Course Leader, HE Sector)

18% of respondents described ‘other’ aspects of the patient experience. Some were described by more than one respondent:

- Focussing on the role of leadership in promoting and improving the patient experience.
- How to interact with patients issuing complaints and conflict resolution.
- How to ensure the patient experience is taken into account when commissioning services.
Figure 2: Aspects of patient experience: what is covered in education and training courses now, compared with what respondents think essential.

Generally, higher education courses are reported to cover more aspects of patient experience. (The full text for each aspect is given in Box 2.)

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 68 HE & 65 NHS respondents.
Further aspects described also included:

“Building governance structures and processes focused on patient experience, patient safety and clinical effectiveness.” (Course Leader, HE sector)

“Looking holistically at communication needs, the role of the individual, significant others, society.” (Assistant Head of Subject Mental Health and Therapeutic Practice, HE sector)

“The patient narrative of their experience of disease or injury.” (Associate Professor, HE sector)

Of particular note were several comments regarding mental health or learning disability service user or client experience, for example:

“Promoting independence; effects / implications of power relationships; advocacy; promoting the client’s story.” (Associate Dean, HE sector)

**Progress since 2006?**

A previous study, Education for Partnership (A Hasman and Askham 2006), asked two key questions about medical education and training:

- To what extent are doctors trained to work in partnership with patients?
- What else could be done to ensure that doctors help patients play a more active role in their healthcare?

The authors concluded “Patient partnership is now on the agenda in medical education. Its importance is emphasised in codes and statements of principle, it appears in some of the new curricula, and methods of assessing the relevant competences have begun to be developed. Despite promising developments in some medical schools and certain postgraduate training programmes, particularly in general practice, we found a general lack of awareness of needs and skill gaps and few examples of good practice.”

Of the nine aspects of the patient experience that our survey considered, the most relevant to this earlier study is: “Involvement in decisions about treatment; and of family and friends.”

We received no replies about medical undergraduate courses and thus we cannot comment on that sector. However, nine out of every ten of those replying about Foundation and specialist medical courses rated as ‘essential’ the inclusion of training about “involvement”. However, only 39% rated this as ‘covered extensively’ in their courses, 52% ‘to some extent’ and 9% ‘not at all’.

While not directly comparable, our findings thus do not suggest that the situation has improved dramatically since 2006.

3) Both sectors – but in particular NHS trusts – should review their courses and consider why key aspects of the patient experience are not covered.

4) More courses should cover the different aspects of the patient experience.
The teaching and training process

Teaching methods
The use of methods differed between the two sectors. Generally, HE sector courses are more likely to use methods involving patients, role play and recordings (Figure 3).

Figure 3: Methods used in the courses
(The full text for each sub-question is given in Annex 2.)

<table>
<thead>
<tr>
<th>Method</th>
<th>Higher Education</th>
<th>NHS trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role play or simulation to represent patients</td>
<td>86%</td>
<td>54%</td>
</tr>
<tr>
<td>Using actors</td>
<td>33%</td>
<td>21%</td>
</tr>
<tr>
<td>Video footage of patients in clinical situations (or podcasts, etc)</td>
<td>70%</td>
<td>24%</td>
</tr>
<tr>
<td>Video footage of patients talking about their experiences (or podcasts, etc)</td>
<td>64%</td>
<td>32%</td>
</tr>
<tr>
<td>Contact by students/trainees with patients in clinical situations</td>
<td>84%</td>
<td>40%</td>
</tr>
<tr>
<td>Contact with patients who come in to describe and discuss their...</td>
<td>81%</td>
<td>46%</td>
</tr>
<tr>
<td>Patients present at multidisciplinary team meetings (MDTs)</td>
<td>30%</td>
<td>17%</td>
</tr>
<tr>
<td>Other</td>
<td>16%</td>
<td>11%</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 64 HE & 63 NHS respondents.

Some respondents provided more detail about how patients and staff discuss their experiences ‘after the event’, either via video and other types of narrative recording, or by interactive meetings with students:

“*Intranet based Patient and Public Involvement Toolkit - this includes a range of real life case studies, examples of best practice etc. Senior managers within the organisation attend the training to share their experiences of engaging with patients and the public.” (Patient and Public Involvement Coordinator, NHS trust)

“Patients and carers are extensively involved in producing resources through offering case studies, being involved in podcasts, helping to moderate student forums, acting as critical readers whilst information is being developed.” (Assistant Head of Department, Nursing, Academic Lead)

“Video & photography surveillance to show ‘through the patients’ eyes’” (Director of Communications, NHS trust)
A different emphasis, again frequently reported, is the contact in ‘live’ clinical situations that happen on placements (for HE sector students) or in work. A deanery interviewee suggested that a more modern take on the old ‘apprenticeship’ model is valued in conjunction with newer techniques involving simulation, with recent studies showing that real-life clinical contact provide useful patient-centred learning. For example:

“Students, during their clinical practice placements would have opportunity to attend multidisciplinary team meetings, it is likely that patients (women) would be present at these meetings. Also students would experience the interactions with women and their named carers who may be midwives or consultant obstetricians.” (Course Leader, HE sector)

A further development of placement experience was described from a university medical school course. Trainees on community placement are required to interview a patient, their care and their GP – thus gaining three different perspectives, plus their own. This helps develop an understanding that not only a patient, but others involved in their care can have differing perspectives to the student themselves.

