

Development of New Models for Collection and Use of Patient Experience Information in the NHS – PRP 070/0074

Final Report

Authors:

Ray Fitzpatrick¹

Chris Graham²

Elizabeth Gibbons¹

Jenny King²

Kelsey Flott²

Crispin Jenkinson¹

¹ University of Oxford

² Picker Institute Europe

Contents

| | |
|--|-----------|
| Acknowledgements | 5 |
| Patient Experience Advisory Group: | 5 |
| Expert Collaborators: | 5 |
| Patient and public involvement (PPI) representatives: | 6 |
| Declaration of competing interests | 6 |
| Disclaimer | 6 |
| 1 Executive Summary | 7 |
| 1.1 Context | 7 |
| 1.2 Phase 1 – scoping | 7 |
| 1.3 Phase 2 – field testing | 8 |
| 1.4 Phase 3 - evaluation | 8 |
| 1.5 Conclusions | 9 |
| 2 Introduction | 11 |
| 2.1 Background | 11 |
| 2.2 Methods | 12 |
| 2.3 Project management and contributors | 13 |
| 3 Phase 1 – Scoping | 15 |
| 3.1 Service Lines | 15 |
| 3.2 Pathways | 18 |
| 3.3 Patient experience framework and questionnaire content | 24 |
| 4 Phase 2 – Field testing | 30 |
| 4.1 Cognitive testing of the core questionnaire | 30 |
| 4.2 Pilot site recruitment | 36 |
| 5 South Coast Stroke services | 39 |
| 5.1 Context / background | 39 |
| 5.2 Planning | 40 |
| 5.3 Delivery / implementation | 42 |
| 5.4 Reporting | 43 |
| 5.5 Dissemination | 44 |
| 5.6 Action planning | 45 |
| 5.7 Sharing of results and what next | 46 |

| | | |
|------|--|----|
| 6 | Sheffield Teaching Hospitals NHS Foundation Trust | 48 |
| 6.1 | Context / background | 48 |
| 6.2 | Planning | 50 |
| 6.3 | Delivery / implementation | 53 |
| 6.4 | Reporting | 54 |
| 6.5 | Dissemination | 55 |
| 7 | West Norfolk Primary care practice | 58 |
| 7.1 | Context / background | 58 |
| 7.2 | Planning | 59 |
| 7.3 | Delivery / implementation | 61 |
| 7.4 | Reporting | 62 |
| 7.5 | Dissemination | 63 |
| 7.6 | Action planning | 64 |
| 7.7 | Sharing of results and what next | 65 |
| 8 | Homerton University Hospital NHS Foundation Trust | 66 |
| 8.1 | Context / background | 66 |
| 8.2 | Planning | 68 |
| 8.3 | Delivery / implementation | 70 |
| 8.4 | Reporting | 72 |
| 9 | Staffordshire and Stoke on Trent Partnership NHS Trust | 75 |
| 9.1 | Context / background | 75 |
| 9.2 | Planning | 76 |
| 9.3 | Delivery / implementation | 78 |
| 9.4 | Dissemination | 78 |
| 10 | Oxford Health NHS Foundation Trust | 80 |
| 10.1 | Context / background | 80 |
| 10.2 | Planning | 82 |
| 10.3 | Delivery / implementation | 84 |
| 10.4 | Reporting | 85 |
| 10.5 | Dissemination | 87 |
| 10.6 | Sharing of results and what next | 88 |
| 11 | Nuffield Orthopaedic Centre | 89 |
| 11.1 | Context / background | 89 |

| | | |
|-------|---|-----|
| 11.2 | Planning | 90 |
| 11.3 | Delivery / implementation | 90 |
| 11.4 | Reporting | 91 |
| 11.5 | Dissemination | 92 |
| 11.6 | Action planning | 93 |
| 11.7 | Sharing of results and what next | 93 |
| 12 | Northumbria Healthcare NHS Foundation Trust | 94 |
| 12.1 | Context / background | 94 |
| 12.2 | Measuring patient experience | 94 |
| 12.3 | Reporting | 95 |
| 12.4 | Service improvement | 96 |
| 12.5 | Barriers and enablers | 97 |
| 12.6 | North Cumbria University Hospitals NHS Trust | 97 |
| 12.7 | Conclusions | 98 |
| 13 | Phase 3 – Evaluation | 100 |
| 13.1 | Context | 100 |
| 13.2 | Testing the new model | 102 |
| 13.3 | Service-line sites | 102 |
| 13.4 | Pathway sites | 103 |
| 13.5 | Methodological considerations | 105 |
| 13.6 | Resourcing | 106 |
| 13.7 | Local variation and national context | 106 |
| 13.8 | Adaptation versus standardisation | 109 |
| 13.9 | The use of a generic survey instrument | 110 |
| 13.10 | Analysis and presentation of results | 111 |
| 14 | Conclusions | 113 |
| 14.1 | Policy implications | 115 |
| 15 | Dissemination | 118 |
| 15.1 | Presentation to the collaborators and PPI panel | 118 |
| 15.2 | Presentation to the project advisory group | 118 |
| 15.3 | Picker Institute Europe and University of Oxford websites | 118 |
| 15.4 | Presentation at the European Care Pathways Conference 2013 | 118 |
| 15.5 | Presentation at the International Forum on Quality and Safety in Healthcare | 118 |

| | | |
|------|---|-----|
| 15.6 | Publication in a peer reviewed journal | 118 |
| 16 | References | 119 |
| 17 | Appendix A: Patient and public involvement in this research | 121 |
| 18 | Appendix B: Surveys reviewed for question mapping exercise in phase 1 | 122 |
| 19 | Appendix C – Formatted generic questionnaire | 124 |
| 20 | Appendix D: Information sheet | 128 |
| 21 | Appendix E: Equality and diversity | 131 |
| 21.1 | Project management | 131 |
| 21.2 | Patient and public involvement | 131 |
| 21.3 | Pilot sites | 131 |

Acknowledgements

This report describes findings from patient and service user experience research with seven pilot sites. We are grateful for the time spent by staff at each of the sites; their participation and thoughtful discussions were invaluable to this research. The sites are:

- Pilot Site 1. A south coast of England stroke network
- Pilot Site 2. Sheffield Teaching Hospitals NHS Foundation Trust
- Pilot Site 3. An East Anglian primary care-led consortium
- Pilot Site 4. Homerton University Hospital NHS Foundation Trust
- Pilot Site 5. Staffordshire and Stoke-on-Trent Partnership Trust
- Pilot site 6. Oxford Health NHS Foundation Trust
- Pilot site 7. Nuffield Orthopaedic Centre
- Case Study 8. Northumbria Healthcare NHS Foundation Trust

Thanks are also given to the members of the public who helped us test the core questionnaire and the patients and service users who took part in the surveys at each of the pilot sites.

Finally, our thanks are given to the members of the advisory group, collaborators and the patient and public involvement (PPI) panel for their guidance and expert opinion.

Patient Experience Advisory Group:

- | | |
|--|--|
| ○ Maggie Bayley (Chair) | |
| ○ Department of Health representatives | ○ Care Quality Commission representative |
| ○ NHS England representatives | ○ NHS trust representatives |
| ○ NHS Institute for Improvement and Innovation representatives | ○ National Voices representative |
| ○ Kingston University, Centre for Public Engagement representative | |

The advisory group are not responsible for the final version of this report.

Expert Collaborators:

- Jocelyn Cornwell
- Angela Coulter
- Louise Locock
- Sophie Staniszewska

Patient and public involvement (PPI) representatives:

- Parv Aley
- Jennifer Bostock
- Milton and Waveney Munroe

Declaration of competing interests

The Picker Institute run the national patient survey co-ordination centre, developing and co-ordinating large scale national patient experience surveys on behalf of the Care Quality Commission. The Picker Institute also support NHS organisations to conduct the NHS friends and family test.

Disclaimer

This report is independent research commissioned and funded by the Department of Health Policy Research Programme ('Development of New Models for Collection and Use of Patient Experience Information in the NHS' – PRP 070/0074). The views expressed in this publication are those of the author(s) and not necessarily those of the Department of Health.

1 Executive Summary

1.1 Context

The 'new models for measuring patient experience' project was funded by the Department of Health's Policy Research Programme and was jointly led by the Picker Institute and University of Oxford. The aims of the project were to:

- Develop a simple, conceptually grounded and unified model for assessing patient experience and to evaluate that model.
- Evaluate whether and how pathway and service line focused assessments of patients' experiences provide added value to standard organisational surveys.

The work was carried out in three phases, which are detailed below.

1.2 Phase 1 – scoping

In phase 1 a definition of key domains of patient experience were agreed via literature review and synthesis and expert consultation. The NHS Patient Experience Framework was chosen as the working definition for use in this project with elements critical to patient experience being:

- Respect for patient-centred values, preferences, and expressed needs
- Coordination and integration of care
- Information, communication, and education
- Physical comfort
- Emotional support
- Welcoming the involvement of family and friends
- Transition and continuity
- Access to care

A standard questionnaire instrument to assess the domains in the framework, plus the principles safety and effectiveness of care, was then developed for use in service–line and pathway-based surveys.

In addition to this the research team came to an agreement regarding the definition of 'service lines' and 'pathways'.

For this project, service lines were considered to be specialised clinical areas with specific functional and operational remits. Typical service lines cover a range of clinical functions: examples include pathology, dental, general surgery, and specialist medicine.

Pathways were considered as a metaphor for the patient journey. Viewing 'pathways' as a metaphor avoided the restrictions of highly structured clinical algorithms, allowing us to take into account the more unpredictable nature of people's experiences with healthcare services.

1.3 Phase 2 – field testing

In phase 2 the developed questionnaire was tested and was revised accordingly. Seven pilot sites were then recruited for field testing. At each site a unique service user/patient group was surveyed using different methods.

In addition to the seven pilot sites, Northumbria Healthcare NHS Foundation Trust, who were unable to take part as a pilot site but were still keen to contribute to the project, provided details of the patient and service user data collections being carried out at their trust. They are included in this report as a case study site.

The pilot sites were:

| Site | Condition of focus | Pathway or Service Line |
|--|---|-------------------------|
| Pilot Site 1. A south coast of England stroke network | Stroke | Pathway |
| Pilot Site 2. Sheffield Teaching Hospitals NHS Foundation Trust | Hip Fracture | Pathway |
| Pilot Site 3. An East Anglian primary care-led consortium | COPD | Pathway |
| Pilot Site 4. Homerton University Hospital NHS Foundation Trust | COPD, Speech & Language Therapy, Surgical Rehabilitation, Sexual Health | Service line |
| Pilot Site 5. Staffordshire and Stoke-on-Trent Partnership Trust | Adult Social Care | Service line |
| Pilot site 6. Oxford Health NHS Foundation Trust | Community Mental Health Teams | Pathway |
| Pilot site 7. Nuffield Orthopaedic Centre | Musculoskeletal Triage Service | Service line |
| Case study 8. Northumbria Healthcare NHS Foundation Trust | Full service acute trust | Service line |

Different approaches to measuring patient and service user feedback of pathway and service lines were employed at each pilot site, with varying results.

1.4 Phase 3 - evaluation

The goal of phase 3 was to evaluate the success of the approaches developed and tested in phases 1 and 2. Key findings and themes to emerge include:

Local variation and national context

The baseline state regarding the work sites and their operational readiness for patient experience feedback varied. National policy and top-down changes (such as the introduction of the NHS Friends and Family Test) impacted organisations' measurement and improvement activities.

Plurality of patient experience collections

Pilot sites were already using a range of different approaches to collecting patient experience information in different formats. Examples included the use of patient stories, comment cards, and handheld devices to collect near-real time feedback.

Importance of active leadership and staff engagement

The success of pilots was somewhat dependent on the presence of 'champions' providing active local leadership. Leaders didn't have to be senior managers; involvement and enthusiasm was required from those involved in planning and administering collections at all levels.

Resourcing

The research team found without exception that there was very limited financial flexibility around patient experience in the pilot sites.

Methods

It soon became evident that it would be impossible to establish a 'one-size-fits-all' approach to measuring along pathways and service lines.

Population size influenced design including sampling and method. For pathways the size of the populations tended to be small and driven by a combinations of conditions.

The use of a generic survey instrument

The core questionnaire developed in phase one of the research was viewed positively. However, in all cases some amount of tailoring was required to ensure that specific local priorities were covered.

Usefulness of service lines and pathway approaches for service improvement

Service line approaches were easier to carry out, interpret and act upon than pathway approaches. The ability to link results to specific services and drill down into the data further was important to all pilot sites.

The pathway approach to collecting feedback was attractive to pilot sites but not always as practicable.

1.5 Conclusions

We found that there is already a very substantial level of local activity underway to obtain feedback about people's experiences in addition to national programmes. The vast majority focus on specific services rather than patient journeys. They includes a range of approaches to measurement and reporting – but there is some tension between the potential benefits of local tailoring on the one hand and standardisation on the other.

In this project we identified a simple, unified, and conceptually grounded model of patient experience and established a short questionnaire to provide a basic inventory of this. The instrument developed was both sufficient to cover the key dimensions of patient experience and malleable enough to be locally adapted where this was required.

Whilst local tailoring of the survey instrument frequently proved useful in the context of the pilot sites, it was clear that most NHS organisations have limited spare capacity to undertake this kind of work on their own. There is a trade-off, then, between the extent to which the core instrument can be tailored and the purposes for and scale at which it can be used. For

national projects focussing on providing data for performance assessment or patient choice, and thus requiring comparability across organisations, standardising on a core instrument without adaptation will generally remain the optimal approach.

The latter parts of the research looked at the feasibility and benefits of measuring people's experiences along pathways and within service lines. We found that whilst there were methodological challenges to both approaches, both were feasible: although implementing pathways approaches proved more complex. Service line measurement could be achieved as an extension of traditional survey approaches, specifically by developing the approach to selecting patients and reporting results. This generally worked well and was viewed favourably in our pilot. For pathways studies, however, we found that there was a demand for people's responses to be attributable to particular services. This perspective may change in the future as new system level policy levers, such as the Better Care Fund, require organisations to take a different approach to integrated care.

Locally, we saw evidence of growing awareness and understanding of what matters to patients – along with a corresponding expansion of activities and dedicated staffing to support work on patient experience. Nevertheless, the majority of our pilot sites had limited spare capacity with which to carry out and report studies of their own. Moreover, there are complex strategic choices to be made locally about which services and patient groups warrant more detailed investigation. These problems raised complicated questions about where and how to deploy capacity to address patient experience, and suggest a need for greater support for local users.

Mechanisms to more comprehensively capture and report evidence are only one part of the solution to raising the quality of people's experiences of care. Additional major initiatives are required in relation to education, training, and culture change. This study shows that it is possible to develop effective mechanisms to ensure services at the local level are attending to the issues that matter most to patients, but further support may be needed to ensure best use of local findings.

2 Introduction

This project is funded by the Department of Health Policy Research Programme and is jointly led by Picker Institute Europe and the University of Oxford. The principal aims of the project are to:

- Develop and evaluate a simple, conceptually grounded and unified model for assessing patient experience.
- Evaluate whether and how pathway and service line focused assessments of patients' experiences provide added value to standard organisational surveys.

2.1 Background

In the last decade measurement of patient experience has become prominent in NHS performance management and service improvement. More recently the importance of patient experience has very significantly increased due to a growing policy focus on users' outcomes and experiences.

In 2012, the National Institute for Health and Care Excellence (NICE) published the 'Quality standards for patient experience in adult NHS services'¹: this lists 14 quality standards for patient experience in generic terms. The aim of the standards are to provide commissioning guidance on the elements of a good patient experience.

The NHS Outcomes Framework 2013/14² establishes patient experience of care as one of five domains used to assess performance of the NHS both nationally and locally. In the short term a number of indicators from existing national surveys are used to monitor patient experience, but the Outcomes Framework makes clear that longer term work is needed to ensure measurement of patient experience is fit for purpose.

The Francis Inquiry report³, published in early 2013, investigates the causes of the failings in care at Mid Staffordshire NHS Foundation Trust between 2005 and 2009. The report notes that effective patient feedback is a powerful means of examining the performance of NHS organisations in terms of safety and quality. It also notes how encouraging it is to see a widening range of options being made available to the public to register their observations about the quality of care provided.

A wide range of surveys have been in use for several years to assess patients' experiences of their care. The national NHS patient survey programme has played a key role and enables the Care Quality Commission and others to build a national picture of people's experience. Since 2002 over 1.6 million patients have reported on their recent experiences of NHS care.

¹ National Institute for Health and Care Excellence. (2012). *Quality standard for patient experience in adult NHS services*. <http://publications.nice.org.uk/quality-standard-for-patient-experience-in-adult-nhs-services-qs15/introduction-and-overview>; retrieved 25th February 2014.

² Department of Health. (2012). *NHS Outcomes Framework 2013 to 2014*. <https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014>; retrieved 17th February 2014.

³ Robert Francis. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. <http://www.midstaffspublicinquiry.com/sites/default/files/report/Volume%201.pdf>; retrieved 26th February 2014.

The introduction of the Friends and Family Test (FFT) in 2013 adds another large scale patient experience data collection to the national picture. The FFT is seen by NHS England as a tool for driving improvements in patient experience and it is a key part of NHS England's business plan 'Putting Patients First'⁴. The FFT is a single question survey which asks patients whether they would recommend the NHS service they have received to friends and family who need similar treatment or care. NHS England reported in November 2013 that over one million individual pieces of feedback had been collected through the test in six months.

There are also many methods of collecting patient feedback developed for local use: for example, many NHS trusts use hand-held electronic devices to capture people's views in 'near-real-time' at the point of care.

The relevance, timeliness, and impact of this rapidly expanding range of collections of patient experience are extremely variable. A wide-ranging review conducted for the Department of Health, "What matters to patients?"⁵, argues that there is considerable convergence of understanding on what matters most to patients, but uneven success in measuring and using evidence of patient experience.

As improving patients' experiences of care is a key objective of current government policy, it is very timely to assess and try to improve arrangements for measuring patient experience, which is why this research is so relevant. Understanding whether pathway and service line approaches to collecting feedback are a viable and a useful addition to standard organisational surveys at a national level will help shape the direction of national data collections in the future.

2.2 Methods

The work has involved mixed methods: quantitative evidence via patients' responses and response rates to pilot surveys, and qualitative evidence via analyses of key actors' and audiences' views of the model and pilot surveys. The research addressed its aims through three phases of work:

- Phase 1 - Scoping
- Phase 2 - Field testing
- Phase 3 - Evaluation

2.2.1 Phase 1 – Scoping

In phase 1 we aimed to achieve an agreed definition of key domains of patient experience via literature review and synthesis, expert consultation, and exploration of the credibility of emerging domains with key stakeholders.

⁴ NHS England. (2013). *Putting Patients First: The NHS England business plan for 2013/14 – 2015/16*. <http://www.england.nhs.uk/wp-content/uploads/2013/04/ppf-1314-1516.pdf>; retrieved 25th February 2014.

⁵ Robert, G., & Cornwell, J. (2011). 'What matters to patients?'. http://www.institute.nhs.uk/images/Patient_Experience/Final%20Policy%20Report%20pdf%20doc%20january%202012.pdf; retrieved 17th February 2014.

We considered existing models of patient experience, such as the Picker Institute and Institute of Medicine frameworks, and examined the extent to which domains can be generically operationalised across a range of services or pathways. Once an agreed set of domains was confirmed, actual questionnaire items to assess domains were then agreed.