While methods involving interaction between students and ‘real’ patients might normally seen as better, there is a case for using the other methods listed in the top half of Figure 3. Apart from being more realistically achievable when large numbers of students are involved, they can provide a valuable training precursor. For example, one medical school’s website describes for potential students the:

“The Clinical Skills Resource Centre (CSRC): a safe environment that allows students to learn key clinical and communication skills before using them in a real clinical setting. Many of CSRC training rooms are replicas of hospital wards or other clinical settings. Students develop the ability to interact with patients and understand individual cases, both physically and psychologically.” (http://www.pcmd.ac.uk/clinical_skills_resource_centre.php)

The teaching methods listed in our survey question focussed on those involving direct face-to-face interactions or listening to people speaking about their experience. However, NHS trust respondents also described a range of other sources of information about the patient experience, including feedback from surveys, complaints, comments or reports from patient advice and liaison services (PALS), incidents, comments cards and focus groups. Training often focuses on how staff can make use of these wider information sources to understand the patient experience and identify how to improve it.

5) More NHS trusts should use the range of training methods involving patients.

Student and trainee assessment

Perhaps unsurprisingly, HE sector course participants are more likely to be assessed (75% of HE courses assess students in the aspects related to the patient experience, compared with 27% of NHS trust courses). The HE sector was also more likely to use a range of assessment methods (Figure 4).

6) Formal assessment methods should be used more in both sectors in relation to courses that cover aspects of the patient experience.
Some respondents described direct patient feedback as one of the ‘other’ ways that students are assessed; similarly an interviewee described how in each of years two and three each pre-registration student nurse is required to have two ‘comments’ from patients completed from their placements. Several respondents described using letters sent in by the public to trusts at which their students had been working – the majority being positive and often detailed comments about how good a student has been and the things they had done for a patient. Discussion about these followed amongst the group to pick out any lessons that all could learn.

**Evaluating course impact**

It is clearly important to know whether courses actually achieve their intention to equip staff to understand and deliver care that takes account of the patient experience. However, few respondents reported having evaluated the impact of the course on patient experiences (18% of Higher Education sector respondents said they had done so; 16% of those from NHS Trusts). Of these, most were described as using relatively unstructured methods of verbal or written feedback from those involved. One example is:

“All attendees have to complete an action learning log to be returned 3 months after the course. This details how they have engaged or involved patients and the public in their workstreams.” (Patient and Public Involvement Co-ordinator, NHS trust)
Only a handful of HE sector respondents described attempting to use measurement. Use of measurement was somewhat more likely to be reported by NHS trust respondents, probably because there is more ready access to patient satisfaction survey findings from the NHS Patient Survey or their own surveys. For example, a course provided under the NHS Improving Access to Psychological Therapies (IAPT) programme includes impact evaluation via measures of patient improvement, using data collected via the Minimum Data Set, plus extended self-report measures. Aspects of ‘Relationships’, ‘Support’ and ‘Independence’ are ‘covered extensively’ by the course, as rated by the Programme Leader for the HE course provider. Other examples are described in the case studies (Annex 6).

One respondent described working across departments to evaluate training impact:

“Head of Education & Training and Asst Director for Nursing Education work with other stakeholders (e.g. data analysts, PALs, Clinical Unit leads who have commissioned training) to measure impact specific training has had on patient experience.” (Head of Education and Training, NHS trust)

One respondent described evaluation of training impact and noted an improvement:

“We monitor survey and complaints data post training to see if any improvement can be identified (in all areas which have had the training, we have seen a reduction in complaints and an improvement in patient experience survey results.” (Director of Nursing, NHS trust)

While undertaking some evaluation of course impact, one respondent actually referred to a lack of more detailed work on this as a barrier to extending education and training in patient experience:

“Theatre Forum - clients are specifically asked to feedback to students on what it was like being with them and how they felt (good and bad)...”

[But more generally another barrier is a] “Lack of evidence that such involvement positively impacts on patient care.”

Faculty Lead for User and Carer Involvement (HE sector)

7) HE organisations and NHS trusts should carry out impact evaluation to see whether their courses result in measurable improvements in patient experiences.
Involving patients

Patients are more likely to be involved in the higher education sector (Figure 5). Involvement is most frequent in delivering the education and training, and least common in evaluating its impact.

Figure 5

Do you involve patients (or patients' representatives) in education/training?

Patients are more likely to be involved in the higher education sector.

<table>
<thead>
<tr>
<th>Patients involved?</th>
<th>Higher Education</th>
<th>NHS trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td>70%</td>
<td>52%</td>
</tr>
<tr>
<td>Delivering</td>
<td>80%</td>
<td>50%</td>
</tr>
<tr>
<td>Evaluating</td>
<td>48%</td>
<td>35%</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 66 HE & 60 NHS respondents.

Single-profession courses within NHS trusts are least likely to involve patients in delivering the training (Table 5a) – although as some of the table cells have few courses described, the findings should be interpreted with caution. Regional variations are also apparent – respondents from NHS trusts within London, South Central and the South West were more likely to report involving patients (Table 5b). Again, small numbers in some cells require these results to be treated with caution.

The most frequent comments added on ‘other’ ways of involving patients was about involving them in the selection and recruitment of students onto HE sector courses (10 of 18 comments were about this). Other comments described the range of ways in which patients are involved, for example:

“Patients and carers are extensively involved in producing resources through offering case studies, being involved in podcasts, helping to moderate student forums, acting as critical readers whilst information is being developed.” (Asst Head of Department, Nursing (Academic Lead), HE sector)
Table 5: The number of courses involving patients in delivering education and training: (a) by profession within sector, (b) by SHA

(a) By profession within sector

<table>
<thead>
<tr>
<th>Profession</th>
<th>YES (number of courses including patients)</th>
<th>Total number of courses</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIGHER EDUCATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>21</td>
<td>24</td>
</tr>
<tr>
<td>AHP</td>
<td>22</td>
<td>28</td>
</tr>
<tr>
<td>Mixed</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>NHS TRUSTS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Nurse</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Office</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Mixed</td>
<td>20</td>
<td>33</td>
</tr>
</tbody>
</table>

(b) By SHA

<table>
<thead>
<tr>
<th>SHA</th>
<th>YES (number of courses including patients)</th>
<th>Total number of courses</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Midlands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>East of England</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>London</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>North East</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>North West</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>South Central</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>South East Coast</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>South West</td>
<td>10</td>
<td>11</td>
</tr>
<tr>
<td>West Midlands</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interviews and survey comments suggest that the most common way of involving patients in the delivery of education and training is by inviting them to interact with students and trainees or by using video (etc) of their stories (see next chapter). However, two respondents noted that the involvement went much further:

“Some taught sessions are delivered by patient groups.” (Senior Lecturer in Operating Department Practice, HE sector)

“User developed learning and teaching resources.” (Faculty Lead for User and Carer Involvement, HE sector)

“People with lived experience also attend the course as learners to accrue learning credits and build up their CV for potential employment.” (Director of Nursing and Practice, NHS trust)

One respondent elaborated on patients’ involvement in the assessment of students:

“We are developing a joint assessment process whereby a group of users and carers assess students’ communication skills.” (Associate Professor, HE sector)

8) More NHS trusts should involve patients in planning and delivering the patient experience training that they provide to staff. Both NHS trusts and the HE sector should include patients more in evaluating the impact of their courses to ensure that education and training leads to improvements in the patient experience.
Barriers and support

Perhaps surprisingly, a minority of respondents identified serious barriers (Figure 6). The factors we listed in the question were seen as ‘to some extent’ a barrier by most, and viewed as things that must be overcome to achieve the desired result.

Figure 6: Issues rated as ‘serious barriers’ to patient experience education and training

<table>
<thead>
<tr>
<th>Issue</th>
<th>Higher Education</th>
<th>NHS trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competition for time from other elements of the curriculum, or other training topics</td>
<td>21%</td>
<td>32%</td>
</tr>
<tr>
<td>Lack of availability of ‘expert’ patients</td>
<td>21%</td>
<td>11%</td>
</tr>
<tr>
<td>Lack of money to pay for patients to take part in the course</td>
<td>28%</td>
<td>25%</td>
</tr>
<tr>
<td>Lack of availability of good video (podcasts, etc)</td>
<td>8%</td>
<td>17%</td>
</tr>
<tr>
<td>Lack of expertise in the subject matter amongst the teaching/training staff</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>Students/those attending training do not see this as a priority for their attention</td>
<td>2%</td>
<td>13%</td>
</tr>
<tr>
<td>Those who might benefit by attending do not know that the course is available</td>
<td>2%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 66 HE & 62 NHS respondents.

Some respondents described difficulties in identifying patients and arranging to involve them in their education and training programmes. These barriers can be overcome, as evidenced by the examples given above and in the case studies of courses that have been able to achieve this. It takes a lot of time and effort, and thus is more likely to take place when a high level of manager and/or the board has decided to take this seriously. With some groups of patients there are special considerations to bear in mind – for example, one respondent noted:

“Communication needs of people with learning disabilities, accessible information, accessible venues.” (Professional Lead - Learning Disabilities, HE sector)
One NHS respondent pointed out the difficulties in ensuring that the patients involved by trusts are somehow representative (a point also raised by a deanery interviewee). This concept can be difficult, by definition, to reconcile with the concept of patient-focused care where the need to treat each patient as an individual – every voice counts, every story should be heard – is such a paramount principle. Nevertheless, there are some real issues to balance here:

“The problem is that there is often a reliance on ‘expert patients’ instead of a balance with other people from whom we take information about their experience. Unfortunately too many ‘expert patients’ develop a reputation for self-righteousness and being antagonistic towards clinicians and this serves to undermine efforts to encourage professional involvement in wider patient experience and community engagement projects (these are two sides of the same coin, because patients need to be able to influence not only their care pathway, but the strategic decisions which shape healthcare planning. It is important to ensure that good facilitators are available to steer the organisation when it tends to over-rely on the same patients to guide its work.” (Head of Community Engagement, NHS trust)

“We are working to review how we can integrate more effectively patient and carer voices throughout our work-based learning provision to ensure that the voices have authentic national expression as well.” (Assistant Head of Department, Nursing, Academic Lead, HE sector)

“We have particular specialist issues with not being ‘tokenistic’ in HE when including people with learning disabilities.” (Professional Lead - Learning Disabilities, HE sector)

An acute NHS trust respondent reported some staff resistance to a customer care course:

“Staff felt they did not need the training and felt patronised by some elements of it. We therefore had to battle some negative word of mouth.” (Head of Education and Training, NHS trust)

And there were some comments about resources, for example:

“Resourcing for this is a challenge. Involving and supporting service users carers/patients in the programme is very resource intensive activity - the ‘climate’ in HIEs is a real threat to the work that we have begun.” (Senior Lecturer and Programme Leader Adult Nursing, HE sector)

9) In a time of competing priorities and resource constraints, the top managers and boards of organisations that provide education and training must make clear to staff their commitment to support inclusion of the patient experience.

The most commonly required type of support is guidance about how to assess the impact of the course on patient experiences, requested by four out of five respondents from each sector (Figure 7).
Figure 7: Kinds of advice and support that would help to develop the patient experience aspects of respondents’ courses

(The full text of each question is given in Annex 2)

10) SHAs and relevant national organisations should review the availability of guidance material for education and training providers, in particular guidance about how to assess the impact of the course on patient experiences.

Source: King’s Fund/King’s College survey of patient experience in education & training winter 2010.