We also developed a standard questionnaire instrument for use in service–line and pathway-based surveys. Initial questionnaire design focused on the identification and/or development of items suitable for use across a range of instruments: these questions were assessed for content validity via cognitive testing with patients. A specific issue to be addressed was the extent to which common indicators can be applied across settings.

2.2.2 Phase 2 – Field testing

In phase 2 we identified contrasting and complementary service and pathway contexts in which to field test the models and key domains identified. Full testing of the survey instrument with up eight pilot sites was carried out in a range of areas.

2.2.3 Phase 3 - An assessment of impact and lessons learned.

The goal of phase 3 was to evaluate the model developed and tested in the field in phases 1 and 2, assessing the meaning, relevance, and usefulness for service improvement of the proposed model. The evaluation included discussions with and feedback from professionals involved in the piloting at each of the pilot sites.

2.3 Project management and contributors

The core research team consisted of researchers from Picker Institute Europe and University of Oxford. The team are experienced in qualitative and quantitative research, development, and thinking in patient experience, Patient Reported Outcome Measures (PROMs), and health surveys. In addition to the core research team there were three important groups of contributors:

- Collaborators
- Patient and Public Involvement (PPI) Panel
- Advisory group

2.3.1 Collaborators

A small team of collaborators provided expert advice on the project. The collaborators were four independent experts in the field of patient experience and engagement research. The collaborators, listed in alphabetical order, were:

- Jocelyn Cornwell, Director, The Point of Care Foundation. Jocelyn has held leadership roles at the Commission for Health Improvement and the King's Fund, and is co-author of the key "What Matters to Patients?" report.
- Angela Coulter, Senior Research Scientist, University of Oxford. Angela is the former chief executive of Picker Institute Europe, and is now director of global initiatives at the Foundation for Informed Medical Decision Making.
- Louise Locock, Director of Applied Research in the Health Experiences Research Group (HERG), University of Oxford. Louise specialises in qualitative interview research into people's experiences of health and illness.

- Sophie Staniszewska leads the Patient and Public Involvement (PPI) and Patient Experiences Programme at the RCN Research Institute, Warwick Medical School, University of Warwick. Sophie chairs the NICE Guidance Development group on Patient Experience.

2.3.2 Patient and public involvement (PPI) panel

Much like the collaborators, the PPI panel provided feedback during each phase of the project. Meaningful patient and public engagement was fundamental to this project and the PPI panel's input on research design and outputs from the project was vital. The involvement of patients and the public in helping create better designed projects, from design to outputs has been noted⁶.

The four representatives on the panel were specifically recruited to be involved in this project. They have been selected following their involvement in previous research conducted by the University of Oxford; the development of the Outcomes and Experience questionnaire. They were:

- Parv Aley
- Jennifer Bostock
- Milton Munroe
- Waveney Munroe

The collaborators and PPI panel were brought together at key points in the project allowing for lively discussion about the core research team's work and aims. Both groups met together with the project team and participated as equal contributors. Recommendations from the collaborators and PPI panel were taken into consideration and amends made before work has presented to the advisory group.

For further information on patient and public involvement in this project see appendix A.

2.3.3 Advisory group

The role of the advisory group was to provide advice, support, and comment on the core research team's work. The core research team met with the advisory group every 3-4 months to present and gather feedback about their work. The advisory group consisted of members from organisations such as:

- Care Quality Commission
- Department of Health
- NHS England
- NHS trusts
- National Voices
- Nursing and Care Quality Forum

⁶ Staley K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh.

3 Phase 1 – Scoping

This section of the report details research activities undertaken in phase 1. As mentioned in the introduction of this report a key aim was to evaluate whether and how pathway and service line focused assessments of patients' experiences provide added value to standard organisational surveys. To do this the research team felt it important to agree on a definition of service lines and pathways from the outset.

In addition to this the research team explored existing literature to decide upon key components of patient experience. These components would be the starting point to the development of a core questionnaire for use in evaluating patient experience at each of the pilot sites.

3.1 Service Lines

Firstly the research team explored the concept of service lines and how a service line focussed assessment of patient experience could be carried out.

The concept of 'service lines' in healthcare settings dates back to the mid-1980s and is rooted in healthcare management – particularly in acute hospital settings. In essence, service lines are specialised clinical areas with specific functional and operational remits. Typically these service lines will be allowed to act with a certain degree of autonomy – sometimes even full financial control – with the aim being to improve quality and financial performance.

In the UK, the financial regulator Monitor has championed the adoption of service line approaches to hospital management. Monitor draws a distinction between service line management (SLM) and service line reporting (SLR), two separate but related concepts. As described on Monitor's website⁷,

“Service line management (SLM) identifies specialist clinical areas and manages them as distinct operational units... Service line management uses the data from service line reporting, to develop an organisation structure and management framework within which clinicians and managers can plan service activities, set objectives and targets, monitor their service's financial and operational activity, and manage performance.”

Service line management is principally focussed on issues related to financial performance, and consequently service lines are usually defined in terms of business units. Typical service lines cover a diverse range of clinical functions: examples include pathology, dental, general surgery, and specialist medicine. Reporting lines for service lines may vary: in some cases organisations will have service lines reporting directly to the executive team, whereas in other cases – particularly larger organisations with more service lines – a divisional or directorate layer might be used to channel reporting of service lines into the executive team. These two types of organisational structure are illustrated in figures 1 and 2, below.

⁷ Monitor. (2010). *Service line management*. <http://www.monitor-nhsft.gov.uk/SLM>; retrieved 1st June 2012.

Figure 1: Illustrative organisational structure: service lines without divisional layer

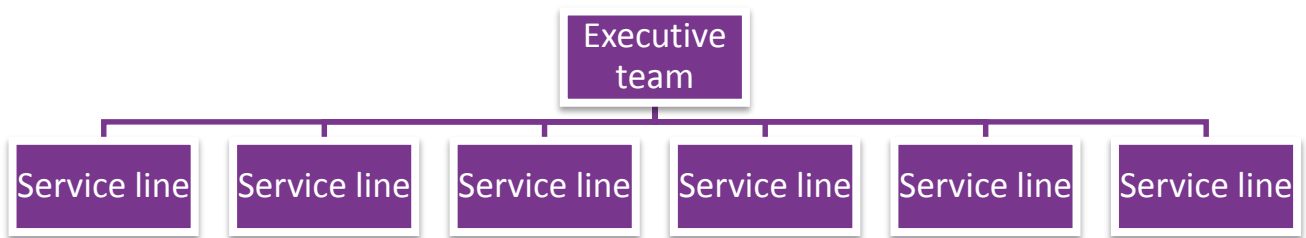
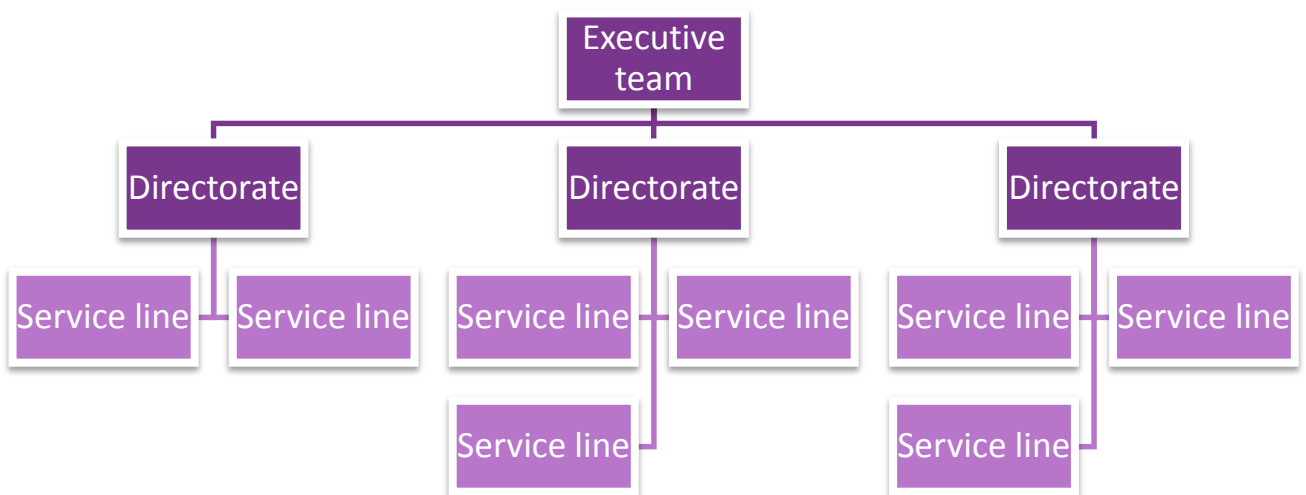


Figure 2: Illustrative organisational structure: service lines with divisional layer



3.1.1 Issues with service line approaches

Whilst service line approaches are claimed to offer “a range of benefits to trusts, clinicians, staff... patients, and... service users”⁸, they also have limitations.

- Service line management is not implemented in all trusts and, where it is, it is certainly not implemented with universal consistency. This presents a challenge, because it suggests that implementing a service line reporting approach requires local knowledge of organisational structures.
- A recent King’s Fund report notes that “SLM is designed for use within hospitals, and is not able to support the wider opportunities for quality and productivity improvements derived from looking at clinical pathways across care settings”⁹. The same report also notes that clinical interdependencies create tensions in SLM approaches: service lines are not generally entirely independent of one another.

⁸ Monitor. (2010). *Op cit*.

⁹ Foot, C., Sonola, L., Maybin, J., & Naylor, C. (2012). *Service line management: can it improve quality and efficiency?* The King’s Fund, London. http://www.kingsfund.org.uk/publications/slm_paper.html

To make a service line approach to patient experience measurement useful and meaningful to NHS organisations it is important to take these issues into account. This points to the need for an approach that is:

- Sufficiently generic that it can be applied locally without extensive remodelling to suit the local operating context.
- Still suitable for immediate adoption by organisations that have implemented SLM and/or SLR.
- Mindful of the interdependencies between care settings within organisations and across pathways.

3.1.2 Proposed approach

If we consider the outline organograms shown in figures 1 and 2, it is reasonable to say that most existing national surveys have been designed for top-down use. Data is collected at an organisational level, providing reliable estimates for board level and senior use. However, sampling approaches have not been designed to allow disaggregation of the data to service lines or directorates/divisions. Post hoc attempts to undertake such disaggregation are inevitably stymied by the overall sample size of the surveys: typically these collections aim to achieve 500 responses per organisation, which leads to dwindling within-unit sample sizes as further disaggregation is attempted.

An alternative approach – and the approach outlined here – would be to approach the problem from the bottom up. If survey samples are designed with a more granular level of reporting in mind – eg service lines – then, with sufficient coverage and with enough background information available, it will always be possible for the data to be aggregated up to higher hierarchical levels (directorates and organisations).

Although the term ‘service lines’ is used here, we are mindful of the fact that not all organisations will have implemented SLM or SLR. Consequently, we envisage a more flexible approach, where organisations could be asked to identify appropriate sub-directorate units. It is possible that a generic set of ‘labels’ could be created to be assigned to services to increase the opportunities for cross-organisational comparisons. That is, whilst organisations might name their services differently, they could be asked to classify them against a pre-defined list of generic service types. Both organisations that have and have not implemented service line approaches could select the best-match labels from a short list to enable comparisons with other organisations. Data collected could then be used for national and local reporting to provide highly precise performance assessment data and highly relevant data for local quality improvement. This information would also be of value for patients: service-line level results could be presented online as a resource to support patient choice, providing more granular evidence about the particular services that patients would use.

Whilst this approach is superficially simple, there are a number of practical challenges that need to be addressed:

- Additional organisational and patient-level data is needed. Organisations will need to be able to identify their service lines – or equivalent groupings – and patients will need to be identified as having been treated by particular service lines.

- Service lines will often have interdependencies and patients will often come into contact with more than one service. Avoiding duplication will be a challenge. Sampling based only on patients accessing a single service line would create bias as more complex cases would be excluded. Directing people to answer about a specific service is possible, but relies on people being able to identify and distinguish different services – which, perversely, may be more difficult in better integrated and more coordinated organisations.
- In most – if not all – cases this approach necessitates a larger overall sample size than for existing national surveys. It would be unrealistic to expect the approach to be cost-neutral relative to existing national surveys, which are very low cost for organisations. Increased costs will need to be borne by the service.

Investigating these issues will be a key aspect of the pilots.

3.1.3 Sectors

As noted above, service line approaches are designed for acute hospitals rather than other types of services. It is not clear to what extent the approach has found traction in community care or mental health, for example, and nor is it clear whether the approach is relevant to ambulance trusts. Nonetheless, it would be desirable for any methodology developed as part of this project to be as broadly applicable as possible – which means extending beyond the acute sector as far as is practical.

3.2 Pathways

The research team then explored the concept of pathways and how a pathway focussed assessment of patient experience could be carried out. Data collection along a pathway could be considered as providing more detailed measurement of patient experience across organisational boundaries, particularly at points of transition in care.

Care pathways come under different guises such as integrated care pathways, care maps, case management plans and clinical pathways. The research team looked at the structure and key features of various care models and a taxonomy of pathway types were identified:

- Algorithms or process systems
- Integrated services
- ‘Pathways’ as metaphor

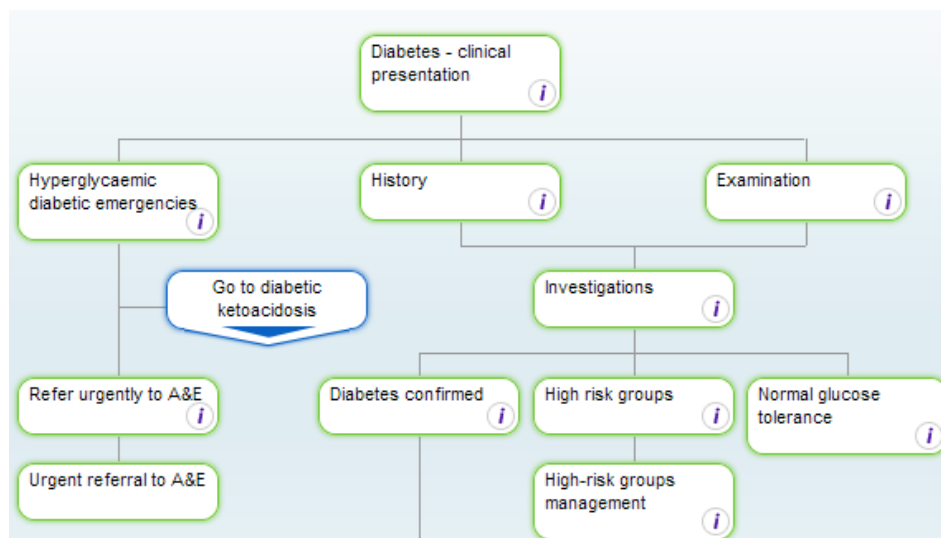
3.2.1 Algorithms or process systems

The first pathway type identified resembles an algorithm or flow chart; a set of steps that defines a sequence of events. An example of this is the Map of Medicine¹⁰ care maps. These pathways are intended to be used by healthcare professionals to determine the best treatment options for their patients. They are tools to help local health communities reduce their costs while improving the quality of healthcare delivery, goals central to the QIPP

¹⁰ Map of Medicine, 2012. *Map of Medicine*. [online] Available at: <http://www.mapofmedicine.com/> [Accessed 11 July 2012].

(Quality, Innovation, Productivity, Prevention) agenda¹¹. A segment of the Diabetes Map of Medicine can be seen in Figure 3 below.

Figure 3: Segment of the Map of Medicine: Diabetes



Algorithms or process systems are highly structured and typically they are tailored to specific ‘clinical topics’. For example, the Map of Medicine currently provides care maps for 300 ‘clinical topics’. The maps can also be customised by commissioners looking to improve pathways in their communities.

The characteristics that make algorithmic pathways suitable for clinical use also raise challenges for their use in patient experience measurement. If we consider measuring patient experience based on pathways as algorithms, developing a set of survey items tailored to individual clinical topics is not practicable. To do this would require question sets tailored to every diagnostic step or decision point in the process. This would create unnecessary burden and an excessive level of survey complexity on organisations who want to measure patient experience along each pathway. Algorithmic pathways also have a medical focus (and necessarily so) but they neglect interactions with social care services which is a limitation when exploring the integration of care. Fundamentally, this type of pathway is designed from and for a clinical perspective: attempts to view these clinical pathways from a *patient* perspective are therefore likely to be forced and unintuitive.

3.2.2 Integrated services

The second type of pathway focuses on the planned integration of services or the provision of healthcare where fragmentation between providers is minimised and where working practices are closely co-ordinated¹². Importance is placed on seamless co-ordinated care being provided to all.

¹¹ QIPP, 2012. QIPP. [online] Available at: <http://www.dh.gov.uk/health/category/policy-areas/nhs/qipp/> [Accessed 11 July 2012].

¹² Thistlethwaite, P (2008). *A practical guide to integrated working*. Integrated Care Network.

One example of an integrated care pathway can be found with Torbay Care Trust's integrated care for older people¹³. Health and social care teams' work with GPs to provide care services enabling older people to live independently in the community. One of Torbay's goals is to develop a system model of integrated care for older people across organisational boundaries. In other words, services in the area have been (re)designed to ensure the integration of related functions for a particular treatment group.

However, integration is unlikely to follow one single path and variations in models of integrated care are to be expected due to the differing needs of individual patients. A patient's journey through healthcare does not always follow a predictable sequence of events, especially with those who demonstrate complex health and social care needs and/or multiple co-morbidities.

Pathways across services also have several complexities. The need to recognise both *horizontal integration* such as the integration between community-based services (general practices, community nursing services and social services) and *vertical integration* between primary care and secondary care has been noted¹⁴. Similarly, our early work identified the concept of *macro* and *micro* level integrated care - pathways occurring not just *between* but also *within* providers – as important to understanding the function of integrated services. The presence of these 'micro' pathways suggests that there may be a false distinction between service lines and pathways: it is not clear that services will always be able to look at their own work in isolation and this needs to be taken into account when thinking about how organisations could best make use of results from evaluations of patient experience along pathways.

Because no one best model of integrated care exists, measuring people's experiences of care provided by integrated services is challenging: any measurement is likely to need tailoring to the specific local model of integration. With such a variance in models developing a measure for each would be impracticable and would not readily allow for national comparisons of experience data. Despite a high level of variance, in all models transitions between providers exist and it is the patient experience of this co-ordination of care that needs to be explored further.

3.2.3 Pathways as metaphor

The third approach is to look at pathways as a metaphor for the patient journey. This is a fundamentally different approach to understanding pathways. If pathways as algorithms are clinician-centred and pathways as integrated services are organisation-centred, then the pathway as a metaphor differs in the sense of being person-centred: it is rooted in and constructed from people's lived experiences of health and care. We recognise that patients' individual journeys are unique and viewing 'pathways' as a metaphor lets us avoid the restrictions of highly structured clinical algorithms. This allows us to take into account the more unpredictable nature of people's experiences with health and social care services.

We are also able to consider the movement of patients between and within services with more freedom; we can evaluate pathways that have a high level of co-ordinated care as well

¹³ Thistlethwaite P (2011). *Integrating health and social care in Torbay: Improving care for Mrs Smith*. London: The King's Fund.

¹⁴ Ernst & Young, RAND Europe and the University of Cambridge (2012). *National Evaluation of the Department of Health's Integrated Care Pilots*. Cambridge: RAND Corporation.