N = 67 HE & 56 NHS respondents.
Moving forward

The broad concept is recognised

The above analyses have shown there is clearly plenty of room for improvement in how patient experience education and training is delivered. However, much of the groundwork has been done – there is a great deal of relevant training taking place already, especially in the HE sector, and the general concept that patient experience should be covered is accepted and apparent in both HE and the NHS. For example:

“We have service users and carer experience threaded through the programme. Shared modules have a service user and carer theme. Undergraduate programmes have clear themes with a high priority put on patient voice and communication.” (Faculty Lead for User and Carer Involvement, HE sector)

Regulatory standards are an important influence

The fact that many respondents recognise the need to include patient experience partly reflects the weight put behind policy initiatives by the DH, emphasis as part of the NHS performance framework and by healthcare regulators,18 and advice from the NHS Institute and other organisations. It is also likely to reflect the fact that the three main bodies responsible for the regulation of education of NHS professions include the concept of patient-focussed care and the patient experience in their standards statements. Those interviewed in higher educational institutions all stated that curricula are generally designed to develop trainees that can understand, and demonstrate that they are able to meet, the basic standards of practice set out by the relevant professional council. Educational quality assurance systems operated by the councils are in turn designed to assess that this is the case.

The three councils’ standards all include statements about the patients’ experience:

- **Doctors:** The General Medical Council (GMC) sets out the six duties of a doctor (General Medical Council 2006; General Medical Council 2009). Three of these are about having regard for individual patients:
  - Make the care of your patient your first concern
  - Treat patients as individuals and respect their dignity
  - Work in partnership with patients

- **Nurses:** The Nursing & Midwifery Council (NMC) sets out four standards of conduct, performance and ethics, of which the first is “make the care of people your first concern, treating them as individuals and respecting their dignity” (Nursing & Midwifery Council 2008). The concept of person or patient-centred care is widespread within nursing.

- **Allied health professions:** The Health Professions Council (HPC) sets out 14 standards, the first two of which are “You must act in the best interests of service users” and “You must respect the confidentiality of service users” (Health Professions Council 2008).

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18 The 2009/10 NHS Operating Framework requires each NHS trust to obtain feedback from patients about their experience of care. The Care Quality Commission will use data from its ongoing programme of patient surveys to calculate this indicator.
In addition, the Academy of Medical Royal Colleges has worked jointly with the NHS Institute for Innovation and Improvement as part of the Enhancing Engagement in Medical Leadership project to develop a Medical Leadership Competency Framework for all stages of a doctor’s career and Medical Leadership Curriculum for postgraduate and specialty training that reflect wider responsibilities:

“While the primary focus for doctors is on their professional practice, all doctors work in systems and within organisations. It is a vitally important fact that doctors have a direct and far-reaching impact on patient experience and outcomes.” (Academy of Medical Royal Colleges and NHS Institute for Innovation and Improvement 2009)

The guidance expects doctors to measure and act to improve the patient experience. One of the competences set out is: “Obtain and act on patient, carer and user feedback and experiences”. One of the skills to be demonstrated is: “Reflect on patient feedback and suggest ways of improving their experiences”; and another is: “Utilise questionnaires / tools to focus on the patient experience”. One of the activities suggested is: “Group analysis of patient experiences and risks, to produce ideas for improvement” (Academy of Medical Royal Colleges and NHS Institute for Innovation and Improvement 2010).

However, while the above suggests aspects of the patient experience will be expected in training, the regulators’ requirements do not specify in detail how these broad standards statement should be interpreted into education and training curricula, content or teaching and learning styles. The number of hours that should be devoted to patient experience education and training is similarly not specified. Each education and training provider is thus responsible for developing their curricula to ensure these concepts flow through.

One medical school visited stated that curricula were indeed under such review to ensure that they reflect the GMC statements cited above. For example, a criteria assesses whether a student’s relationship with patients includes considering the patient perspective during discussions and when making plans. Another assesses whether a student actively seeks out the opinions of others including the patient perspective. Similarly nursing school interviewees described a school’s freedom to flesh out how the standards should be taught, with colleagues developing the education details that will lead to ‘their’ nurses behaving to their expectations once at work.

The details need improvement
So the groundwork is largely in place, or being put there. It is in the detail of exactly what aspects of experience are/are not included in education and training now, and how the education and training is conducted and evaluated that is where most room for improvement lies – as the analyses in the preceding chapters have set out.

Of course there are always good practice examples to be found. For example, an NHS trust reported trying to reach as many staff as possible via:

Lunch Bite - 60 Minute Learning Makeovers - or Half Day Sessions on ‘Capturing and Enhancing the Patient Experience’ (Associate Director Patient and Public Relations, NHS trust)

The general acceptance posited above does not always work through to real improvement in the way education and training happens, because of practical constraints on time:

“Inter-professional education, if it is to be done well and effectively, is labour intensive. Due to the time constraints of other essential curricular activity it sometimes feel that we are really having to make time for this rather than it being considered on an equal footing with other learning activities.” (Asst Director of Nursing, NHS trust)
Further questions
Some questions related to education and training merged from other strands of the work programme after the survey had been completed, including:

- Do course providers develop a ‘business case’ for patient experience training (ie, on the cost-benefit of training staff to capture, measure and improve patient experiences)? How do organisations justify investing in this kind of training?
- Does training exist that explicitly includes teaching staff how to feedback to patients on how changes have been made to services based on their input/involvement and developing an ongoing relationship/partnership with patients?
- Does education and training contribute to creating the necessary resource/infrastructure regarding patient experience data - handling, analysis and reporting?
- Is there any teaching/training about the methodology of using patients’ stories - how to obtain them; how to use them; the strengths and limitations of this kind of information?