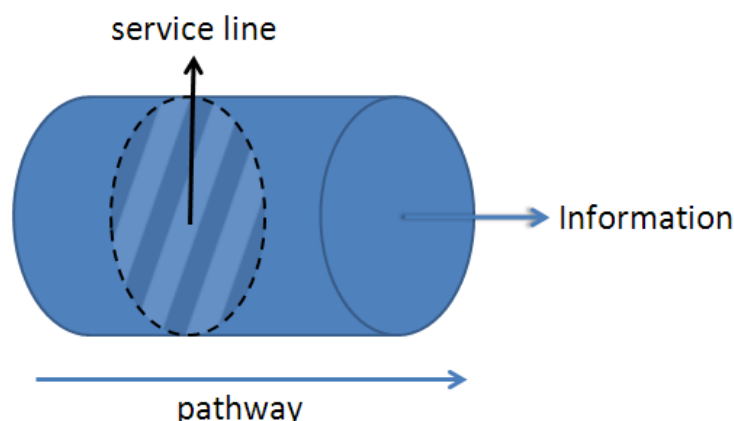
as the patient experience of services which are not so well integrated. To assess the performance of survey items and survey methodology it was important that we recruit a mix of pilot sites which operate with different degrees of integration.

3.2.4 The relationship between service lines and pathways

To help our understanding of pathways and how to measure people's experiences along pathways we needed to give consideration to their relationship with service lines. Figure 4 illustrates that pathways will involve patients accessing a range of services at different points in time/treatment. Patient's interactions with any particular provider can be seen as a cross-sectional view of the pathway and a means of assessing service lines. More information on service lines is provided in section 3.1.

The model seen in figure 4 highlights that a 'patient pathway' is about integrating information, not necessarily services: this helps us to avoid the inherent limitation of approaches based on designed systems, which is that collection of feedback needs to be highly tailored to fit those systems. This is instead a generic model with broader applicability.

Figure 4: Modelling the fit between service lines & pathways



Although figure 4 implies that service lines and pathways are somewhat distinct, one collaborator suggested that a good pathway is actually a 'service line' in itself rather than a pathway of services. This is particularly true from the patient perspective: in a sense, truly well-integrated services should appear so seamless to patients that the actual transitions in care may not be obvious. With this in mind, the idea of producing a set of question items to be used in both contexts was seen as strongly attractive.

3.2.5 Possible approaches to measuring patient experience along a pathway

Potential approaches to measuring patient experience along a pathway were identified by the research team all of which would be considered when rolling out field testing. Three key suggestions are described below:

- **Population surveys** may provide a relatively straightforward approach to identifying people on certain pathways and measuring their experiences. In this approach, patients would be identified based on their membership of a defined population: eg having a particular condition or disease (eg people who have had a stroke or who have long-term musculoskeletal conditions), or being in contact with a particular type of service (eg community mental health service users).

Where a broad population can be identified within a specific geographical area this should capture people at different stages on their 'journey' through care. Surveying a sample of these people and asking them about their experiences of a range of specified services within, say, the last year would allow us to build a picture of the care provided by these services as well as the transitions between them.

The advantage of this approach is that it should be relatively simple in cases where disease registries exist or where the presence of a condition is well recorded in patient records (for example, areas where the Quality and Outcomes Framework (QOF) incentivises strong record keeping by General Practitioner (GP) practices). This advantage is limited to certain conditions, though: others may be less comprehensively or consistently recorded, and accessing patient identifiable data from GP records may be problematic. It is also not clear that this approach would be able to fully address more complex and less common journeys (eg people entering health or social care via the police or criminal justice system).

- **'Mapping' approaches** are a more complex alternative suggested by some stakeholders in the early stages of the project. In this approach respondents would be asked to describe or map their own pathways, possibly visually. This could, for example, take the form of providing several blocks of identical, generic questions, with participants asked to list health and social care professionals or services with whom they had recently been in contact and to answer about each separately.

This is an interesting and novel approach that would provide rich information. In some ways it has parallels with patient defined outcome measures, in that patients would be directly involved in providing the structure of data collected. Whilst this arguably provides the truest way of assessing patient's perspectives on their own pathways, it presents a number of difficulties. For example, using the data for benchmarking with other organisations and at a national level would be difficult. Similarly, it would be challenging to devise an implementation of the approach that was simple and accessible enough to be used effectively by patients from a broad range of backgrounds.

- **Multiple cross-sectional provider surveys** could also be used to construct an 'information pathway' of patient experience. In this approach a range of services relevant to a particular pathway would need to be identified. Surveys of each of these services – or potentially service lines - could then be undertaken, focussing on recent users.

Although the samples would most likely involve different individual patients we could, by measuring at different points on a 'typical' pathway, build a picture of where the quality of care was strong or weak, and particularly where transitions between services might be problematic. This would require asking patients within each service about their entry to and exit from the service: ideally administrative data on their referrers and destinations could be linked to this to identify whether differences exist in the experiences of patients following different routes.

A key advantage of this approach is that it could potentially unify service line and pathway measures, and enable providers and commissioners to use an essentially standard approach to meet a broad range of needs. Whilst this would be a

parsimonious solution, it does not attempt to follow individuals' pathways in the truest sense, which may be viewed as a limitation. Furthermore, the approach is reliant on all services in a pathway participating: this could lead to gaps in the patient pathway if some services do not take part, potentially limiting the usefulness of data for commissioners.

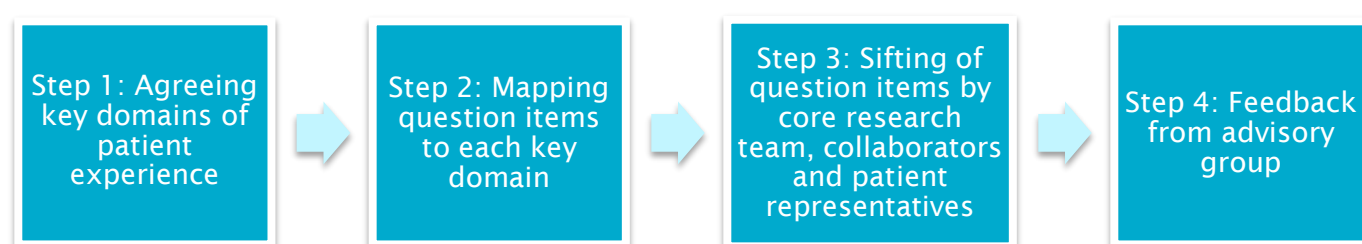
- **Longitudinal studies** could theoretically be used to track the experiences of individual patients over time, by following a fixed cohort of people and repeating asking them about their experiences of interacting with different services. This would generally be considered a powerful – if resource intensive and time consuming – approach, and would give a genuinely individualised view of patient pathways. However, such studies are complex to plan and manage – issues such as dealing with attrition, panel management, and the inevitably slow turnaround of data mean that longitudinal approaches are a realistic option for few if any front-line NHS organisations. Moreover, the limited time available for this project meant that a longitudinal approach was not feasible for use here: such approaches are therefore considered out-of-scope.

These examples illustrate the research team's initial thinking. However, as can be seen in the details from each of the pilot sites, further work was carried out with each site to fully explore a suitable methodological approach for testing.

3.3 Patient experience framework and questionnaire content

In phase 1 it was also important to agree the definitions and understanding of the key components of patient experience. The overall objective was to establish a limited set of questions, covering the core components of experience that could be used in phase 2 of the research. The process of determining the core set of questions followed four key steps, seen in Figure 5, below.

Figure 5: Steps to creating survey questions for use in phase 2.



3.3.1 Step 1: Agreeing key domains of patient experience

Firstly the research team set out to agree definitions of key domains of patient experience. Published and frequently used frameworks applied in patient experience surveys were reviewed and mapped with each other including:

- The NHS Patient Experience Framework¹⁵
- Picker: Principles of Patient Centred Care¹⁶
- NICE Patient experience in adult NHS services quality standard¹⁷
- World Health Organization: responsiveness of Health care systems (for inpatients)¹⁸
- The Senses Framework. Improving care for older people through a relationship-centred approach.¹⁹

Considerable overlap between domains, and quality statements, in many of these patient experience frameworks was evident. For example the domain ‘Respect for patient-centred values, preferences, and expressed needs’ seen in the NHS Patient Experience Framework covers a number of the NICE Patient experience in adult NHS services quality statements as can be seen in figure 6 below.

¹⁵Department of Health. (2012). NHS Patient Experience Framework. Department of Health: London. Retrieved from <https://www.gov.uk/government/publications/nhs-patient-experience-framework>.

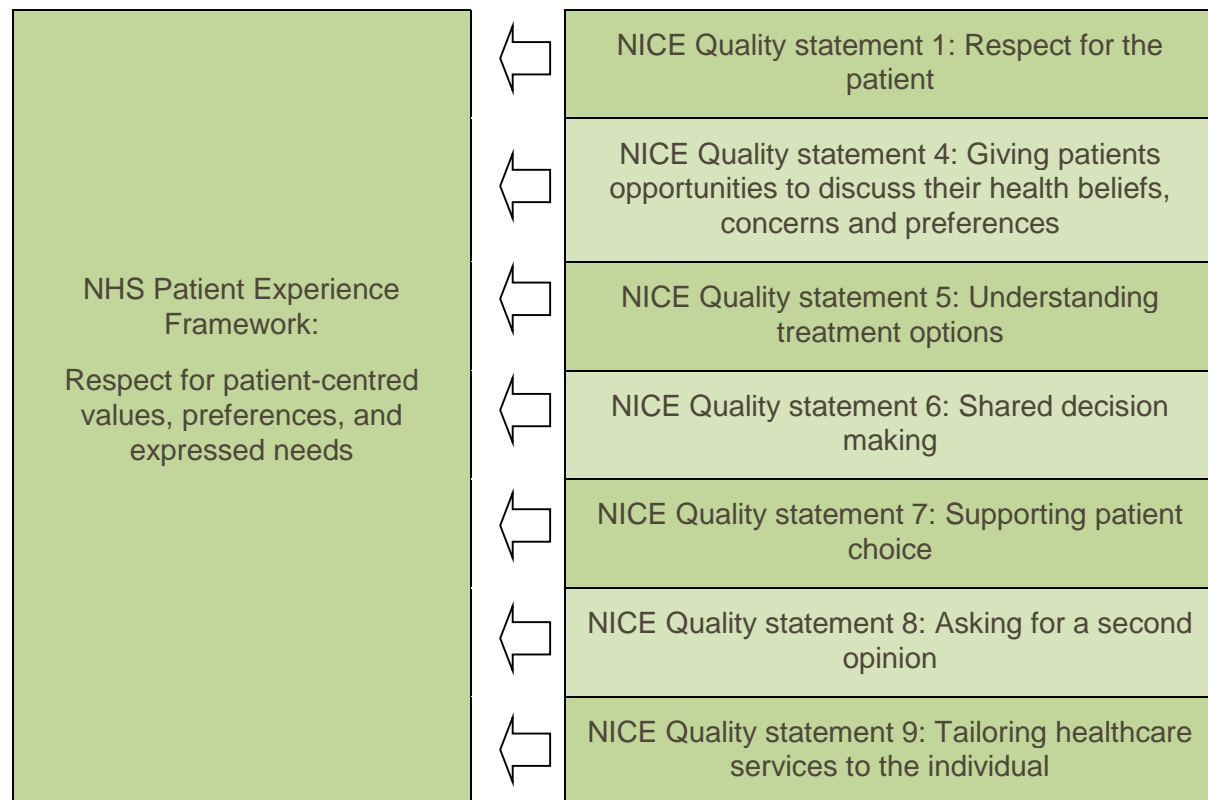
¹⁶ Picker Institute, 1987. *Picker Principles of Patient-Centered Care*. [online] Available at: <http://pickerinstitute.org/about/picker-principles/> [Accessed 03 April 2014].

¹⁷National Institute for Health and Care Excellence. (2012). *Quality standard for patient experience in adult NHS services* [online] Available at: <http://publications.nice.org.uk/quality-standard-for-patient-experience-in-adult-nhs-services-qs15> [Accessed 03 April 2014].

¹⁸ World Health Organization. (2000). *The World Health Report*. Geneva: World Health Organization.

¹⁹ Nolan, M. R., Brown, J., Davies, S., Nolan, J. and Keady, J. (2006). *The Senses Framework: improving care for older people through a relationship-centred approach. Getting Research into Practice (GRiP) Report No 2*. Project Report. University of Sheffield.

Figure 6: NICE Quality Statements mapped with 'Respect for patient-centred values, preferences, and expressed needs' domain seen in the NHS Patient Experience Framework.



The great similarity between frameworks gave us confidence that a consensus on what factors are essential for a good patient experience already exists. And with The NHS Patient Experience Framework being agreed by the National Quality Board and disseminated by the Department of Health in February 2012, the research team chose it as the defining framework for this project.

The NHS Patient Experience Framework is based on the Picker Institute's Principles of Patient-Centred Care and includes the following eight domains:

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

- **Welcoming the involvement of family and friends**, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers.
- **Transition and continuity** as regards information that will help patients care for themselves away from a clinical setting, and co-ordination, planning, and support to ease transitions.
- **Access to care** with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

This framework helps healthcare organisations to focus quality improvement efforts as it provides an evidence-based list of what matters to patients that can be used to improve the services they provide.

3.3.1.1 Effectiveness of care and patient safety

Some of the frameworks reviewed by the project team included domains which specifically addressed patient safety and effectiveness of care, areas not covered by the NHS Patient Experience Framework. For example, Ware et al (1978)²⁰ included '*technical quality of care, efficacy, and outcomes of care*' and suggested questions that directly ask patients the extent to which an intervention has helped improve their health or their direct experience of treatment. Doyle et al (2012)²¹ reported some evidence of a relationship between patients' perceptions of staff competency and trust and compliance with treatment guidelines and medicine adherence, resulting in improved outcomes. In addition the NICE patient experience quality standards for mental health specifically addresses 'safety' via quality standard 14: '*using control and restraint and compulsory treatments*'.

Improving the quality of services provided to patients is the focus of The NHS Outcomes Framework²² with patient experience, effectiveness of care and patient safety the three principles of quality outlined by Lord Darzi in the NHS Next Stage Review²³. With this in mind the research team felt it important to consider perceptions of safety and effectiveness of care when evaluating patient experience and so approached the mapping of question items with all three principles of quality in mind.

3.3.2 Step 2: Mapping question items to each key domain

We identified questionnaire items from all major NHS surveys and important other (mainly North American sources, grouping them under the main domains and sub-domains. Key for the research team was primarily the consideration of the patient experience surveys used at a national level by the NHS in the United Kingdom. These surveys are developed by organisations expert in patient experience measurement (such as Ipsos Mori and the Picker

²⁰ Ware, J., Davies-Avery, A., Stewart, A. (1978). The Measurement and Meaning of Patient Satisfaction. *Health and Medical Care Services Review*, 1:2-15

²¹ Doyle C. (2012). Experience as an Aspect of Quality. *PEPP Patient Experience Excellence Framework*

²² Department of Health. (n.d.). *NHS Outcomes Framework*. Department of Health: London. Retrieved from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122944

²³ Darzi, A. (2008). *High quality care for all: NHS next stage review final report*. London: Department of Health.

Institute) and are used by regulators such as CQC and NHS England to monitor and evaluate quality. Because of this the research team can be confident that they contain validated, tried and tested, questions.

In addition to these surveys used by the NHS the research team went on to consider those used by the Consumer Assessment of Healthcare Providers and Systems (CAHPS) programme run by the Agency for Healthcare Research and Quality in the United States. Again the research team were confident of the quality of these questions as the HCAPS programme adopts extensive testing with patients/services users.

Over thirty surveys were reviewed including those developed for different care settings and for various health conditions. See appendix B for the full list of surveys reviewed.

This mapping exercise resulted in a comprehensive database of survey items. To illustrate the scope of this exercise, over 100 items were compiled under the domain 'Information, communication and education' alone.

This exercise demonstrated that many comparable items exist across surveys – illustrating again that there are many similar priorities in patient experience across settings and conditions.

3.3.3 Step 3: Sifting of question items by core research team, collaborators and patient representatives

The core research team took this database and, with the aim of ending up with one or two questions per domain, reduced the file down to a group of thirty items. Included in this list were a number of new items, developed by the research team.

These thirty items were then independently assessed by the wider collaborative group of research experts and the Patient and public involvement (PPI) panel involved in the project. This process proved valuable with many thoughtful comments provided. Where the group were not in agreement over items or felt that an important area of patient experience was not being adequately covered, the full database of items was referred back to and the shortlist subsequently revised.

The inclusion of items to cover patient safety and effectiveness of care was discussed. The collaborators and patient representatives noted that a relationship between these and patient experience exists and agreed that items looking at patients perceptions of each of these aspects of quality should be included.

This process resulted in twelve items plus demographics that the project team, collaborators and PPI panel saw as suitable for use in assessing patient experience along a pathway or service line. These items are presented in appendix C of this document.

3.3.4 Step 4: Feedback from the advisory group

The final step to questionnaire development in phase 1 was for the advisory group to comment on the selected domains and candidate items.

The advisory group were in agreement about the use of the NHS Patient Experience Framework. They also noted that the three pillars of quality, patient experience, clinical effectiveness, and safety, should be considered alongside each other as the patients' perspective on each is important.

As a response to feedback from the advisory group a number of amendments were made to the item set. For example the importance of patients and service users being involved in decisions about their care and treatment was noted by the group and an item added to the set to cover this.

Answer options were then added to each item with the full set formatted into a core questionnaire for use in phase 2 cognitive testing. The full set of questions to be cognitively tested can be seen below. Items are grouped to correspond with the domains used in the NHS Patient Experience Framework.

Table 1: Questions to be cognitively tested in phase 2.

| |
|---|
| Respect for patient-centred values, preferences, and expressed needs |
| How much did hospital staff respond to your individual needs [<i>during your most recent hospital visit?</i>] |
| Do you feel that the service has helped you to better understand and manage your own health? |
| Information, communication and education |
| Were you given clear and understandable information about your <i>condition and treatment?</i> |
| Were you given clear and understandable information about your <i>care?</i> |
| Physical comfort |
| Did staff do everything they could to make you feel physically comfortable? |
| Welcoming the involvement of family and friends |
| Did the hospital staff offer your family the opportunity to be involved in decisions about your care and treatment? |
| Emotional support |
| Were you given the opportunity to talk about your worries and fears? |
| Overall, were you treated with kindness and understanding while you were in the hospital? |
| Coordination and integration of care across the health and social care system/ Transition and continuity |
| Did the different people treating and caring for you work well together to give you the best possible care? |
| Access to care |
| How easy did you find it to get the care you needed? |
| Outcomes and effectiveness |
| How helpful has your most recent interaction with staff/the service been in helping you deal with your condition? |
| How helpful has your care been in dealing with the problems you[came to hospital] |
| About you |
| Who was the main person or people that filled in this questionnaire? |
| Do you have any of the following long-standing conditions? |
| Does this condition(s) cause you difficulty with any of the following? |
| What is your ethnic group? |
| Are you male or female? |
| Age |

4 Phase 2 – Field testing

This section of the report details research activities carried out in phase 2. Tasks carried out in this phase were:

- Cognitive testing of the core questionnaire
- Recruitment of pilot sites
- Field testing at each pilot site

4.1 Cognitive testing of the core questionnaire

As described on page 29, a core questionnaire containing items relating to domains seen in the NHS Patient Experience Framework as well as covering perceptions of safety and effectiveness of care was developed as part of phase 1 of the research. It was important to evaluate the items included in the questionnaire with patients to ensure their meaningfulness.