Only in relation to the last of these questions can we report anything of direct relevance. The importance of eliciting and using patients’ stories was frequently mentioned by respondents. The case study Unlocking the past described in Annex 6 describes assessing students on how well they have elicited stories. One might assume therefore that students are first taught how to elicit them. A different respondent described a planned development as “Use of methods of gathering patient experience information, including patient stories” (Chief Nurse, PCT) –suggesting that the trust will be developing training in how to obtain stories. “We also intend to support patients to tell their stories in safe, supported and controlled settings so that practitioners and commissioners learn viscerally from the firsthand accounts. We also intend to extend this to discussions of fairness and discrimination.” (Head of Community Engagement, NHS trust)

Another issue beyond our remit is how many staff take advantage of the training on offer and how valuable they find it. Our study considered the education and training made available, but not its uptake or the views of staff about it. The findings of the 2010 NHS Staff Survey will shed some high-level light on this (as discussed earlier), but further work is required to provide the details. A working hypothesis might be that pre-registration education about the patient experience might find it hard to compete for students’ attention, if it is viewed as competing for attention with the details of clinical care, and before students have a real life reference point. For example, a junior doctor quoted in a King’s Fund Point of Care report said: “It’s part of what is seen as soft and fluffy. People ask ‘Is it on the exam?’ and of course it isn’t so it’s hard to see it as important. Where it is judged, it’s like a tick-box exercise – a mark for shaking hands, for saying your name…” (Firth-Cozens and Cornwell 2009). If this reaction is widespread, then courses that bring students into contact with patients are more likely to succeed.

Involving patients further is the key
To some extent the intention to improve education and training in the patient experience is there - the majority of respondents plan to make further developments to their courses over the next 12 months (76% of HE respondents and 80% of those from NHS trusts). The great majority of the described developments within the HE sector were about involving patients further (35 of 49 comments). Of the many comments that could be quoted on this (see Annex 4 for a full list), these are typical examples:
“Developments in involvement with recruitment to the course, planning, delivering & evaluating teaching including involvement in curriculum development” (Course Director Pre-registration Mental Health, HE sector)

“More fine tuning [is] needed on all courses to reflect more overt central role of patient experience.” (Chief Nurse, NHS trust)

“As a consequence of participating in this survey I intend to investigate opportunities to develop patient experience video clips and evaluate patient input to the … Programme.” (Senior Lecturer, HE sector)

Worryingly, however, the sector that is currently least likely to involve patients – NHS trusts – is also less likely to be planning to further involve them (14 of 41 developments described concerned involving patients further). This reinforces the weight that needs to be put behind our recommendation in chapter X: More NHS trusts should include patients in planning, delivering and evaluating the patient experience training that they provide to staff.
Annexes

Annex 1: Study methodology

We gathered information on whether and how the need to focus on patient experience is covered in professional education and training by:

- A survey of all English providers of medical, nursing and allied health professions pre-qualification professional training.
- A survey of NHS trusts (including PCTs) in England, to access information about in-service training.
- Case studies following up the survey results.

Survey design

The survey questionnaire is given in full in Annex 2. Note that the questionnaire was administered as an online survey using Survey Monkey, and included skip logic. Thus each individual respondent did not see the full questionnaire as displayed in the PDF annex file. For example, respondents answering the sector question by clicking on ‘university,...’ did not subsequently see the questions asking about which SHA or NHS trust they worked at.

Development of the survey question wording was greatly helped by the time and ideas given during interviews. We are very grateful to staff at:

- The Florence Nightingale School of Nursing & Midwifery, King’s College, London.
- The General Medical Council.
- The London Deanery.
- A university medical school.
- The Royal Free Hampstead NHS Trust.

There are no readily available email lists (or any other type of personalised lists) of those responsible for patient experience education and training. This is reflected in the chapter above that describes how diffused responsibilities are within most organisations. We therefore emailed NHS trust chief executives and asked them to forward emails (see annex with email wording below). Given that for most universities healthcare will be just one of many disciplines, we decided that an email to the top post with a request to forward would be unproductive. Instead we extracted publicised contact lists from the UCAS and NHS Careers website. This was later supplemented by a nursing educational network list, and an approach to an umbrella medical education group (Medev).

An introductory email was sent to the organisations listed in Table 1.
A great number of comments on the question content, design and how to target appropriate potential respondents were provided by members of the project team, NHS III and DH.

The survey was live between November 2010 and early January 2011. Answers were encrypted by the software before transmission. Respondents were able to enter the survey at any time while it was open to continue with or edit their responses; but respondents were only able to enter answers about one course per computer.

**Response**

In total 265 people entered the survey – 88 from the HE sector, 158 from NHS trusts and 19 from other types of organisation (eg, SHAs). Of the 265, 154 completed the survey (ie, entered each page of the survey and exited from the last page). The numbers responding to each individual question varied, and are given in the body of the report and in the overall frequencies annex...

Little systematic knowledge existed about this topic before we began. One of the main reasons is because there is no clear set of organisations, departments or posts with responsibility for the inclusion of patient experience in education and training. Pre-registration/qualification course are provided by a wide range of different universities and colleges, regulated by three different bodies professionally and also subject to the general higher education regulatory environment. Within NHS trusts there is also a mix of responsibilities – for example, doctors will be linked to deaneries for Foundation and specialist training, but they may also be involved by trust management in induction or other training, and linked to the royal college of which they are a member for CPD.

This made producing a research framework that could yield useful results challenging in the tight timescales available. In the end we concluded that a single online questionnaire, using skip logic to filter the questions seen by different types of respondent, would be the best approach. In the end this yielded sufficient responses to give meaningful findings and enable lessons to be learnt. However, we cannot report accurately on response rates because:

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**Table 6: Organisations to which the invitation email was sent**

<table>
<thead>
<tr>
<th>Provider</th>
<th>N</th>
<th>Target recipients</th>
<th>Type of education/training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical schools</td>
<td>23</td>
<td>Course contact email address (derived from UCAS)</td>
<td>Medical pre-registration</td>
</tr>
<tr>
<td>Nursing &amp; Midwifery schools</td>
<td>57</td>
<td>Course contact email address (derived from UCAS)</td>
<td>Nursing and midwifery pre-registration</td>
</tr>
<tr>
<td>Universities and colleges</td>
<td>100</td>
<td>Course contact email address (derived from UCAS)</td>
<td>Courses for 21 different broad allied health professions.</td>
</tr>
<tr>
<td>Deaneries</td>
<td>19</td>
<td>Heads of school</td>
<td>Medical foundation training</td>
</tr>
<tr>
<td>Trusts</td>
<td>390</td>
<td>Director of Medical Education; Director of Nursing; Human Resources Director; Medical Director (via Kings Fund list*)</td>
<td>Medical foundation and specialist training; CPD</td>
</tr>
</tbody>
</table>

*The King’s Fund email list is for trust chief executives. The covering email will ask that the email be forwarded to the directors listed in the table, and/or anyone else that the chief executive wishes to nominate.*
• There is no pre-existing dataset listing how many courses exist, and each respondent, who might be responsible for more than one course, was restricted to answering about one course only. (We tried initially to design a Q that allowed responses about multiple courses but it did not pilot successfully.)

• There is no pre-existing list of email addresses (or postal addresses) for those running courses. We thus mailed to the chief executive of NHS trusts, asking them to forward the email to relevant post holders. We do not know how many forwarded the email nor, if they did, to how many people. In addition we emailed a self-selected subset of medical directors, director of nursing, HR directors, etc, known to the King’s Fund. For the universities we gathered contact addresses given on NHS Careers and UCAS websites. While some of these were for named individual people, most were generic ‘enquiries@’ addresses, and again we do not know whether our request to forward to course leaders was successful. We also used a list of email addresses for an HE nursing network.

• The majority of respondents from Higher Education described themselves either as tutors on the course about which they were to answer questions, or as the course leader. By contrast the majority of NHS trust respondents described themselves as designated leads for patient experience training, working at a level above a single course, or having some other relevant role. This will partly be a reflection of the finding described above (in the ‘taking a lead’ section) that there were fewer reported designated leads in higher education. Second, it may reflect that NHS training courses are of shorter duration than most HE courses and thus less likely to have a single long-lasting figurehead. Finally it will reflect that the introductory email was more likely to have reached managers within trusts than any course leaders that did exist, because of the way we had to make contact with trusts. We cannot separate these out.

Thus both the population size and the proportion of that population that we reached are unknown. However, we can say how many replies were received from each sector, which organisations they worked for, what were their job titles and the names of the courses they selected to describe – the details are given in full in the ‘frequencies’ Annex.

In particular we received no full responses in relation to undergraduate medical courses. By contrast replies were received from NHS trust directors of medical education (and similar job titles) about medical foundation and specialist training.

Possible response bias

During questionnaire development, we trialled a version that attempted to collect information about all of the course provided by a single institution. However, it became impossibly complex to design something that could allow respondents to rate a whole set of course on something like the degree to which each included the different aspects of patient experience, when there could be so many courses and one respondent would not know the details of all of them. There could be response bias, and overall if there is it is probably in the direction of over-estimating the true amount of patient experience inclusion:

• Respondents were asked to choose just one course to rate, and were suggested it might be an ‘exemplar’.

• Ratings about the course were ‘self-report’ and we cannot verify how accurately they have been rated. The most likely direction of bias is for over-rating.

• Potential respondents receiving the introductory email with responsibility for a course where there is no current inclusion, would have been more likely not to participate in the survey.
Annex 2: Introductory emails
(a) Email to HE sector
National survey of NHS education and training to improve patient experiences

If you are unable to view the email below please view our web version

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Dear Colleague

The King's Fund and King's College London are conducting an important national survey, aimed particularly at:

- the course leader for each NHS staff course
- those responsible for co-ordinating the curricula for each of the health care professions for which you provide courses.

So we would very much appreciate it if you could please forward this email to these postholders. Thank you.

Please accept my apologies if this email has already reached you via another route and you have responded to the survey.

About the survey:
This online survey was commissioned by the Department of Health’s Public and Patient Experience and Engagement team and the NHS Institute for Innovation and Improvement.

The survey takes about 10 minutes to complete, and all survey participants will receive a copy of the report early in 2011.

The questions ask about:

- whether, and how, aspects of patient experiences are included in NHS education and training
- where there needs to be further development and improvement in education and training provision in relation to patient experiences.

To enter the survey please click on the following link:
https://www.surveymonkey.com/s/patients_experience_training

We hope that you will forward this email to any other colleagues within your university or deanery responsible for delivering NHS education and training.

Please complete the survey by 31 November 2010. We very much appreciate your help.

[name] [post]
Dear Colleague

The King's Fund and King's College London are conducting an important national survey, aimed particularly at the following posts:

- Medical Director
- Nursing Director
- HR Director
- Director of Medical Education
- Director of Nurse Education and Training
- Director of Patient Involvement and Experience

So we would very much appreciate it if you could please forward this email to your colleagues holding these posts. Thank you.

About the survey:
This online survey was commissioned by the Department of Health's Public and Patient Experience and Engagement team and the NHS Institute for Innovation and Improvement.

The survey takes about 10 minutes, and all survey participants will receive a copy of the report early in 2011.

The questions ask about:

- whether, and how, aspects of patient experiences are included in NHS education and training
- where there needs to be further development and improvement in education and training provision in relation to patient experiences.

To enter the survey please click on the following link:
https://www.surveymonkey.com/s/patients_experience_training

Please complete the survey by 31 November 2010. We very much appreciate your help.