4.1.1 Interview schedule

A pre-defined interview schedule, containing probes for each question, was used to guide interviews and keep to task. Interviews lasted 30-45 minutes. Participants were asked to complete the questionnaire to confirm that their understanding of the questions was as intended and therefore to demonstrate, non-statistically, the content and construct validity of items. In doing this we considered the cognitive process of responding in terms of the model described by Tourangeau (1984)²⁴, seeking to establish consistency in:

- **Comprehension** - people understand what the question is asking in a consistent way that matches the intended question.
- **Retrieval** – people are able to retrieve from memory the information necessary to evaluate their response to the question.
- **Evaluation** – people are able to use retrieved information to evaluate the question meaningfully, and do this in an unbiased manner (eg. not simply acquiescing or providing socially desirable responses).
- **Response** – people are able to match their evaluation to one of the available responses in a meaningful and appropriate way; the response selected adequately reflects the person's experience.

Within this model questions asked of participant's included:

- First impressions; length, font size, are the instructions clear?
- Does the question make sense to you? If not, what don't you understand?

²⁴ Tourangeau, R., *Cognitive sciences and survey methods*. In T. Jabine, M. Straf, J. Tanur, & R. Tourangeau (Eds.), *Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines*, pp. 73-100. Washington, DC: National Academy Press

- What do you understand by 'INSERT CONCEPT SEEN IN QUESTION'?
- Was the question difficult or easy to answer?
- Do the response options provided make sense to you?
- Are there any response options missing or redundant?

It should be noted that additional probes specific to questions were also asked for example the distinction between care and treatment in question one.

After testing the researchers made amends to items as appropriate.

4.1.2 Recruitment

Twenty members of the public were recruited and interviewed by telephone to provide feedback and gain views on the questionnaire. The specific inclusion criterion was that they had experienced health services during the last year. Table 2 below outlines participants' demographic characteristics.

Table 2. Participant characteristics (n=20)

| Characteristic | Number of participants |
|------------------------------|------------------------|
| Gender | |
| Male | 7 |
| Female | 13 |
| Age | |
| 18-24 | 1 |
| 25-34 | 3 |
| 35-44 | 1 |
| 45-54 | 9 |
| 55-64 | 2 |
| 65-74 | 3 |
| 75-84 | 1 |
| Ethnicity | |
| Black Caribbean | 2 |
| Indian | 1 |
| White British | 15 |
| Mixed/multiple ethnic groups | 1 |
| Jewish | 1 |
| Occupation | |
| Retired | 6 |
| Working | 10 |
| Student | 1 |

| Reason for hospital admission | |
|--------------------------------------|----|
| Primary care | 6 |
| Hospital inpatient-planned admission | 10 |
| Hospital inpatient- emergency | 1 |
| A&E | 2 |
| Maternity | 1 |

4.1.3 Results

As a result of cognitive testing a number of the items seen in the core questionnaire were revised. Comments from respondents and associated revisions by the research team are detailed below.

4.1.3.1 General comments on the questionnaire

Overall, interviewees considered the questionnaire to be easy to read, used comprehensible language, and was well presented with an appropriate font size and layout. Only one interviewee, one of the older participants, thought there were too many questions. One person suggested folding the A4 printed survey to A5 size to reduce postage costs.

It was considered by all that there was a need for the questionnaire to be signposted to relate to use of specific services such as a visit to their GP; planned surgery; emergency care etc. This comment was taken on board by the researchers when the questionnaires were rolled out in field testing clearly describing the experience/service respondents should focus on when answering the survey, except when in pathway approaches questions invited more general reflection across services.

Most participants could see the value of having a comments box at the end of the questionnaire. Indeed, some felt that it would be helpful to include comments boxes following each question to enable elaboration of their responses. This mainly applied to individuals who had experienced many different services following a pathway of care: elective surgery for example and on-going cancer therapy. In addition, those who had a poor experience stated they would like to have an opportunity to provide examples and suggestions for improvement.

For the core questionnaire, the addition of text boxes to accompany every question was considered but rejected. Adding these spaces would be impracticable as it would make the questionnaire very lengthy, and would be challenging to incorporate into quantitative reporting of the results. Instead the decision was made to keep one comments box in the core questionnaire and for the discussion with pilot sites to inform the insertion of any extra comments boxes.

4.1.3.2 Comments relating to specific items

4.1.3.2.1 Question 1

1. How easy did you find it to get the care you needed when you wanted it?

1 ☐ Very easy

- 2 ☐ Fairly easy
- 3 ☐ Not very easy
- 4 ☐ Difficult
- 5 ☐ Very difficult

The suggestion was made that the question could be re-worded to include mention of both treatment and care: for example, 'How easy was it to get the care and treatment you needed when you wanted it?'. The focus on both treatment and care was discussed with collaborators and patient representatives during questionnaire design in phase 2. They agreed that care and treatment were different and distinct concepts and as such the decision was made to keep the question text as seen.

4.1.3.2.2 Question 4

4. Were you given the opportunity to talk about your worries and fears?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No
- 4 ☐ I had no worries or fears

Generally this was considered a clear and relevant question. The suggestion was made to include '...with regards to your condition(s)' in the question text which the researchers felt was a good idea as it gave the question extra focus. As such the question text was amended to read 'Were you given the opportunity to talk about your worries and fears with regards to your condition?'

4.1.3.2.3 Question 5

5. Did the different people treating and caring for you work well together to give you the best possible care?

- 1 ☐ Yes, always
- 2 ☐ Yes, sometimes
- 3 ☐ No, never
- 4 ☐ Can't remember

No problems were found with the text for this item. However it was suggested that, as some people only have contact with one person, for example their GP, it would be sensible to include a 'not relevant' answer option. Consequently, a 'not relevant' answer option was added to the question.

4.1.3.2.4 Question 8

8. Did healthcare staff do everything they could to make you feel physically comfortable?

- 1 ☐ At all times
- 2 ☐ Most of the time
- 3 ☐ Some of the time
- 4 ☐ None of the time

It was felt that there was limited scope to answer this question if one had only visited their GP, but that it would be relevant for an inpatient experience. One participant suggested removing the word 'physically'. However, as this question directly relates to the patient experience domain 'physical comfort', the researchers felt it important to make no changes to the question text.

4.1.3.2.5 Question 11

11. Have services helped you to better understand and manage your own health?

- 1 ☐ Yes, definitely
- 2 ☐ Yes, to some extent
- 3 ☐ No

The majority of participants had difficulty understanding what was meant by 'services'. A suggestion was made to change the question to 'Have healthcare staff and/or services...' which the researchers accepted; consequently the question text was changed to 'Have healthcare staff and /or health services helped you to better understand and manage your own health?'

4.1.3.3 Missing items

A number of respondents detailed topic areas they would like to see added to the questionnaire. The main topics that were considered important to some of the participants were:

- Food
- Cleanliness
- Waiting times and access to healthcare
- An item relating to 'risks and benefits' and 'alternative treatments'
- An item related to 'discharge planning'.

The research team felt that these topics would be dependent on the site and services evaluated, for example food might only be relevant in a hospital setting rather than care through a GP for services at home. Such additions were discussed with each pilot site when deciding on the approach to field testing.

4.1.3.4 Finalised core question set

The final formatted core questionnaire for use with pilot sites can be seen in appendix 3. The questions, by the domains used in the NHS Patient Experience Framework, are as follows:

Table 3: Final questions for use in core questionnaire

| |
|---|
| Respect for patient-centred values, preferences, and expressed needs |
| Did healthcare staff respond to your individual needs? |
| Have health services helped you to better understand and manage your own health? |
| Information, communication and education |
| Were you given clear and understandable information about your <i>condition and treatment</i> ? |
| Were you involved as much as you wanted to be in decisions about your condition and treatment? |
| Overall, did healthcare staff keep you informed about what would happen next? |
| Physical comfort |
| Did healthcare staff do everything they could to make you feel physically comfortable? |
| Welcoming the involvement of family and friends |
| Did the healthcare staff offer your family, carers or friends the opportunity to be involved in decisions about your condition and treatment? |
| Emotional support |
| Were you given the opportunity to talk about your worries and fears with regards to your condition? |
| Overall, were you treated with kindness and understanding? |
| Coordination and integration of care across the health and social care system/ Transition and continuity |
| Did the different people treating and caring for you work well together to give you the best possible care? |
| Access to care |
| How easy did you find it to get the care you needed when you wanted it? |
| Outcomes and effectiveness |
| How helpful has your care been in dealing with the problem(s) you sought help for? |
| About you |
| Who was the main person or people that filled in this questionnaire? |
| How many times have you used NHS services in the past 6 months? |
| Do you have any of the following long-standing conditions? |
| Does this condition(s) cause you difficulty with any of the following? |
| What is your ethnic group? |
| Are you male or female? |

4.2 Pilot site recruitment

To evaluate whether and how pathway and service line focused assessments of patients' experiences provide added value to standard organisational surveys the research team needed to recruit pilot sites so that different approaches could be tested. The research team used different avenues to identify possible pilot sites:

- Own established contacts and networking.
- Recommendations from the collaborators and advisory group.
- Winners of the NHS Patient Feedback Challenge²⁵.

In addition to this, to ensure broad coverage across a number of criteria the research team used purposive maximum variation sampling to identify sites for inclusion in this project. The broad criteria used to select sites are described below:

- Inclusion of a mix of more and less predictable pathways to test the suitability of our approach to cases where there may be differing levels of variation in patients' typical journeys. For example, musculoskeletal (MSK) pathways are relatively predictable in that there are a number of common elements to the care of most individuals. Long-term neurological conditions, by way of contrast, are far less predictable and may involve a diverse range of services over a very long period of time.
- An organisation's capacity and willingness to work with us on developing the project over the course of fieldwork and evaluation. To be able to make a proper assessment of the value of our piloted approaches, access to staff at pilot sites both at early and later stages of the fieldwork was vital. This access was considered important as working with patient experience leads, clinical directors/leads & other managers was vital to understanding an organisations' service configuration, current practices and structures.
- Sites covering different sectors - including acute, tertiary, mental health, primary care, and community services – to be involved.
- Commissioning organisations should be identified and their participation sought, although not necessarily to be used as primary sampling units.
- In order to test our approach and methods with organisations at different stages in implementing and using patient experience measures, the research team looked at organisations that were already doing considerable, detailed local work as well as others who made limited use of patient experience information. Data from national surveys was used to help identify trusts undertaking less patient experience work (for example, the national inpatient survey includes a question on whether people were asked to give their views whilst in hospital: we assumed that the lowest scoring organisations were likely to be doing less independent work on patient experience). We also used information on local work conducted outside of national programmes as an indication of organisations' levels of commitment to patient experience

²⁵NHS Institute for Innovation and Improvement (2013). NHS Patient Feedback Challenge. http://www.institute.nhs.uk/images/documents/Share%20and%20network/Patient_Feedback_Challenge/Programme%20Brochure.pdf; retrieved 20th March 2014.

measurement. Recommendations on pilot sites were also sought from the collaborators and advisory group.

- A mix of urban and rural sites in different regions provided a balance between a range of factors such as age and ethnicity.

Using these criteria, the research team contacted a number of organisation's to explore the opportunity of working with them to evaluate their patients' experience of care along a pathway or service line. An information sheet (Appendix D) providing details of the research and what would be required of a pilot site was provided to all contacted organisations. Those who expressed an interest in taking part were then contacted by phone to discuss further.

As a result seven pilot sites were recruited by the research team. In addition to these we include a case study focussing on patient experience data collection activities carried out at Northumbria Healthcare NHS Foundation Trust. The research team had approached Northumbria Healthcare NHS Foundation Trust to become a pilot site and although they were keen to participate this ultimately did not prove feasible given the respective timetables and requirements of the project and the trust. They were, however, keen to share their experiences of carrying out different approaches to collecting patient and service user feedback, and the research team considered that the trust's own work provides a useful and informative addition to evidence from the pilot sites we worked with. Their experiences are therefore presented as a further case study in section 12.

Details of each site can be seen in Table 4.

Table 4: Pilot sites recruited

| Site | Condition of focus | Pathway or Service Line | Method |
|--|--|-------------------------|--|
| Pilot Site 1. A south coast of England stroke network | Stroke | Pathway | Paper-based mail out. Three sample groups. |
| Pilot Site 2. Sheffield Teaching Hospitals NHS Foundation Trust | Hip Fracture | Pathway | Paper-based mail out and hand out. Four sample groups. |
| Pilot Site 3. An East Anglian primary care-led consortium | COPD | Pathway | Paper-based mail out. One sample group. |
| Pilot Site 4. Homerton University Hospital NHS Foundation Trust | Four service lines (COPD, Speech & Language Therapy, Surgical Rehabilitation, Sexual Health) | Service line | Paper-based hand out. Four sample groups |
| Pilot Site 5. Staffordshire and Stoke-on-Trent NHS Partnership Trust | Adult Social Care | Service line | Paper-based mail out. Two sample groups |
| Pilot site 6. Oxford Health NHS Foundation Trust | Community Mental Health Teams | Pathway | Paper-based mail out. |

| | | | |
|---|--------------------------------|--------------|---------------------------------|
| Pilot site 7. Nuffield Orthopaedic Centre | Musculoskeletal Triage Service | Service Line | Paper-based hand out in clinic. |
| Case Study 8. Northumbria Healthcare NHS Foundation Trust | Full service acute trust | Service Line | Variety of approaches taken. |

Once signed-up the approach to gathering feedback was co-designed with each participating pilot site and broadly followed the process seen in Figure 6 below.

Figure 6: Design process with each pilot site



Our work with each pilot site is presented in this report separately and structured as follows:

- **Context / background.** This section provides details on organisational structure, current arrangements for collecting patient/service user feedback and information on the services or pathways of focus. Details of the project team at each site are also provided.
- **Planning.** This section covers the planning of the approach to data collection including discussion of methods, sampling and questionnaire content.
- **Delivery / implementation.** We cover survey administration, including response rates, and look at costs and economic considerations.
- **Reporting.** Here we look at respondent profile, key results, and the use of 'freetext' comments.
- **Dissemination.** In this section we look at the success of the approach, action planning and what the pilot sites plan to do next.

5 South Coast Stroke services

5.1 Context / background

This research site was a collaboration with Dorset HealthCare University NHS Foundation Trust, The Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust, Dorset County Hospital NHS Foundation Trust and Poole Hospital NHS Foundation Trust. The project was carried out with support and leadership from Dorset Stroke Network (subsequently Dorset Clinical Commissioning Group).

The survey focused on patients who were six months post discharge from hospital following a stroke and represents a pathway approach to patient experience collection, taking account of their experiences across all services received after discharge.

5.1.1 Structure

Services provided by Dorset HealthCare Trust for stroke patients can be given at day hospitals, clinics, or at home. Specialist staff include physiotherapists, occupational therapists, speech and language therapists, stroke specialist nurses as examples. Care for patients is also in some cases provided by social care and voluntary organisations.

The three acute trusts serve local populations but also have a large number of patients admitted who are holiday makers from outside of the area. Within the hospitals there are specialist stroke services.

5.1.2 Current arrangements for patient feedback and action planning at the trust (as of April 2013)

5.1.2.1 Acute services

Since June 2009 all three acute stroke units in Dorset have been using easy-read patient and carer feedback forms. Data are collected four weeks post discharge from the Stroke unit. There are currently around 500 patients discharged per year. Feedback forms are sent out to every patient and carer after patients are discharged, with an explanatory letter and a pre-paid return envelope. The feedback is collated and analysed monthly. Feedback is discussed at team meetings where necessary changes are agreed. “You Said – We Did” flyers/posters are used to provide feedback to patients, carers and staff on the ward.

Data collected include age and gender as well as 17 items focusing on admission, care on the Stroke Unit, rehabilitation in hospital, plans for leaving hospital and an overall rating. There are freetext boxes for each question. Staff feel the textual data is more informative for service improvement than the results from the closed questions.

The questionnaires used by the service were reviewed by Bournemouth University who provided advice on question setting, layout, response options etc. There are plans for further psychometric evaluation. In addition to information provided from responses informing service-improvement, data incorporate questions to provide feedback on a number of quality markers within the National Stroke Strategy (2007).

5.1.2.2 Dorset HealthCare University NHS Foundation Trust

Patient Experience data is collected at community hospitals using handheld tablets including CQUIN items and the Friends and Family Test. This information is not stroke specific.

5.1.2.3 Other

Other patient experience feedback initiatives have been conducted on specific projects such as:

- Early Supported Discharge Pilot Project
- Dorset Improving Psychological Support after Stroke (DIPSS) in the community

The development of patient experience feedback on community services was explored but several challenges prohibited implementation:

- The feedback loop was not clearly defined across providers.
- Several providers are involved in care in the community and each patient access these based on need. Examples are different trusts, social services and voluntary sector.
- Different IT systems are in place across trusts which complicates data collection and sharing
- Challenges of data sharing and confidentiality were also raised.

5.1.3 Project team

The project team for the current research was led by an Engagement and Communication Lead from NHS Dorset Clinical Commissioning Group and Dorset Stroke Network. Other members included:

- Consultant Stroke Physician
- Community Services Manager & Community Lead for Stroke
- Patient Experience and Customer Services Manager
- Consultant Therapist
- Speech and Language therapist
- Stroke specialist nurses
- Local authority representatives
- Voluntary organisations representatives

Other staff were consulted during specific phases of the project while the Stroke Service Delivery Group who approved the project were consulted throughout the pilot. The Patient Participation Group (Cardiovascular Patient and Carer Representatives Panel) was also informed about the study and provided comments on material for fieldwork.

Administrative support was provided by staff at the acute trusts.

5.2 Planning

5.2.1 Agreeing the approach

The following points were raised and discussed at the initial meeting between members of the research team and site staff:

- Stroke patients do not all follow the same pathway of care. Some patients are discharged home with access to community services as required (rehabilitation, speech therapy etc) or end of life care; some have Early Supported Discharge with support provided by the voluntary sector for approximately 2 weeks; some transferred to community hospitals. The challenge would be to identify methods and processes of feedback to different providers.
- Challenges of collecting feedback via a survey for people with cognitive and memory problems for recall of information.
- Sentinel Stroke National Audit Programme (SSNAP) audit. The clinical component of SSNAP was due to begin in December 2012 when SSNAP would prospectively collect a minimum dataset for every stroke patient. This core dataset would initially cover acute care including rehabilitation and early follow-up, and would collect outcome measures. It was likely that patient experience would be included in the outcome dataset. There was a risk therefore of overburdening patients.

The possibility of collecting Patient Experience data at the six months review (as above and also within the pan-Dorset model) was discussed. Data collection at the 6 month review was considered but it was thought that results may be inflated due to acquiescence bias if it was too closely linked to the 6 month review itself. It was therefore suggested that the questionnaire could be mailed to the patient with the appointment letter. The questionnaire would need to signpost patients to the care they have received across all services and since their stroke.

A pathway approach was considered to be an innovative methodology.

Through discussion with the pilot site it was agreed that a paper-based survey mailed out to patients home addresses would be the most appropriate method. The Easy Read format was preferred; it aligned with current surveys in the trust and had been evaluated with patients.

5.2.1.1 Use of personalised letters

Staff were very keen to adopt a more personal approach by inserting patients' names in the covering letter. There was strong preference for individualised, personal letters with electronic signatures of the consultant stroke physician from each trust, which was intended to help maximise response rates.

5.2.1.2 Use of staff and patient information sheets

It was considered important to inform staff of the project and a staff information sheet was developed and disseminated to staff via the Stroke Service Delivery Group and by key project stakeholders. Patient Information posters were provided and displayed on the wards at the acute hospitals.