[name] [post]
The King's Fund
## Annex 3: N&M and AHP course by specialism

<table>
<thead>
<tr>
<th>N of courses</th>
<th>Pre-registration</th>
<th>Post-registration</th>
<th>Induction</th>
<th>In-service, CPD</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALL N&amp;M courses</td>
<td>72</td>
<td>87</td>
<td>49</td>
<td>91</td>
<td>299</td>
</tr>
<tr>
<td></td>
<td>24%</td>
<td>29%</td>
<td>16%</td>
<td>30%</td>
<td></td>
</tr>
<tr>
<td>All types</td>
<td>18</td>
<td>29</td>
<td>16</td>
<td>26</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>24%</td>
<td>30%</td>
<td></td>
<td></td>
<td>6%</td>
</tr>
<tr>
<td>Adult nursing</td>
<td>18</td>
<td>20</td>
<td>7</td>
<td>19</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>21%</td>
<td>24%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>11</td>
<td>9</td>
<td>8</td>
<td>13</td>
<td>41</td>
</tr>
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Annex 4: Further case study details

Case studies reported to us during the current study

**Case Study 1:** A mental health trust linking a private sector-provided training course with its own audit to identify and work through improvements.

An NHS trust reported an Improving Service User Experience course, provided by an independent not-for-profit organisation (MHMTS). The course was multidisciplinary (including non-clinical staff) for those working in a secondary care setting. The respondent rated the patient experience aspects of ‘relationships’, ‘support’ and ‘customer care’ as ‘covered extensively’. Service users were involved in planning, delivering and evaluating the course.

The provider uses theatre techniques, including improvisation, forum-theatre and scripted role-play, delivered by professional actor-facilitators - “We tend to use actors on our ‘high volume’ courses such as this and another mandatory Relating to People course due to the numbers involved” (Head of Organisational Development and Learning, NHS trust).

Improvement measures were identified by the trust via an audit following evaluation of a service user survey. The trust also plans to change its induction training “to make it more customer/service user focused”.

In addition to this specific case study, this training provider offers courses in Working Effectively with Service Users, Increasing User Satisfaction and Improving Customer Care (http://www.mhmts.com).

**Case Study 2:** Unlocking the past

The Unlocking the past project seeks to elicit service users’ stories about living in the Royal Albert Hospital, a large Victorian long stay institution for people with learning difficulties which closed in 1996.

The project website notes that: The existing public archive landscape is dominated by bureaucratic and medical perspectives; the viewpoint of residents and rank and file nursing/non-nursing staff is under-represented, and largely absent - thus reinforcing the inequalities of institutional life. By concentrating on these sections of the institutional community the project will enable individuals to reclaim and own their histories…”I'd just like people to know so they can realise what it was we'd to go through. It's not true what was written down! They did it just to keep us locked up, so that people would think we're mental”… Recollecting and sharing stories, making sense of our lives seems to be part of our humanity. For people with learning difficulties, as with other groups who have experienced oppression, their stories, their voices have often been marginalised and excluded. It is not surprising therefore that for some the telling of their stories has been such a powerful experience. Not being heard at all and/or being misrepresented has often been the experience of people with learning difficulties, particularly those with lives spent in large long stay institutions. The very fact of being listened to, being believed, is a key motivating force….“It’s so people can understand what I’ve been doing. It has let people know what I’ve been doing in my life, and what I’ve been through”.

The project is not primarily designed as a staff training course, but has education and training benefits associated. The project is described as an integral part of the curriculum for students on a pre-registration learning difficulties nursing course.
All of the listed aspects of the Patient experience were rated as ‘covered extensively’ (apart from customer care, covered ‘to some extent’. In addition the other, and main focus, of the initiative is described by the respondent as “Promoting independence; effects / implications of power relationships; advocacy; promoting the client’s story” (Associate Dean, including responsibility as designated lead for patient experience, HE sector).

Students are assessed on the way in which their interviewing has successfully drawn peoples’ experiences out.

http://www.unlockingthepast.org.uk

**Case Study 3:** A multidisciplinary course involving service users with evaluation planned.

An in-service/CPD course Recovery degree module for learning disabilities and mental health nurses and AHPs is provided by an HE sector organisation for an NHS trust. Relationships, involvement, independence, context and measurement are aspects of the patient experience ‘covered extensively’.

Service users are reported as being involved in planning, delivering and evaluating the course. Teaching methods used that involve service users included video footage of patients talking about their experiences, contact with patients who come in to describe and discuss their experiences with the staff, and “Reflective journals of student experience of applying recovery into their clinical practice - including feedback from the people they support” (Director of Nursing and Practice, NHS trust).

“We are planning to evaluate the impact of the course on people's experience of services and will be asking our R&D department to design the methodology for this”. In response to the survey question ‘What kinds of advice and support would help you to develop the patients' experiences aspects of your course?’ the respondent chose ‘Guidance about how to assess the impact of the course on patient experiences’.

**Case Study 4:** A multidisciplinary customer care course at an acute trust

A large acute NHS trust reported a multidisciplinary private sector-provided ‘customer care’ training course, that also ‘to some extent’ covered the patient experience aspects of ‘context’ and ‘communication’. Carers were involved in planning and delivering the training, with video and role play/simulation used.

The course was provided by Energize Learning & Development.

The course focussed on attitude, motivation, leadership and how colleagues treat each other (based on the premise that colleague experience within an organisation is as important as customer experience). Another concept is to create an environment where staff treat patients as they would like to be treated.

“Although the course is now over we have blended the theory behind it into other programmes. We tried to measure impact through patient & staff surveys and PALs information.” (Head of Education and Training, NHS trust)

A similar course for another NHS client, a PCT, aimed to measure the impact of the course by looking for improvements in mystery patient scores, reduction in complaints and improvement in staff survey response rates and scores on key questions.