5.2.2 Sampling

Patients were selected from discharge records at the acute trusts in monthly waves to obtain a sample size of n=600. Designated staff at the acute trusts selected patients eligible from electronic records, checking for deceased patients, patients living out of the area and those transferred to nursing homes. Packs were then mailed with personalised letters to remaining eligible patients. Reminders were sent to non-responders after four weeks by staff at the trusts.

5.2.3 Questionnaire content

The questionnaire used for the survey was the core instrument but with modifications suggested by staff from the trusts. Specifically, the survey was modified to include additional items relevant to stroke patients and services they may access. It was formatted in an easyread style to be consistent with other surveys used in the trusts. Extensive input was given by Speech and Language Therapist at Poole Hospital and other staff members involved in the project. The questionnaire made use of illustrative pictures as can be seen in the snapshot below:

| | | | |
|---|---|---|---|
|  |  |  |  |
| Yes, definitely | Yes, to some extent | No | I was offered information but chose not to take it |
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |

There was concern expressed as to how specific services would be identified for improvement if patients had received multiple services. The use of the text in the comments box asking patients to identify anything that was particularly good or bad was intended to help capture differential responses to different services. It was acknowledged to be a challenge when evaluating patients' experiences along a pathway of care; the survey would be ambitious in attempting to elicit diverse experiences across the whole of the patient journey. It was agreed that implementing several service-specific surveys was not feasible. A list of different services was included at the beginning of the survey.

Currently, not all patients receive a formal six months review as specified in the National Stroke Strategy and measured in the SSNAP audit but some people do have a review from a Stroke Coordinator or Specialist Stroke Practitioner. This may be in the form of a telephone discussion. An additional response option was included for patients who were unsure if they had received such a review. It was thought that the survey would be a useful baseline for pre-implementation of the county-wide six months review service.

5.3 Delivery / implementation

5.3.1 Administration

A total of n=682 patients were eligible for inclusion in the study based on patients discharged during fieldwork. Bournemouth had twice as many patients discharged per month and eligible for inclusion (n=108) than Dorchester (n=56) and Poole (n=61). Following exclusion of deceased people, patients moving out of area, and those transferred to nursing homes, n=475 patients were posted the survey from June to December 2013. The response rates from the first mailing overall (all trusts) was 34%; this was consistent with reported response rates for the trust's inpatient survey. Reminders to non-responders increased the response rate to 48%.

Table 5: Response rates

| Step | Response rate |
|-------------|---------------|
| Bournemouth | 104 (42%) |
| Dorset | 55 (54%) |
| Poole | 71 (54%) |
| Total | 230 (48%) |

5.3.2 Costs and economic considerations

It was noted that identifying and screening patients and practical aspects of posting surveys was labour intensive. Payment for staff at the trusts to carry out administrative tasks was agreed. In addition to this, there were costs related to the printing, packing, posting and data entry. These can be seen in the table below:

Table 6: Fieldwork costs

| Fieldwork activity | Cost |
|--------------------------------------|-----------------|
| Printing and packing | £1549.00 |
| Delivery of questionnaires to trusts | £40.75 |
| Postage for mailing | £580.00 |
| Data entry | £501.30 |
| Administrative support (all trusts) | £640.01 |
| Total | £3311.06 |

5.4 Reporting

A report was generated and covered:

- Overall patient characteristics
- Patient characteristics per trust
- Number of services accessed
- Response rates
- Responses to survey items. Charts detailing overall responses and comparative trust results
- Data was also presented comparing patients experiences based on whether they had Early Supported Discharge or not and furthermore, comparing experiences and number of services accessed. Data was presented separately for patients receiving less than 5 services compared to those receiving 5 or more services.

5.4.1 Key results

Generally responses to questions were very encouraging. There was a very slight trend of less favourable patient's responses from Dorchester patients. However, this may be inflated

by a larger number of patients not replying to questions (>10%), compared to other trusts. Over 60% of patients who received a six month review found it helpful, very or extremely helpful.

Global ratings of stroke care since leaving hospital were positive; 19% reported poor or very poor experiences.

Patients receiving early supported discharge had a slightly better experience of care compared to those who did not (81% vs. 73%). 31% of patients receiving more than 6 services (n=39) reported poor care compared to only 10% who accessed less than 5 services. This is based on the patient's responses on item 'Overall how you would rate your experience of your stroke care since leaving hospital'.

5.4.2 Free text comments

Both quantitative and qualitative results were considered to be informative although, free text more interesting.

5.4.2.1 All trusts

There were many encouraging comments from patients reporting excellent care from specific individuals and healthcare professionals- physiotherapists, nurse, consultants, speech and language therapists, occupational therapists (OTs). Several Bournemouth patients reported excellent and valuable help and care from the Early Supported Discharge team. Staff were referred to as professional, trusting, and care and support given to be very helpful for their recovery and improvement of health.

5.4.2.2 Bournemouth

Specific comments related to the need for more information about having a stroke but presented in summary and stages; patients reported that it was very difficult to retain information. There were some reports that their discharge seemed to be rushed; there was a lack of practical help for incontinence for example; more follow-up needed; disjointed treatment, and in one case a perceived lack of rehabilitation.

5.4.2.3 Dorchester

Patients reported a lack of physiotherapy and continuation of OT, no follow-up and/or coordination of care, a need for more information on their condition.

5.4.2.4 Poole

The main comments were related to not knowing how to access services and waiting times too long to receive services, too early discharge from hospital and a preference for seeing the same person.

5.5 Dissemination

5.5.1 Success of the method

5.5.1.1 Response rate

Staff were generally pleased with the response rates and noted that the response rate was slightly higher than the local inpatient survey. However, the current survey, unlike their usual survey, sent reminders to non-responders. The personalised approach to covering letters, using individual's names and staff signatures was also thought to be a positive influence on responses.

5.5.1.2 Patient experiences

Limitations of the questionnaire were highlighted. The question related to whether patients had a carer or not could have been clearer to enable identification of those patients with paid, formal carers. It was difficult from responses to identify those who were receiving informal care from relatives and those with formal carers. This item was included in the 'services accessed' section. Although patients indicated which services they had accessed, it wasn't clear whether any specific services provided a better or worse experience for patients. It was noted that there were several positive comments in the free text section of the survey about Early Supported Discharge services, mainly from Bournemouth. This was not a surprise to staff and corroborated results from Early Supported Discharge evaluations of patients' experiences in the trust.

Although there was enthusiasm for using the questionnaire again, there was still a feeling that free text, qualitative comments were useful and informative specifically for service improvement. One approach which was used at Poole, was to code the qualitative text using the NICE Patient Experience Quality Standards as a framework. Staff reported that this was carried out during analysis of any patient feedback and cross referred to the local inpatient survey, real-time feedback, PALs and complaints. This then underpinned Customer Service awards at the trust where staff were rewarded for good patient experience.

5.5.2 Friends and Family Test (FFT)

Although the survey included in this pilot did not include the FFT there was much support for its implementation in the future. Perceptions were different at the beginning of the project; staff did not see the relevance for community services and highlighted the challenges of interpretation as patients may receive several services.

It was thought that the FFT was meaningful but only in the context of other data. It was considered to be a powerful tool and could be linked to Customer Services awards at the trusts. It was stated that the FFT was the 'sound voice of the patient'.

5.6 Action planning

Staff involved in the management of patient experience collections provided thoughtful reflections in discussion of the results of the survey and future strategy at the trusts. Patient experience data are incorporated into the trust's Quality report and linked to safety data. It was felt that assessing patient experience at the six month review had proved fruitful and was likely to be the focus of further monitoring by the Clinical Commissioning Group (CCG). There was discussion about the challenges of collecting feedback from patients in terms of safety and confidentiality. This was specifically for patients providing feedback about personal care; often patients were frightened, vulnerable and grateful for care. This may impact on the accuracy of feedback.

The importance of drilling down through results for service improvement was highlighted, especially in terms of enabling staff to understand and engage positively with granular feedback. Staff often felt threatened about such feedback if it is negative.

Staff reported that the attitude to patient feedback was changing. It was no longer just related to achieving better results but about the meaning of the results. There was a feeling that there needed to be a culture change where staff were not afraid of negative feedback.

5.6.1 Commissioning

It was reported that local Commissioners require providers to carry out Patient Experience collections and provide the resources to do it. This will be part of the annual cycle of contracting. It was noted that following the Stroke Strategy (DH 2007/8) Patient Experience collection was established with high level support from the PCT (now Clinical Commissioning Group)s within Dorset Stroke Network. There were dedicated staff in place to promote engagement and delivery.

5.7 Sharing of results and what next

NHS Dorset Clinical Commissioning Group: Stroke Service Delivery Group (SDG)

The study was presented to the SDG by a researcher at Oxford University. The group comprised of clinical commissioners, GP lead for cardiovascular services, pharmacists, clinicians and managers. There were also patient and carer representatives and voluntary sector membership. Only two members present at the meeting had been involved in the research project team.

The group had been informed about the study and had formally given permissions at the beginning of the project. The group were given a copy of the report prior to the meeting.

Generally views of the value of the survey and process were similar to the feedback from the evaluation meeting with the research project team. It was thought to be timely in light of current patient experience related policy. The approach extended the current collections of feedback from patients and complemented existing surveys such as the inpatient survey and ongoing specific service focused surveys (ESD, TIA service).

The results were considered interesting and encouraging. However it was noted that although there were generally positive responses to the survey items, these were not all in the highest categories. Furthermore, it was noted that there were some reports of poor care and that this was of more concern.

Further thought and discussion focused on the need for drilling down the data to specific services. It was not clear from the results whether a patient's overall experience was influenced by good or poor experience with a particular service. Furthermore, linking the qualitative comments to quantitative responses at an individual level was thought to be of value. For example, one person had expressed in the free text section of the survey that they thought their discharge was 'rushed'. The group were interested if this person had received ESD despite several positive comments from other patients who had received the service.

It was noted that some patients had provided free text comments about their inpatient experience, some reporting poor care. Again, the group were interested whether these individuals also reported poor care from services since discharge and whether their poor experience in hospital influenced their responses to the study survey.

Considerable importance was reflected in discussions about stroke patient's psychological well-being following a stroke and the length of time to adapt to their life changing illness. This was reported to be dependent on the severity of stroke as well as whether they received appropriate support services and psychological interventions. These factors were thought to impact on their perceptions and experiences of care and services and potential

responses to survey items. Although this level of detail is challenging to extract from the data, the group were interested if this might bias responses in other conditions evaluated in the pilot sites.

Interest was expressed related to capturing patients' experiences of integration and reference made to the 'Better together' programme. This was specifically related to those patients receiving six or more services. The group were informed about current 'Integrated care indicator' development.

It was agreed that the results were useful as a baseline and it would be valuable to repeat the survey in its current format once Intellectual Property arrangements had been agreed. It was noted that despite generally positive responses, staff should not be complacent.

There was willingness to repeat the survey but with added emphasis on finding methods to drill down to experiences of specific services.

Staff expressed interest in sharing success and learning with other pilot sites in the study. This was considered to be valuable for joint learning and networking in the future.

6 Sheffield Teaching Hospitals NHS Foundation Trust

6.1 Context / background

Sheffield Teaching Hospitals NHS Foundation Trust is a large trust with over 15,000 staff. The trust operates five hospitals and since April 2011 has integrated community health services such as community nursing and health visiting. The trust wanted to collect data on the experiences of patients on their hip fracture pathway.

6.1.1 Structure

The clinical services at Sheffield Teaching Hospital are split into nine care groups, each headed by at least one Clinical Director. The nine care groups are:

- Community Services
- Diagnostic and Therapeutic Services
- Emergency Care
- Head and Neck Services
- Obstetrics, Gynaecology and Neonatology
- Operating Services Critical Care, Anaesthesia,
- South Yorkshire Regional Services
- Specialised Cancer, Medicine and Rehabilitation
- Surgical Services

6.1.2 Current arrangements for patient feedback at the trust (as of April 2013)

The trust participates in the Care Quality Commission's (CQC's) NHS national patient survey programme, and uses data from the surveys for performance management and service improvement locally. Outside of the national patient survey programme, the trust undertakes two approaches to collecting patient experience data:

- **Approach 1: 'Frequent feedback'.** Frequent feedback is carried out using PDAs ('Personal Digital Assistants'; hand held devices) with data collected for approximately 250 patients per month. The frequent feedback surveys were developed using questions from national patient surveys. In wards where high proportions of patients have dementia or are non-communicative, volunteers aim to conduct surveys during visiting hours so that carers or friends of patients can respond on their behalves.
- **Approach 2: Comments cards.** Comments cards are filled in by approximately 80 patients per month. The comments cards include a simple rating question, and results were bimodally distributed with responses of 'very good' and 'poor' most common. The trust moved to using volunteers to actively hand out comment cards in a bid to increase the number of responses: this saw the distribution of responses shift to a more normal distribution with 'poor' the least common response. The research team suggested that

this change might be due to patients being reluctant to criticise their care when approached by volunteers; it was also suggested that the change from a self-selecting sample to inviting patients to respond may be responsible.

At Beech Hill (the community rehabilitation unit) specifically, near real-time surveys are conducted regularly and results fed back to staff on a quarterly basis.

For both frequent feedback and comments cards reporting is carried out at trust, directorate, and ward level. Results are reported monthly to the patient experience committee and quarterly to the board. Results are reported at ward and directorate level quarterly. As in the acute settings, proxy respondents are used when patients are unable to answer for themselves.

6.1.3 Current arrangements for action planning and quality improvement (as of April 2013)

The trust have an action planning process in place, and formal action plans are required annually. Trust-wide data is reported to the trust's patient experience committee on a monthly basis, and to the trust's board on a quarterly basis. The patient experience committee is chaired by the deputy chief nurse and includes the trust's medical director, nurse directors, and representatives from Sheffield LiNK (Local Improvement Network).

Additionally, data is reported back to wards on a 'continuous' basis. A standardised action planning approach has been put in place, which includes an annual review for each ward by the patient experience team. Each ward is asked to identify at least three improvements based on patient experience information, which the patient experience team follows up after three to six months.

The community rehabilitation services, which are relatively new to the trust indicated having their own approach to action planning. This involved action planning for each unit, with regular reviews. The trust felt that this worked well.

The trust indicated that there can be a number of barriers to using data to improve services, such as staff lacking time and understanding regarding action planning. The size of the trust (15,000 plus staff) also proved a challenge with a lack of "passion and ownership" regarding patient experience in some areas.

6.1.4 Project team

The staff involved in this project from Sheffield Teaching Hospital were:

- Head of Patient Partnership
- Consultant geriatrician
- Hip Fracture Nurse
- Therapy Lead
- Matron, Beech Hill Community Rehabilitation Unit

The roles represented by the project staff gave good coverage of the hip fracture pathway and allowed for a comprehensive discussion about the important elements of the pathway to

focus on. The involvement of the Head of Patient Partnership was key to ensuring that the approach complemented other patient experience collections underway at the trust.

6.1.5 The Hip Fracture Pathway at Sheffield Teaching Hospitals NHS Foundation Trust

The majority of the patients on the Hip Fracture Pathway are admitted as emergency patients (a very small proportion are inpatient falls). They are transferred to A&E via ambulance and move on to the surgical assessment unit under orthopaedic surgeons once hip fracture is confirmed. They are then seen by the orthopaedic doctors, anaesthetists, and ortho-geriatricians, and are taken to theatre for operation. They then go to the Acute orthopaedic wards (Huntsman 6 and Huntsman 7) or (post-operative surgical unit (POSU)) if they are medically unwell and need level 2 care. The physiotherapists and occupational therapists see them 24-72 hours after their operation. They remain under the orthopaedic care for 48 hours after surgery and are then transferred to Ortho-geriatric care.

Some of the patients are discharged back to care homes or use early supported discharges (community intermediate care service (CICS) or home care) from these acute orthopaedic wards. However, the majority of the patients move on to a dedicated multi-disciplinary hip fracture ward, Vickers 4, where they stay for an average of seven to 21 days.

The discharge service options are either a move to a permanent care home or discharged home with either none or community (CICS) or social care services. A few of these patients are also discharged to offsite rehabilitation units (either Pexton or Beech Hill) if they need an additional three to four weeks of rehabilitation and have no acute medical needs needing an acute hospital bed. From these units again either they go home with or without CICS and social services or are discharged to permanent care homes. Around 4-10% of the patients die during their in-hospital admission due to their medical comorbidities.

6.2 Planning

6.2.1 Agreeing the approach

A project start up meeting with the team from Sheffield was held where discussion focused on the different approaches that could be taken for data collection; a single, retrospective cross-sectional survey, a longitudinal study, or using several independent cross-sectional surveys at different stages on the pathway.

The Head of Patient Partnership noted that a pathway approach to data collection would be new to the trust, although something they had wanted to do for a number of years. The trust had considered undertaking a longitudinal approach to measuring patient experience before but it was ruled out as being impractical.

The team discussed the use of a single retrospective cross sectional survey with one member of the research team raising an important point about recall: *'I see everyone [hip fracture patients] pre & post operatively: sometimes they don't remember what's happened at previous stages'*. This suggested that a complex retrospective survey would be impractical for at least a proportion of hip fracture patients. For example those at the services at home stage might not be able to adequately recall their experience as an inpatient.

The use of several independent cross-sectional surveys was then considered and was quickly established as the preferred approach. The research team felt that this would be less burdensome for patients, and that it would address “hot spots” along the care pathway. Key to this was the ability to capture the different experiences at different points in time. The project team noted that looking at individual services or service lines in isolation does not always tell you everything you need to know about people’s experiences along pathways.

With the decision to take a pathway approach to data collection made, the team agreed on the key stages in the pathway that they would like to receive feedback on. These stages were:

- Acute step 1: acute orthopaedic ward (Huntsman 6 & 7).
- Acute step 2: multi-disciplinary hip fracture ward (Vickers 4).
- Community Rehabilitation Unit (Beech Hill & Pexton).
- Services at home: early supported discharge (CICS).

Other services were considered but deemed less practical to cover. In particular, A&E was discussed but there was concern that patients would be in too much pain and distress at the point of care, and that recall would be too difficult retrospectively. Ambulance services were also considered but similar practical problems were raised and the trust felt that this might overcomplicate the approach.

After the four stages were agreed upon we then discussed the approach to surveying and sampling.

6.2.2 Method used for data collection

When the planning for the hip fracture survey was taking place the trust had an embedded near-real time feedback approach to data collection. A volunteer workforce used handheld devices to collect feedback from patients about their experiences. Initially the intention had been to use handheld devices to collect feedback during the first two steps of the pathway (the community rehabilitation unit as mentioned above was yet to roll out the use of handheld devices for gathering patient feedback, whilst step 4 involved contacting patients after they left hospital meaning the use of handheld devices was not feasible).

This method of collecting patient feedback was highly dependent on the availability of Sheffield’s volunteer workforce. With the introduction of the Friends and Family Test from 1st April 2013, however, this became impractical. With volunteers administering the Friends and Family Test, volunteer resource at the trust was at its capacity and we were unable to utilise the handheld devices for this project. The use of bedside televisions was considered as a possible alternative, but was quickly dismissed as these were not currently used by Sheffield for the collection of any feedback.

The project team therefore decided upon the use of paper-based surveys for each stage of the pathway. The project team at Sheffield commented:

“It will be sensible to have this paper pilot and see what the challenges of doing the survey are.”

The first three stages of the pathway adopted a hand-out approach with members of the research team distributing questionnaires to patients still in acute care or community

rehabilitation. Patients filled in the questionnaire with staff collecting the forms back in at a later date. For the fourth stage the questionnaires were sent out in the post to patients. Patients posted the questionnaires back in a freepost envelope.

6.2.3 Sampling

Once the method was agreed we then discussed the volume of patients moving through the pathway to determine the size of the sample to survey. The research team spoke about the length of time of fieldwork and how many patients we would be able to approach.

The research team indicated that they have around 550-600 hip fracture patients coming in a year to A&E (approximately 45-50/month). Around 50% of these patients return home with 30% of the total number of patients having an early supported discharge (CICS). 10-15% go to Intermediate care rehabilitation unit. 12-15% go to nursing home care; and 5-9% go back to their residential care.

With these numbers in mind the team thought that 30 patients at each step would be a realistic number to aim for.

The project team indicated that good records are kept for patients and that they are maintained in real time so the trust can easily locate hip fracture patients and identify the wards that they have previously stayed on. These records meant that we could avoid repeatedly surveying the same people within the same wards or indeed at different stages of the pathway.

6.2.4 Questionnaire content

To cater for the different needs and wants of each stage of the hip fracture pathway, slightly different questionnaires had to be designed. Through discussions with the project team it became apparent that the core questionnaire alone could not cover all the issues relevant to the pathway. For example, at the 'services at home' stage important elements of care such as provision of equipment needed to be addressed.

The core questionnaire was first circulated to the project team who were asked to review the content and suggest further topic areas they would like to see covered. The project team reviewed the questionnaire and came back with key topic areas for each stage:

Pathway step 1 - Acute hospital journey - this involves A&E, surgeons, anaesthetists, surgical experience, nursing care, pain management, hospital food, cleanliness, dignity, privacy, information and involvement, waiting times.

Pathway step 2 - Rehabilitation journey - this involves rehabilitation, hospital food, cleanliness, nursing care, dignity, privacy, information and involvement, waiting time, transition of care, involvement of family.

Pathway step 3 - rehabilitation in the community – this involves waiting times, coordination of discharge planning services, rehabilitation, nursing care, dignity, hospital food, cleanliness, involvement of family, information and involvement.

Pathway step 4 - services at home - this involves the 'leaving journey experience', medicines management, help from community therapists, district nurses, GPs, handover of

medical information, equipment and support, managing long term health issues, dignity, involvement of family, information and involvement.

The topic areas were reviewed by the Picker Institute and, using the database of questions compiled during phase 1 of the research, additional questions were suggested for each of the steps. This resulted in four versions of the questionnaire, all of which contain questions specific to the step but also the core questions. This allows an element of comparison along the pathway to take place.

One member of the research team noted that “*our frail patients may sometimes have visual disturbances and memory problems—and it will be worth designing a paper survey that takes into account the disabled group’s needs*”. Taking this comment on board each version of the survey was designed with size 14pt font (the norm for surveys is a 12pt font) and instructions made it clear that the patient could ask someone for help to complete the questionnaire - but that the views must be those of the patient.

Questionnaire packs included a covering letter, questionnaire and freepost envelope. Questionnaires were returned to the Picker Institute for data entry.

6.3 Delivery / implementation

6.3.1 Administration

Fieldwork was rolled out during the spring/summer of 2013. In total 120 questionnaires were given to patients, 30 questionnaires at each of the four stage of the pathway. An overall response rate of 46% was achieved. Response rates by stage can be seen in the table below:

Table 7: Response rates

| Step | Method | Response rate |
|-------------------------------|----------|---------------|
| Acute step 1 | Hand-out | 14 (46.6%) |
| Acute step 2 | Hand-out | 12 (39.9%) |
| Community Rehabilitation Unit | Hand-out | 16 (53.5%) |
| Services at home | Postal | 13 (43.3%) |

The return of questionnaires was slow and response rates differed between steps in the pathway. This was thought to be down to a number of factors:

- Patients were not staying long enough in acute orthopaedic beds to be given a questionnaire.
- Post-operative surgical problems experienced by those in acute beds.
- Patients stay longer in community rehabilitation units and so have more time to fill in the survey.
- Given that patients were not given any prior information or warning that the survey was taking place surprise was expressed at the higher response rate received in the services at home stage.

6.3.2 Costs and economic considerations

Due to the small sample size, 120 questionnaire packs in total, the costs for survey fieldwork (printing and packing of questionnaires) were minimal at approximately £300.

The main cost was trust staff time. Three of the four stages required staff to hand out questionnaires to patients. Although the methodology chosen for this pathway required staff to dedicate time to the distribution of the questionnaires staff were able to use ward rounds as an opportunity to hand out the surveys. The small sample size, split over stages of the pathway, also meant that distribution wasn't considered a burden.

6.4 Reporting

The trust received a report detailing results in table (showing counts and percentages) and chart form (using a RAG system). Free text comments were also listed. The report for Sheffield detailed results in five sections:

- Results for Acute step 1 and 2. Combined because of the low number of responses.
- Results for the Community Rehabilitation Unit.
- Results for Services at Home.
- Overall results where questions mapped across stages.
- Results showing a comparison between stages.

Providing the reporting in this way allowed for each stage to see their results separately (for example the community rehabilitation unit could view the results only for their unit) but also allowed for the comparison between stages highlighting poor/good performance.

The results showing a comparison between stages was of most interest to the project team as it allowed them to see how each stage compared against each other and revealed a number of unexpected results. For example one member of the research team said that although the figures for community care were excellent as expected the high ratings of hospital care were a pleasant surprise. They also noted:

"Having done my thesis on hip fracture patient experience, the acute phase- predominantly before theatre time and the first few days was a blur and the patients were forever grateful for surviving this first hurdle. In the community rehab phase, they had time to reflect, analyse and were more critical [honest] in their comments."

6.4.1 Key results

A few key results from the survey are detailed in this section.

Most (80%) of respondents said they had always been treated with kindness and understanding. No one indicated that they had not been treated with kindness and understanding.

Overall, 83% reported being treated with confidence and trust by staff. This rose to 93% at the services home stage.

46% indicated that they had been given the opportunity to talk about their worries and fears with regards their condition. 13% overall said they had not been given the opportunity, and this rose to 23% at the services at home stage.

Ratings of food were more positive from respondents at the community rehabilitation unit than from those on acute wards.

6.4.2 Free text comments

The team also found the free text comments to be a powerful source of feedback. The majority of the free text comments were positive and the research team felt that these in particular would be great to show staff as a motivator and an indicator of the good work they do.

One member of the research team felt that the patient's free text comments could be more reflective and honest in capturing information rather than a tick box.

6.4.3 Respondent profile

When looking at the profile of those who filled in a questionnaire, the project team found the results of 'Who was the main person or people that filled in this questionnaire?' to be of interest. See table 8 below for the breakdown of results for this question.

Table 8: Respondent profile

| Main person who filled out questionnaire | Acute steps | | Rehab | | Home | |
|--|-------------|-----|-------|-----|------|-----|
| | No. | % | No. | % | No. | % |
| The patient | 8 | 14% | 7 | 44% | 11 | 85% |
| A friend or relative of the patient | 14 | 54% | 3 | 19% | - | - |
| Both patient and friend/relative together | 4 | 15% | 6 | 38% | 2 | 15% |
| The patient with the help of a health professional | 3 | 12% | - | - | - | - |
| No answer | 2 | 8% | - | - | - | - |

Looking at the results for this question, a difference in respondent profile was seen between the stages. At the acute stage just over a half of those to fill in a questionnaire were a friend or relative on behalf of the patient. This reflects the view that many of the patients at the acute stage were too frail or sick to complete the questionnaire. In contrast at the services at home stage the majority of those to complete a questionnaire were the patient themselves, the research team felt this was indicative of patient's having more time and being further down the road to recovery.

6.5 Dissemination

The research team received a copy of the final report and a meeting was organised to discuss the results of the project. In addition to this, the research team indicated that as part of the action planning process the findings would be shared with teams responsible for providing care at each of the four stages of the pathway.

6.5.1 Success of the method

The research team were asked to feedback on the success of the approach taken to evaluate patients' experience of the hip fracture pathway. Overall, the research team felt that using several independent cross-sectional surveys provided interesting and actionable results. They indicated that they would be keen to take a similar approach to collecting feedback in the future. With that said, the team noted a few reflections that should be taken into account if rolling out the survey again.

6.5.1.1 Sample size

As noted previously the sample size for this survey was small, so handing out questionnaires to patients was considered manageable by staff. The staff involved in handing out the questionnaires indicated that they got a useful insight about the patient experience just through the distribution process itself:

"Patients expressed (verbal conversations!) and gave a true opinion/reflection while handing the forms — [we] found those moments extremely useful [when] personally distributing them."

However, for surveys with a larger sample size consideration should be given to the burden it will place on staff if they were required to hand out questionnaires.

Small sample sizes may be an issue for similar pathways to this one where the entrance and flow of patients through the pathway is slow. This creates a problem when interpreting results: should changes to service design be based on the responses from only a small number of people?

6.5.1.2 Turnover of patients

The movement of patients in the different stages varied. For example at points patients were not staying long enough in acute orthopaedic beds to be given a questionnaire; as these were the patients considered well enough to complete a survey, the handing out of forms stalled. Conversely, patients were staying longer in community rehabilitation which meant that there were no new patients to give surveys to (the research team noted that there were no new patients admitted to Beech Hill for 10 days).

6.5.1.3 Survey burden

The research team became aware that patients were being over burdened by simultaneous surveys being carried out by individual teams and wards. Examples given were:

- General Medical Council (GMC) revalidation requirement for registrar & consultant.
- NHS Friends and Family Test.
- Discharge surveys.
- Therapist surveys.

One of the research team noted that one patient's daughter apologised in the corridor as his survey had not yet been completed by him.

When planning any new patient experience survey it is important to take into account other data collection activities being carried out in the trust to ensure that patients aren't being targeted multiples times in a short period of time.

6.5.1.4 Vulnerable and sick patients

The research team noted that a number of the patients, especially in acute step 1 were very sick and frail. This resulted in a selection bias at the acute phase as the research team only gave questionnaires to those considered medically stable, noting that *“it just did not seem right to give very sick patients the forms to fill.”* The team felt that giving forms to patients so early in to their journey (eg just out of surgery) was a challenge *“with all the drips, confusion, [and medically] unwell states”*.

If carrying out the survey again the team said they would think carefully about including patients in acute step 1 who were so soon out of surgery.

The research team also said that they felt removed from the process at the services at home stage. They felt that they did not have an opportunity personally to tell patients that they would be posting the forms. The specific concern was that if the patient was living alone they may not be able to access help to post the form back.

6.5.2 Action planning

The research team circulated results to the individual teams involved at each stage of the pathway with the local clinical governance teams producing action plans. For example the Acute Orthopaedic wards (step 1 and step 2 in the pathway) developed a plan focussing on areas of improvement and related actions one of which was to update the information booklet provided to patients during their care to ensure they have clear information about treatment. A further action was to decrease the number of beds on the acute wards to increase the staff to patient ratio allowing staff more time to spend with patients. As well as areas for improvement, areas of excellence were identified for example the results for cleanliness of ward were extremely positive and so the associated action was to give positive feedback to the domestic supervisor so they can feedback to their staff.

Results and actions were also disseminated to the Chief Nurse and Deputy Nurse both of which indicated that they are keen to repeat the survey but only once we act on the action plans first.

In addition to this a member of the research team at Sheffield presented findings to their senior clinical leaders' forum where there was strong senior representation from medicine, orthopaedics, and community. They were impressed with all the hard work that had gone in to the project locally and could see the immense potential of *“patient experience as a driver for service improvement”*.

6.5.3 Sharing of results and what next

The project team were keen to put actions in place and then carry out a follow-up survey (possibly just focusing on the action points) in six to twelve months' time. However, this would depend on whether they had the funds available to do so. The team also spoke about sharing results with the rest of the organisation on the trust intranet.

Looking at other services across the trust the research team thought that the learning from this research could inform other data collection activities. Understanding how to implement a pathway approach to collecting feedback gave the trust another data collection method to consider.

7 West Norfolk Primary care practice

7.1 Context / background

This pilot site represents a primary care practice in West Norfolk who wanted to look at the patient experience of chronic obstructive pulmonary disease (COPD) services. The pilot evaluation was driven and led by healthcare professionals with specific responsibilities for the care and management of patients with COPD. The practice manager and admin staff were also represented in the project team.

7.1.1 Structure

West Norfolk provides services for a population of 163,000 people; there are 23 primary care practices. The pilot site practice is located by the coast and there are approximately 8000 patients registered with a large proportion of patients over 65 years of age. During the summer, care is provided for temporary residents- holiday makers.

COPD services include Pulmonary rehabilitation programmes commissioned by West Norfolk Clinical Commissioning Group which are held in various locations in the region. Care and education is provided at the classes by physiotherapists, COPD nurses and technical instructors. COPD clinics are held in the practices and there is also a COPD specialist nursing team who care for patients following discharge from hospital and those in community settings. Care is also provided at the practice by the GPs and COPD nurse practitioners. In some cases, patients are cared for by the district nursing team. There are around 150 patients QOF registered with COPD at the practice.

7.1.2 Current and past arrangements for patient experience feedback (as of April 2013)

As well as the national GP patient survey the practice had carried out several other relevant surveys in the previous two years.

- **Respiratory services.** The practice conducted 10 discovery interviews with the findings compiled into a report and recommendations made to help inform service improvement. The recommendations included a COPD Outreach Worker, business case for nebuliser service and planning for a GP with a Special Interest (GPwSI) - all of these came to fruition. In addition to this a questionnaire developed by the COPD team in conjunction with the CCG Patient Experience team was posted to a random sample of existing patients on the caseload. 48 questionnaires were sent out with an 88% return rate and helped support how the current service is greatly valued by patients.
- **Practice based survey.** A Patient Survey was developed (based on the General Practice Assessment) - in collaboration with partners at practice clinical governance meeting and patient participation group (PPG). The survey was conducted in January 2012 and ran for a period of two months. The survey was available to all patients over the age of 16 years from a random selection (500) from the 8000 permanent patients attending two practices in the region. 486 were issued during January and February 2012. A total of 212, 43.6% patients responded. Service improvement was discussed with partners and the patient participation group.
- **New referrals.** A satisfaction questionnaire is sent to new referrals to the COPD team approximately 2 weeks after first appointment.

7.1.3 Current arrangements for action planning and quality improvement (as of April 2013)

The practice has a Patients Participation Group (PPG) which consists of patients registered with the practice and medical, nursing and non-medical staff of the practice.

The activities of the group include evaluation and feedback about the provision of healthcare in the area and local services and arranging health talks for the local population, fundraising.

Activity to date has included:

- Sustaining the Chiropractic Service.
- Helping the elderly to have screening within NHS guidelines.
- Helping patients' complete Attendance Allowance forms.
- Helped with a transport system for people within the local villages.
- Supported the practice in their successful application as a dispensing practice for patients more than one mile from their pharmacy.
- Worked with the practice staff with the patient survey and feedback.
- Raising funds to help provide:
 - medical equipment & services.
 - donations to local health support groups

7.1.4 Project team

The project team included:

- GP
- COPD specialist nurse
- COPD practice nurse
- Administrator
- Practice Manager
- Commissioner for West Norfolk CCG
- Two patients

Other staff were consulted during specific phases of the project. The Patient Participation Group was also informed about the study and provided comments on material for fieldwork.

7.2 Planning

7.2.1 Agreeing the approach

Two meetings were held at the practice with the project team prior to fieldwork to determine method and area of focus.

A pathway approach was considered to be useful and several populations of people with long-term conditions were discussed. Staff felt that it would be useful to gain feedback from

those with COPD and as those with COPD are QOF (Quality and Outcomes Framework) registered the practice knew they would be an easy group to identify from their records.

The project team commented that patients with COPD often receive care from different services and settings- inpatient, community COPD specific services, district nursing services and at the practice. This would need to be taken into account when rolling out the survey.

7.2.2 Method used for data collection

Through discussion with the pilot site it was agreed that a paper-based survey mailed out to patients home addresses would be the most appropriate method. Two mailings were carried out, the reminder mailing being sent to non-responders only after four weeks.

The practice were responsible for generating personalised covering letters which were added to survey packs by carrying out a mail merge. The practice generated the reminder mailing ensuring that only those who had yet to respond to the survey were sent a second survey pack.

7.2.2.1 Use of personalised letters

Practice staff were very keen to adopt a more personal approach by inserting patients name in the covering letter. There was strong preference for individualised, personal letters with electronic signatures of the GP, COPD specialist nurse and COPD practice nurse to patients to maximise response rates. The covering specifically stated that the focus of the questionnaire was to improve services.

7.2.2.2 Use of staff and patient information sheets

It was agreed that two posters would be drafted: one for staff at the practice to inform them about the study and one for patients. The poster for staff was put on the staff information board to help staff answer questions from patients about the study or questionnaire. The poster for patients was used to inform them of the forthcoming survey. This was displayed in the waiting area of the practice.

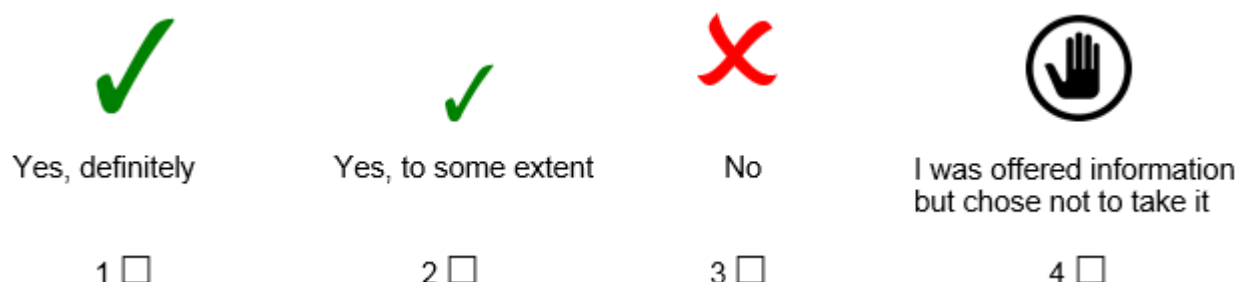
7.2.3 Sampling

The survey was sent to a census of COPD patients registered with the practice. As mentioned previously the practice indicated that they could identify all eligible patients with ease. To maximise sample size, it was suggested to include two other practices. This would also provide diversity in practice demographics. However, it was agreed that this could be phased and the Heacham practice would be the first pilot site.

7.2.4 Questionnaire content

The core questionnaire developed for the study was considered by the team alongside an easy read version of the questionnaire that had been developed through work with another pilot site. It was agreed that the easy read version should be used in the fieldwork as this might maximise response rates considering the older population in the sample and nature of the disease.

The questionnaire made use of pictures on a Likert scale as can be seen in the snapshot below:



Minor edits to the core questionnaire were made and questions were inserted to replace the existing item on coordination. These focused on staff 'working well' together and 'consistency in advice given'. A couple of revisions were made to the demographic questions with Eastern European included in the question regarding ethnicity (there are a considerable number of people from Eastern Europe living in Norfolk and the practice wanted to recognise this).

Practice staff raised an issue related to which services patients might be referring to when responding to questions. While the questionnaire was aimed to provide a global judgement of care received in the last year the practice staff felt it would be difficult to identify which services patients were referring to despite patients completing a question asking them to tick the services they had accessed. It was suggested that a comments box be inserted at the bottom of each page for patients to refer to specific services if necessary.