(http://www.energizelearning.com)
### Case Study 5: An SHA’s work linked to the NHS Institute for Innovation and Improvement’s Patient Experience Learning Programme

The Department of Health commissioned the NHS Institute to deliver a Patient Experience Learning Programme. The programme focuses on collecting and using patient experience feedback to inform commissioning decisions, support contract management and improve services. The programme starts by aiming “To have a greater understanding of patient experience and why we want to improve the Patient Experience” by identifying what is and what makes a great experience, and why we want to improve the patient experience. Participants then identify their own project, and work through the details of how to make that happen. There is an emphasis on the need to evaluate and measure, including how to use data to improve decision-making and identify real improvements. An evaluation of the programme was published in December 2010 (Shared Intelligence 2010).


A respondent described developing a programme based on this involving 33 trust participants (ranging from PALs leads to directors) who are required to complete a work based project. “The programme contains all aspects of development on an organisational and personal level regarding the patient experience” (SHA Assistant Director of Nursing-Patient Experience Lead). Of the nine aspects of patient experience listed in our questionnaire, ‘relationships’, ‘involvement’, ‘support’ and ‘measurement’ are covered extensively. A formal evaluation of the course and each of the projects has been commissioned.

### Case Study 6: A multidisciplinary course not involving patients and with serious barriers to staff involvement noted

An NHS trust reported a Quality Service Experience Collaborative course, provided by an HE sector organisation for NHS trusts within one SHA. The course is multidisciplinary, including non-clinical staff working in both primary and secondary care settings.

‘Communication’ and ‘Measurement’ are the two aspects of patient experience ‘covered extensively’. Patients were not reported as being involved in planning, delivering or evaluating the training. All of the potential barriers that we listed in our question were rated as ‘a serious barrier’ to patient experience training.

(Response from an NHS trust Associate Director for Communications, Engagement and Marketing).
Case Study 7: Governance in Action

A new multidisciplinary course was described, provided by an HE sector organisation. The Governance in Action course will ask students to “Develop a governance structure that assures clinical effectiveness, patient experience and patient safety, and have this assessed by a mock board composed of real board members.” (Director of PG Education). The board members will include a non-executive director who is also chair of the LINk.

The course will cover the “Leadership qualities that enhance patient experience” (Director of PG Education). It is intended that patients will meet with course attendees to describe and discuss their experiences.

The course will also entail the “Verbal and written presentation of a clinical governance strategy which includes within it patient experience” (Principal Teaching Fellow). The course will be evaluated: “I believe that understanding the organisational impact of such courses is critical.” (Director of PG Education).

Case Study 8: The Patient Experience Network

The Patient Experience Network seeks to bring together organisations committed to improving the patient experience – “It is not our intention to preach, rather to provide a medium to share and celebrate what has worked, and perhaps not worked, in real life settings and to provide practical tools and support” (website statement).

As well as being a forum for the exchange of ideas and good practice it offers, via a private sector company link, accredited Patient Experience E-Learning (PexEL). A 30 hour, nine module course is spread over 10 weeks, with three hours of tutor-led interactive study per week. (“The tutor helps you focus on the important aspects of service delivery. The sharing of best practice amongst participants and the tutor really made me think about how I could do things differently and more successfully” – an NHS Customer Service Team Leader quoted on the Network’s website). The course is based on a written guide - Best Practice Guide for Customer Service Professionals – and thus has influences from outside of healthcare.

An online self-assessment tool is offered for an organisation to benchmark itself against attributes of good practice organisations. The Network also runs a national awards programme with the aim of recognising, celebrating and sharing patient experience examples.

http://www.patientexperiencenetwork.com/
## Case studies from other sources

### Case Study 9: Putting You First

A case study described as part of NHS Employers Shared Learning initiative.

West Suffolk Hospital NHS Trust involved staff across the trust in a continuing campaign to improve patients’ experiences. It began with a series of events run by consultants April Strategy, designed to enable staff to hear patients’ real stories and experiences first hand. Staff surveys and workshops followed, with nearly 40% of staff directly involved in shaping the content of the programme. A Patients First handbook was issued, containing 10 service standards to help staff understand how they individually and as teams can change their behaviours to consistently put patients first, and a pledge to give them the support they need to make the change. About a quarter of the workforce has already taken part in a Patients First personal development session, to help staff to improve their communication and customer service skills.

Since launch services have developed their own action plans to ensure that their patients ‘feel safe, feel cared for and feel confident in their treatment’. Measurement suggested that in the initial three months patient satisfaction increased by 40% with a commensurate decrease in dissatisfied patients.

[web]

### Case Study 10: iCARE

A case study described as part of NHS Employers Shared Learning initiative.

Yeovil District Hospital NHS Foundation Trust’s iCARE programme (Communication, Attitude, Respect and Environment) aims to equip staff to meet and exceed the expectations of all service users, as well as shape how they work with each other. The ‘i’ stands for the individual and stresses that every member of staff has a fundamental role to play in delivering exceptional care. The programme was developed following complaints and conciliation meetings that highlighted poor standards of care for some patients and their relatives, with areas for improvement linked to leadership, interpersonal skills and behaviour, and the ability to demonstrate the ‘human’ face of care.

Initially developed by a senior matron, the trust identified that the approach should become the central focus of the organisation's developing culture and strategy. Development involved 'discovery work' with patients and carers and awareness sessions for all staff covering the principles behind the concept and the opportunity to explore how iCARE could influence their own area of work and responsibility. A weekly update on computer screens reminds staff about training sessions and to share examples of positive patient feedback. Questionnaires suggest that the focus on the four key areas has improved the patient experience.

[web]
References


• Academy of Medical Royal Colleges and NHS Institute for Innovation and Improvement (2010). Guidance for Undergraduate Medical Education: Integrating the Medical Leadership Competency Framework, NHS III.

• Academy of Medical Royal Colleges and NHS Institute for Innovation and Improvement (2009). Medical Leadership Curriculum, AOMRC, NHS III.