It was also suggested to include a Quality of Life/health status question to explore the relationship of responses to severity of symptoms/disability. The Medical Research Council breathlessness scale was agreed- based on frequency of use in clinical practice.

7.3 Delivery / implementation

7.3.1 Administration

A list of patients was generated using the COPD QOF register at the practice with questionnaire packs provided to the practice for them to add the covering letter and mail out. Fieldwork commenced in March 2013 and the closing date for non-responder reminders set as May 2013. The response rate for the survey can be seen below.

| | | |
|-----------------|---|------------|
| Response Rates: | Mailing 1 | 174 |
| | | |
| | Completed questionnaires | 112 |
| | Response rate | 64% |
| | Reminders for non-responders | 62 |
| | Completed questionnaires after reminder | 13 |
| | Opted out (Total) | 5 |

| | | |
|--|--------------------------------|------------|
| | Blank questionnaire returned | 0 |
| | Overall total completed | 125 |
| | Response Rate | 72% |

7.3.2 Costs and economic considerations

It was noted that identifying and screening patients and practical aspects of posting surveys was labour intensive. Payment for staff at the practice to carry out administrative tasks was agreed at £250 as a standalone payment. In addition to this, there were costs related to the printing, packing, posting and data entry. These can be seen in the table below:

Table 9: Fieldwork costs for West Norfolk Primary Care Practice

| Fieldwork activity | Cost |
|--|-----------------|
| Printing and packing | £677.78 |
| Delivery of questionnaires to practice | £16.30 |
| Postage for mailing | £95.40 |
| Data entry | £450.65 |
| Invoice for Norfolk administration | £250 |
| Total | £1490.13 |

7.4 Reporting

A report was generated for the practice and given to other members of the COPD nursing team; pulmonary rehabilitation team, respiratory consultants and staff at the acute hospital. The report covered:

- Demographic description of responders
- Number of services accessed
- Overall ratings for each question
- Ratings for participants with a COPD diagnosis less than or greater than five years
- Ratings for patients with MRC Breathlessness scale scores less than or greater than 3
- Free text comments by theme

7.4.1 Key results

A few key results from the survey are detailed in this section.

There were no striking differences of responses for patients with long-standing COPD compared to those diagnosed in the previous 5 years. However, there was generally a very slight trend of more positive experiences for patients with long-standing COPD.

We were interested whether we could identify experience based on advanced disease or severity of illness measured on the MRC breathlessness scale- there were no apparent trends or differences. Results are though based on 48% of the sample of patients- a large number of patients had difficulty completing this scale- some indicating more than one response and others failing to provide an answer.

Over 80% of patients reported their experiences of COPD care over the last year to be Excellent (51%) or Good (33%). The majority of patients were treated with kindness and understanding. No patients reported negatively but some either didn't respond or couldn't remember.

7.4.2 Free text comments

Both quantitative and qualitative results were considered to be informative- although, free text more interesting. The questions though provided more focused information for improvements.

7.5 Dissemination

7.5.1 Success of the method

7.5.1.1 Response rate

Staff were pleased with the 72% response rate. The personalised approach to covering letters, using individual's names and staff signatures was conceived to be an essential ingredient. The patients would have known at least one of the named signatories, if not all- some having built up a close relationship with staff over the years. It was thought that patients at the practice may have completed the survey as they had investment in the practice and their contribution can help shape services.

7.5.1.2 MRC breathlessness scale

There were a large number of patients who failed to respond to the scale (58%)- some with multiple responses and others failing to complete it. Staff felt this was more of a reflection of the lack of sensitivity and validity of the MRC scale rather than patient specific biases. The scale is often used in practice as a clinical adjunct assessment by clinicians- taking into consideration other clinical indicators (spirometry; oxygen use etc) and not as a standalone tool. It was also noted that often patients are breathless when dressing but are able to get out to the shops using a mobility aid. It was highlighted though that the scale scores are often indicators used in identifying patients who may benefit from pulmonary rehabilitation, although not as an isolated tool.

Nurses often use the BORG dyspnoea scale in practice [*modified version- single item 0-10 reflecting patients perceived breathlessness*]. The CCG representative wondered if the MRC scale might be useful for patients to use as a self-monitoring/management tool; they could then decide what interventions they might need based on their illness symptoms etc.

7.5.1.3 Patient experiences

Overall scores were pleasing and correlated with other patient experience feedback in the past for example feedback from the GP Patient Survey and the practice's own survey of patients carried out.

7.6 Action planning

7.6.1 Carers

It was noted that there were more carers than expected and that there was a wider distribution of scores on item 4 (*Did the healthcare staff offer your family, carer or friends the opportunity to be involved in decisions about your condition and treatment*). The results from the item and qualitative comments suggested that some patients would have liked their family to be involved in decisions about their care. This was considered something that could be actioned. At the time of the survey there were only 25 registered 'carers' in the practice but it is likely that there are many more who are providing care and support. There is currently a West Norfolk Carers Association being developed which may be of benefit to existing carers and those newly identified. Staff suggested inviting members to the practice to provide information and support to local carers. A 'drop-in' information day was discussed. It was highlighted though that there are many people who have moved to Norfolk to retire and therefore isolated from their families.

7.6.2 Information needs

The results highlighted in some cases that patients did not have sufficient knowledge of their condition and would have liked more information. Staff felt that this in part reflected the general lack of understanding of the definition of COPD by the public and to some extent, healthcare professionals. For patients, they may have had a primary diagnosis of asthma which has led to chronic lung disease and therefore classified as COPD. Other terms used which cause confusion are chronic bronchitis and emphysema. Staff at the practice mostly use the British Lung Foundation (BLF) information sheets and terminology. In the past, staff have generated their own information sheets but now use BLF resources to ensure consistency.

7.6.3 Access

Some patients reported difficulties getting appointments and seeing the same person. This was noted to be an issue raised in results from the GPPS too. It was considered to be difficult to action. Weekend access had also been highlighted as a problem for some patients. Staff reflected that at weekend's patients feel insecure and panic if they are not coping with symptoms etc. The emergence of Telemedicine/Telehealth was thought to be a mechanism to improve this. Staff were sceptical about the sustainability of Telemedicine across conditions and despite a Local Enhanced Service locally, there were too many things happening at once, and little time to implement.

7.6.4 Number of services

It was noted that there were only a small number of people who had received pulmonary rehabilitation. Also, the report highlighted that there were more patients receiving support and care from carers than they had thought. Staff reported that the Breath Easy support group was poorly attended. It was suggested that one possible reason for this was that patients generally were quite poorly. However, more promotion of the group was thought to be important. In the waiting area of the surgery, there is a plasma screen which advertises and provides information about different services- for example, flu vaccinations etc. It was suggested that the Breath Easy group could be displayed on the screen to encourage patients to attend.

7.7 Sharing of results and what next

Several methods of dissemination of the results to different audiences were discussed and the following agreed:

- A summary would be submitted to the safety and quality meeting at the CCG- this would also be put to the CCG board. A summary would also be inserted in the GP newsletter for West Norfolk.
- An abridged version was generated and made available on the practice website and given to the PPG.
- A poster summary will be presented in the waiting area of the surgery.

Staff expressed interest in sharing success and learning with other pilot sites in the study. This was considered to be valuable for joint learning and networking in the future. Webinars were also considered useful.

8 Homerton University Hospital NHS Foundation Trust

8.1 Context / background

Homerton University Hospital NHS Foundation Trust provides hospital and community services to areas of East London including the City of London and Hackney. They offer specialist services ranging from obstetrics to neuro-rehabilitation. The trust wanted to collect data on the experiences of patients across a variety of service lines.

8.1.1 Structure

Homerton University Hospital NHS Foundation Trust contains three divisions each with a set of services. Each of the services perform a variety of tasks that fall within their remit.

- **Surgery, Women's and Sexual Health Services:** Gynaecology, Obstetric/Maternity, Sexual Health, Surgery, Anaesthetics/Theatres, Intensive care unit.
- **Children's Services, Diagnostics and Outpatients:** Outpatient & Support, Services, Children's Services Diagnostic Services.
- **Integrated Medical and Rehabilitation Services:** Urgent Care Musculoskeletal Medical Specialties Rehabilitation Therapy Services Community Services.

8.1.2 Current arrangements for patient feedback at the trust (as of February 2014)

As a trust Homerton participates in the National Patient Survey Programme, and has a comprehensive approach to collecting patient experience data locally (in both acute and community settings). They make use of the following approaches:

- Frequent Feedback (electronic devices)
- Paper-based surveys
- Telephone surveys
- Patient stories

Specifically the trust maintains a library of questions and questionnaires which they can adapt as needed. Some of these questionnaires focus on specific areas of care like nursing, learning disability services and children's programmes. Like this project, each of these questionnaires includes a core section of comparable questions; these relate to communication, cleanliness and information.

Frequent Feedback is carried out using handheld devices with data collected for approximately 1000 patients per quarter. Volunteers administer the surveys using hand-held devices. Because of the high proportion of non-English speaking people, volunteers aim to conduct surveys during visiting hours so that carers or friends of patients can respond on their behalves. The trust has three permanent advocates specifically designated to assist the large Turkish population that uses the trust's services. The trust indicated having tried to translate an inpatient survey in the past but did not find this successful.

The trust also uses telephone surveys. In the first quarter of 2013 the trust completed 73 telephone interviews. The telephone interviews take the form of a semi-structured interview where specific questions are asked (that relate to the existing framework of patient experience). The telephone interviews are also a chance to get extra detail, and in some cases these form the patient stories also collected.

These approaches relate to the trust as a whole, but they also target specific wards. For example they roll out a patient experience survey on a particular ward and then staff on that ward would also complete a similar survey (staff surveys include questions on appraisals, bullying, and a recommend question). Those on that ward would then be targeted with a follow up telephone interview after discharge from hospital. Furthermore the Surgical Rehabilitation Team have been in the process of rolling out a Patient Reported Experience Measure (PREM) with questions that are very specific to the service.

Finally the trust uses the mandated friends and family test. Homerton carry this out using a postcard system. Because frequent feedback uses a volunteer workforce the trust felt that they couldn't guarantee a 100% hit rate and so opted for postcards instead.

8.1.3 Current arrangements for action planning and quality improvement (as of February 2014)

The trust has a Patient Experience and Engagement Committee (PEEC) which meets every 2 months and has members of staff from all of the different specialties, plus a governor and a member of Healthwatch.

This committee is responsible for ensuring they deliver improvements for patients and it reviews all patient experience data collected and monitors the action plan.

8.1.4 Project team

The staff involved in this project from Homerton were:

- Head of Patient Experience
- Lead Nurse Sexual Health Services
- Head of Adult Speech & Language Therapy
- Team Lead Surgical Rehabilitation Team
- Nurse Consultant

Other members of staff at Homerton were also involved in administration of the project including three members to staff to label and mail out envelopes.

8.1.5 Service overviews:

The four services involved in this project had unique functions and served different populations.

COPD – The COPD service at the Homerton University Hospital Foundation Trust is called Acute COPD Early Response Service or ACERS. Service users who participated in the survey either saw a specialist nurse or physiotherapist at home, in hospital, or used the pulmonary rehabilitation group. ACERS is specifically designed for people diagnosed with COPD, it sees 250 service users each three month period, a reasonably large amount compared to the other services involved in this study.

Sexual Health – Homerton Sexual Health Services provide information, testing, diagnosis and treatment for sexually transmissible infections. They also offer care and support for people seeking contraception and for people living with HIV. The service is very large and sees approximately 2,000 service users each three month period. This was by far the largest service included in this study.

Surgical Rehabilitation – The Homerton Surgical Rehabilitation Team (SRT) is a team of physiotherapists, occupational therapists, specialist nurses, rehabilitation assistants and a geriatrician. They work closely with the surgical teams to see patients pre-operatively, through their in-patient stay, and into the community after discharge. They can take patients home from hospital to ensure they have a safe discharge. This service only treats service users having surgery at the Homerton Hospital, about 60 people each three month period. This was the smallest service involved.

Speech and Language Therapy – The speech and language therapy service provides assessment, advice and therapy to adult inpatients in Homerton University Hospital who have communication or swallowing difficulties. This service typically sees about 140 service users each three month period.

8.2 Planning

8.2.1 Agreeing the approach

The patient experience lead contacted a variety of services that might be interested in and able to take part. This resulted in four different services participating in measuring patient experience:

- Sexual Health
- Surgical Rehabilitation
- COPD
- Speech and language

At the beginning of the project two other services considered participating but were ultimately not included.

- Angiogram
- Diabetes

This was due to a combination of factors. In the case of the Diabetes Service, staff decided that the core questionnaire was not relevant to their service users. In the Angiogram service staff members lacked the time to take part in the process and survey design.

8.2.2 Method used for data collection

Two methods of data collection were considered by the trust. The first option put forth was for service users to be handed a self-completion questionnaire upon discharge over a three month period. These would be filled out after the appointment and returned via a freepost envelope. This would require some staff commitment over the three months in making sure that questionnaires are handed out, and for those services that have a high volume of patients this could be quite burdensome.

The second option was to draw a sample of service users from three consecutive months leading up to the survey, using the patient record system to select all eligible patients. For the small services it would be all patients over the last 3 months. For the larger services it would be a random sample of 600 patients. Questionnaire packs would be delivered to the trust for names and addresses to be added. Questionnaires would then be sent out by trust.

The trust chose the second fieldwork option to ensure that all relevant service users received a questionnaire. One of the deciding factors in selecting this option was that option one would have placed a significant burden on staff. Also the hand-out approach would have been highly dependent on the availability and engagement of staff and volunteers. Furthermore, during busy periods, there would have been a potential risk that staff and volunteers would neglect handing out questionnaires to focus on other tasks.

8.2.3 Sampling

Given that each service discharged a different number of people each month, the project team decided to take a census of the services seeing less than 600 people in a three month period and a 600 person sample for those services seeing that many (or more) people within three months. The resulting sample is represented in Table 10.

Table 10: Sample Sizes for services

| Service | Sample size |
|-------------------------|-------------|
| COPD | 250 census |
| Sexual Health Services | 600 sample |
| Speech and Language | 140 census |
| Surgical Rehabilitation | 60 census |

Each service drew their own sample and submitted the names and address details to a central contact. The services used slightly different records systems, but they all held the relevant name and address details to send a postal questionnaire.

8.2.4 Questionnaire content

The questionnaire for each service included sixteen core questions that were the same across all services. The core questionnaire was developed in the earlier stage of this research. Each service was shown the core questionnaire and given the opportunity to add up to ten questions of their own to cater for their different priorities. All four services were very engaged with this process and submitted additional questions. These went through revisions and were eventually integrated into the core questionnaire. The introduction to the questionnaire was also tailored such that it referred to the individual service. Services provided descriptions of their services that would ensure that users recognised what the survey was about. The following additional question areas for each service were considered and four versions of the questionnaire developed:

COPD – questions focused on the experience of those having a flare up of their lung condition and accessibility of the service.

Sexual Health – questions focused on the clinician and their ability to put the service user at ease, take emotional needs into account, and being able to speak to them about areas of concern.

Surgical Rehabilitation – questions included whether the patient would recommend the service and if the patient got enough support after leaving hospital.

Speech and Language Therapy – questions focused on help with communication and swallowing. This service has two units, stroke and acute. They decided that it would be optimal to have a breakdown of results by unit, so a numerical coding was added to each questionnaire sent to someone from the stroke unit.

8.3 Delivery / implementation

8.3.1 Administration

Fieldwork was rolled out during December, 2013 and January 2014. In total 1,050 questionnaires were sent out to patients/service users. An overall response rate of 13.5% was achieved. Response rate by service can be seen in the table below:

Table 11: Response Rates

| Service | Response rate |
|-------------------------|---------------|
| COPD | 65 (26%) |
| Sexual Health Services | 51 (8.5%) |
| Speech and Language | 8 (5.7%) |
| Surgical Rehabilitation | 18 (30%) |

Administration of the postal questionnaire faced a few logistical hurdles which delayed the beginning of fieldwork after the questionnaires were printed and delivered to a central contact at the Homerton.

Once the questionnaires were delivered it became apparent that the labelling and mailing out of the survey packs would be very labour intensive. This was primarily due to the fact that records had originated from four different services and could not be easily collated and converted into address labels. The research team was able to support this process and compensate three trust staff members for their overtime hours spent on this aspect of the survey. Although the research team was able to pay for this work, it was still difficult for staff to allocate time for this when they had not budgeted for it. This delayed the mail out slightly.

Before the delivery actually took place, one service suggested using a hand-out methodology rather than the postal methodology that had been previously established. The sexual health team would have preferred this methodology to enhance response rates; however, if it had gone ahead it would have been problematic for the results of the overall survey. Had the trust used different methodologies across services it would have limited the comparability of the results. It is critical to remember in future surveys that a streamlined methodology would require oversight from a survey manager to prevent rogue applications of methods.

The delivery timetable was also altered due to staff priorities and a difference in availability than was originally anticipated. Ultimately the survey packs were mailed out December 4th, officially commencing fieldwork.

8.3.2 Respondent profile

The return of questionnaires was slow and difficult to monitor effectively as it took place over the Christmas holidays. Generally it took quite a while for surveys to be returned from each of the services, and overall response rate was very low.

The response rate did not come as a surprise to staff at the Homerton Trust, as they have historically struggled to achieve high response rates in national surveys. For instance the trust response rate for the most recent National Inpatient Survey was 30%.

The patient experience lead and representatives from each service were consulted as to the reasons for such low response. They cited a variety of possible reasons particularly relating to the demographics of the surrounding area.

Young service users: As demonstrated by Table 10 the Sexual Health Sexual Health Service had a much higher proportion of young service users which may have contributed to a very low response rate (8.5%). Typically younger service users do not respond to surveys as much as their older counterparts.

Table 12: Overall age compared to Sexual Health Age

| Age | Overall (n =145) | Sexual Health (n=51) |
|-------------|------------------|----------------------|
| 18-25 years | 7.59% | 21.56% |
| 26-35 years | 13.10% | 37.25% |
| 36-45 years | 10.34% | 23.52% |
| 46-55 years | 9.66% | 11.76% |
| 56-65 years | 14.48% | 3.92% |
| 66+ years | 40.70% | 0% |

- English language: Staff at the trust also explained that many service users do not speak English as a first or fluent language. This could have been an immediate deterrent to filling out the self-completion questionnaire which was only issued in English. While this is a significant issue, the trust's patient experience lead did explain that they have run surveys in different languages previously that also received poor response rates.

There is no way to know the first language of the service users who were included in the samples, to see if those who do not speak English responded less.

- Deprivation: One underlying concern for response rates is the general social deprivation in the catchment area of the trust. The community in that part of East London is relatively transient with many people in insecure housing arrangements. This makes it a particularly challenging environment in which to administer a survey, especially a postal survey that requires accurate address information.

8.3.3 Costs and economic considerations

The major cost considerations for this trust surrounded survey delivery. As described above, even when staff are engaged with the project and support the survey methodology, there is no guarantee that budgets will allow for them to help in the survey delivery within standard working hours.

The project team at Homerton noted that the hardest part of the process was sorting out and sending the questionnaires with mailing out the questionnaires themselves causing considerable burden. They noted “even things you think would be simple such as working out how to pay the staff for their time are time consuming”. They noted that burden on admin would be a barrier if they were going to roll out a mail-out approach across all services at the trust.

Funding for staff to work overtime on the delivery of the questionnaire was provided by the research team. In any replication of a postal survey the trust would have to budget not only for the raw materials, but also for the time, even if minimal, for staff to administer the survey.

Table 13: Fieldwork costs for Homerton

| Fieldwork activity | Cost |
|--|------------------|
| Project management and data prep | £696.27 |
| Delivery of questionnaires to practice | £30.56 |
| Postage for mailing | £762.63 |
| Invoice for Homerton administration | £247.93 |
| Total | £1,737.39 |

8.4 Reporting

The trust received a report detailing the overall results from the whole service as well as breakdowns for the individual services. The report included tables showing counts and percentages of how service users responded to each question. This data was also displayed in bar graphs. The survey also included a variety of open ended questions, so the free text elicited from those were also reported anonymously in the reports. The report for the trust detailed results for three of the four services individually:

- Results for COPD.
- Results for Sexual Health Services.
- Results for Surgical Rehabilitation.

The same type of reporting was not possible for the Speech and Language Therapy services due to the small number of respondents. The service only received eight completed surveys, and reporting those results on their own could have breached confidentiality rules. Data from the eight completed Speech and Language Therapy surveys were included in the overall results.

For the other services, this reporting allowed each service to see their results separately and allowed for comparison between the other two services and the overall results. This helped highlight areas of good and bad performance.

All services said they understood the report and found the layout useful. Services liked the comparison seen in the report as it demonstrated that services were quite different but also made them think about their own service: “useful to know what you need to work on”.

8.4.1 Key results

A few key results from the trust as a whole are detailed in this section.

Over 70% of all respondents felt that all of the different people treating and caring for them worked well together to give the best possible care. This question received very high responses across services.

Although respondents felt that people were working together, much fewer, only 34% felt that healthcare staff offered family, carers or friends the opportunity to be involved in decisions about your condition and treatment. This was the only noticeably negative response.

82% of respondents across all services said that they were always treated with kindness and understanding. This very positive finding was also evidenced in the fact that 77% of people said they had confidence and trust in the healthcare staff treating them.

These overall results give a broad overview of the findings. However, the report sent to the trust breaks the results down in a way that makes them much more meaningful to the staff at the trust.

8.4.2 Free text comments

All services found the free text comments interesting with the Head of Patient Experience indicating that similar themes to those seen from the national survey and the FFT cards were evident (dignity, respect, being cared for).

Free text comments were viewed as really rich and important. The team noted that compliments need to be fed back to staff as they are powerful.

They liked the free text comments just being listed rather than coded as they wanted the information as the patient has said it. They also indicated that it is good to have the comments split out by services.

Dissemination

A final meeting was held with the project team to explore how they found the process, discussion of results and what they intend to do next.

8.4.3 Success of the method

The Head of Patient Experience said that the results were valuable and that they add to other data collections in the trust: “results are confirmation of our patients experiences, matches other findings.” The Sexual Health Service said the results were as expected and supported the results from other surveys they have carried out.

Identifying patients/services users from the trust’s record system was easy for all services.

8.4.4 The questionnaire

Overall, the team liked the questionnaire and didn’t think there was anything missing. All services said that the additional questions were useful and they found it easy to think of questions they wanted to use. They said that the free text box meant people could vocalise anything not covered in the questions. They also noted that while they appreciated the

professional look of the questionnaire they felt it could be made more engaging: “people need visuals”.

The project team indicated that if they were to try and roll out the approach to other services lines that there could be one or two other services as enthusiastic to take part but they weren’t sure of the feasibility of including the whole trust “there are a lot of data collections going on in the trust and so would not want people filling in surveys for the sake of it”.

8.4.5 Response rates

The project team felt that the low response rates were reflective of the population they serve and they weren’t surprised by the low response. The trust has a lot of non-english speakers in the community who, it was felt, are less likely to respond to surveys. Response rates to the national survey programme are also low and when looking at demographics from this survey and the national survey, the gender profile matches but other demographics differ (such as ethnic background).

Speech and Language Therapy staff were not surprised by survey results. They also used ward level feedback cards for which they received low response rates. They commented that many of their patients have had a stroke so any method which used a lot of words for them was not a good approach. The use of pictures was suggested as a better idea and they wondered whether face-to-face interviews would be a good approach and indicating they might get their trainees to conduct interviews.

Speech and Language Therapy thought that another reason for the low response was that patients don’t necessarily differentiate between their staff and other staff. They work closely with other professionals so it’s difficult for patients to differentiate.

The Sexual Health Service said that the low response “was not a surprise as people use us and they want to forget us”.

8.4.6 Action planning, sharing of results and what next

As previously noted, the Head of Patient Experience felt that the findings from this research would add to other data collected by the trust. The findings would be added to discussions the trust have about patient experience and will considered when looking at the trust wide action plan.

Each service plan to feed results back to their individual teams so discussions can be had about local actions. The Sexual Health Service said they would use the results to update their “you said we did” board. The Head of Patient Experience indicated that the “you said we did” boards are being rolled out across wards.

The Speech and Language Therapy Service said that knowing the paper-based method doesn’t work with their patients is important information to have. They indicated that things like follow up groups would also not work as people don’t want to come and speak in front of others because of communication problems.

The Sexual Health Service indicated that they would like to find out why they, and the trust, get such a low response rate. They felt that it could be that they are asking questions they want to know the answers to rather than what patients want. The Head of Patient Experience indicated the patient forum and local Healthwatch could be used to explore this “what do you need us to know”.

9 Staffordshire and Stoke on Trent Partnership NHS Trust

9.1 Context / background

Staffordshire and Stoke on Trent Partnership NHS Foundation Trust provides community health services and adult social care in Staffordshire and health services in Stoke on Trent. The Partnership Trust is the biggest integrated health and social care provider in the UK. The Partnership Trust wanted to explore the experiences of their adult social care services, improving on the data collection carried out by the council previously.

9.1.1 Structure

The Partnership is made up of 32 integrated care locality teams. The Partnership Trust took over adult social care services in April 2012 and provide social care in Staffordshire excluding Stoke-on-Trent.

Adult social care services provided by the Partnership Trust include the Community Intervention Service (CIS) and Living Independently Staffordshire (LIS); including Brighton House and The Staying Home Scheme.

The Community Intervention Service and the Living Independently Service are the services to be evaluated in this project.

9.1.2 Current arrangements for service user feedback at the trust (as of June 2013)

Since September 2012 the Partnership have been asking the Friends and Family Test. In addition to this they also carry out a number of local collections.

- **Monthly patient experience survey.** This is a survey carried out with handheld devices and has been in place since 2010. The devices are rotated around the Partnership (both the community hospitals and community services) to get a good coverage of feedback from the different services. Community staff take the devices out with them on rounds and ask patients to fill in the survey at the end of the visit. A core questionnaire is used across the board, however it is reviewed every few months to see if updates need to be made. The patient experience data is presented back to teams and localities as crosstabs showing numbers and percentages.
- **Story boards.** These patient stories are gathered on an ad-hoc basis and are often fed back to the board.
- **Consultation events.** The trust runs a series of consultation events allowing them to gauge stakeholder opinion on proposed changes to how an organisation runs or what it produces/delivers. For example the trust ran a consultation giving all partners the opportunity to share their views on the proposed Quality Improvement Priorities for 2014/15.

9.1.3 Current arrangements for action planning and quality improvement (as of June 2013)

When the Partnership took over adult social care services in 2012 they held a number of listening events to understand more about this new user group. The feedback from these events fed into service improvement activities.

The Partnership has an organisation wide action planning system in place, data collected from the monthly patient experience survey are presented at team level. Every month each team receives comments about improvements which could be made, these are typically the simpler things the teams can act on quickly.

9.1.4 Project team

The team from the Partnership involved in this project were:

- Professional Head of Social Work
- Patient Experience Lead
- Patient Experience Officer
- Resource Manager - Personalisation and Quality

Other trust staff were involved in the sampling and validation of the sample.

9.2 Planning

9.2.1 Agreeing the approach

The team wanted to evaluate both the Community Intervention Service and the Living Independently Service, being able to compare results from both of the services was seen as important. The team discussed how best to evaluate these service lines and with the Trust wanting to introduce a monthly data collection alongside the monthly collection already carried for patient experience it was agreed to follow this approach.

Through discussion it became apparent that targeting individuals who had recently had a six week review would be the best point at which to survey. This would include individuals who have had a review following a period of input from the enablement team and individuals who have had a review following an assessment and services provided following the input of Adult Care or neighbourhood teams.

9.2.2 Method used for data collection

At the start-up meeting with the Partnership they expressed an interest in introducing a monthly adult social care data collection that could run alongside the patient experience collection already being carried out in the Partnership. It was decided to start a monthly paper-based survey to users. The first three months of data collection would be covered and evaluated by this research.

However due to delays in getting the collection up and running it was decided to instead give the Trust a baseline from which to compare to in the future with monthly collections. This baseline would be comprised of users to experience a review between September 2013 and December 2013.

9.2.3 Sampling

When deciding on the sample to include in the survey the research team thought about common criteria which could be used to select service users. Selecting new users who had had a six week review was thought to be the most suitable criteria.

The team then explored the number of adult social care users in 2012/2013 to determine sample size. From provisional outturn data for 2012/2013 the number of new people receiving services and having a 6 week review was 3,170. These individuals had a 'mainstream' service provided i.e. ongoing domiciliary care or residential care and received a 6 week review.

As previously mentioned the original plan had been to conduct a monthly data collection over a four month period (September~December) sending a questionnaire out to all those having a review each month. Using the provisional outturn data as a guide the number of users to be sent a questionnaire each month was expected to be approximately 250. However, due to the delay in getting the collection up and running it was decided to create a base line which the Partnership could use to compare monthly results to in the future.

At the time of sampling a new system (Care Director) had been introduced within social care which caused some local issues. It was unknown whether the criteria could be used to pull users from the system. This was queried with the information team who confirmed that it would be easy to extract the sample but that there would need to robust validation checks done before using the sample due to issues around data quality.

The main criterion was for the person to have had a six week review; i.e. was in receipt of a new support package within the given dates. But the accuracy of this data was questionable in terms of how/whether the six week reviews were recorded on Care Director. Therefore the starting point was to select all new clients within the date parameters (September ~December 2013) with follow up checks.

Using this approach enabled the sample to be produced within two weeks from the point of request. The estimate of 250 users having a review each month was found to be too high. The reason given for this was that on the information system pre-Care Director users could enter the date of the six week review in advance as a planned date so it was never a reliable indicator that the six-week review had actually taken place. The actual number of users identified to receive a questionnaire was 396, so nearer 100 users a month.

The last step in the sampling process was to carry out validation checks, these had to be run by the district teams and the purpose was to ensure that all service users on the sample were those who had capacity and that there were no deceased clients included that weren't picked up by the Care Director system.

9.2.4 Questionnaire content

The Partnership Trust were in the process of developing a local adult social care survey when the opportunity to take part in this pilot arose. The local adult social care survey was being developed through public and staff consultation and therefore the Trust felt it important to use this survey rather than the core questionnaire developed by Picker/Oxford. Instead the Picker/Oxford team provided comment on the questionnaire and supported the Trust in its design, layout and formatting.

The adult social care survey contained similar themes as the core questionnaire such as information and involvement in decisions but also service specific questions around the use of aids and support at home.

The questionnaire was presented as an easy read version. This was considered important because of the user group. The questionnaire made use pictures on a likert scale as can be seen in the snapshot below:

a. Answer for CIS:

| | | | |
|---|---|---|---|
|  |  |  |  |
| Yes, definitely | Yes, to some extent | No, not really | No, definitely not |
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> | 4 <input type="checkbox"/> |

9.3 Delivery / implementation

9.3.1 Costs and economic considerations

The Partnership Trust highlighted that they would have to recruit an agency staff member as they had no capacity to undertake additional activity (such as the labelling of survey packs) within their existing staffing establishment.

Table 14: Fieldwork costs for Staffordshire and Stoke on Trent Partnership NHS Foundation Trust

| Fieldwork activity | Cost |
|-------------------------------------|-----------------|
| Printing and packing | £345.00 |
| Delivery of questionnaires to trust | £16.70 |
| Postage for mailing | £306.00 |
| Data entry | £334.05 |
| Invoice for administration | £750 |
| Total | £1751.75 |

9.4 Dissemination

At the time of publishing this report the survey for the trust was still in field (this was due to the process of drawing a sample taking much longer than expected). At time of writing the survey had a response rate of 15%

Final data will be presented to the trust in a way that allows them to look at results for the individual services, Community Intervention Service (CIS) and Living Independently Staffordshire (LIS). Freetext comments will also be separated by service.

The trust indicated that results would be fed in to the trust wide action planning

9.4.1 Success of the method

9.4.1.1 Sample selection and validation

The sample required validation to ensure that everyone selected had received a review in the period September~December 2013. In addition to this, checks needed to be carried out

by district teams to ensure that all those in the sample had capacity. Whilst with all surveys samples should go through a process of checking to ensure that only eligible people are included, moving forward if implementing a monthly collection of CIS/LIS it would be important to make sure that reviews are logged in a consistent manner on Care Director. This would minimise the checking required and burden on staff. However, if the Care Director system is unable to log reviews in a consistent manner then the roll out of a monthly data collection using this criteria would have to be reconsidered. The process of asking each district team to check the sample would also be viable if rolling out a monthly data collection.

9.4.1.2 Questionnaire

As previously mentioned the trust had a questionnaire already in development for use in an adult social care data collection. This questionnaire had been through a consultation process with a variety of staff contributing to the questions and format. This gave an extra sense of ownership to the questionnaire and data above that seen with the other pilot sites (where the generic core questionnaire was rolled out with a handful of specific questions).

10 Oxford Health NHS Foundation Trust

10.1 Context / background

Oxford Health NHS Foundation Trust is a community focused organisation that provides physical and mental health and social care.

This pilot site represents a survey of community mental health services in Oxford. The pilot evaluation was driven and led by managers at the trust with key guidance and support from the Lead for Registration and Quality.

10.1.1 Structure

Oxford Health NHS Foundation Trust provides a range of mental health and community services across Oxfordshire, Buckinghamshire, Swindon, Milton Keynes, Wiltshire, Bath and North East Somerset. Prior to April 2014 there were four main groups of services:

- **Mental health services**- community and inpatient covering adults and older adults.
- **Oxfordshire Community Services**- providing support and services for adults and older adults with long-term physical conditions.
- **Children and families services** – community and inpatient mental health services and providing support for children with long term physical conditions.
- **Specialised services**- salaried dental services, inpatient and community forensic mental health services and hard-to reach groups (substance misusers and offenders).

There are a range of mental health services provided which include inpatient care, community mental health teams (CMHTs), crisis and acute services, day hospital and a range of complementary services for older adults. This survey focused on adult community mental health services provided by a selection of CMHTs.

10.1.2 Current and past arrangements for patient experience feedback (as of December 2013)

There are patient experience leads for each of the four groups of services provided at the trust. A comprehensive patient experience strategy, discussed and approved at trust board level outlines current arrangements and future approaches to patient experience. This was undergoing revision at the start of the project and a revised strategy approved.

Surveys carried out included:

- **Postal and electronic surveys** for specific services (developed locally but using a few core questions across all surveys)
- **NHS Community Mental Health Service Users Survey.**
- **Focus groups**- one example was with homeless people with MH problems who access GP surgery designed specifically for the homeless.
- **Patient and carer forums** – one example was the Patient Councils established for the Forensic inpatients.

The trust has five years' of experience of using electronic methods including online, hand held tablets and kiosks. Hand held tablets have been used with varying success; palm held were considered too small. There are also kiosks for capturing real-time feedback. The trust uses two external companies to support the paper and electronic solutions to collect feedback.

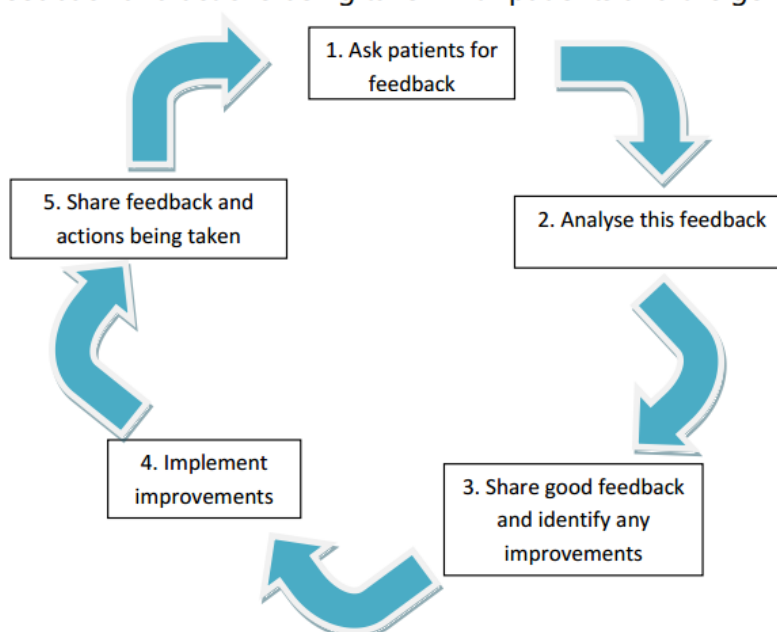
10.1.3 Current arrangements for action planning and quality improvement (as of December 2013)

Results of all surveys (national and local) are compiled and key areas for action and improvement are identified and monitored by the four groups of services, and overseen by the Trusts Integrated Governance Committee.

The trust uses the definition that patient experience is feedback from a person about their individual feelings, views and opinions on the care they have received and which sometimes also explores level of satisfaction. The trust's Patient Experience Strategy 2013-2016 focuses on using feedback to confirm that they are delivering care in the way a patient expects, to share good practice and to make improvements.

The trust has developed a Communications and Involvement Strategy which reports quarterly to the Board of Directors on activity and progress with public and patient involvement. The figure below outlines the trust's approach to patient experience and service improvements.

1. Regularly ask patients for feedback
2. Analyse this feedback
3. Share good feedback and identify any improvements with clinical teams
4. Work with clinical teams to implement the improvements
5. Share feedback and actions being taken with patients and the general public



10.1.4 Project team

The project team for the survey included a range of senior managers:

- Lead for Registration and Quality

- Manager of services
- Director and Deputy of Nursing and clinical governance

Other staff were consulted during specific phases of the project.

10.2 Planning

10.2.1 Agreeing the approach

Much thought was given to the different populations served by the trust. It was mutually agreed to take a 'pathway' approach of capturing patient's experiences of a number. There were many service-line approaches to local collections and the trust was keen to pilot new approaches. A pathway perspective was to be tested by asking respondents to report their experiences of all services received in the previous year.

It was identified that there was a need to gather feedback from older people who receive both mental health and physical health services. These patients are likely to have dementia and have complex physical needs and therefore access other community services. It was considered to be valuable to collect patient feedback from this population along their patient journey rather than each service using a different survey. However, as these people are likely to have cognitive impairment, it was considered to be very challenging for this pilot.

Patients who were on Community Treatment Orders (CTOs) were also considered as potential inclusions but staff at the trust stated that this would only be a small sample of patients and that recent feedback had already been collected from this group of patients as part of telephone interviews in October 2013 and January 2014.

There was consideration given to include patients with psychotic illnesses such as schizophrenia, psychotic depression and bipolar who have a severe mental illness. It was decided to select a sample of patients from mental health clusters 11-17 aged between 18 and 65 years.

The following patients would be excluded - clusters 1,2,3 (mild depression, autism) and 10 (Early intervention/first episode). Severity of illness was not considered important in the analysis. Patients would be selected from central electronic systems using computer generated random selection, those patients who had been sent a survey through the national MH community or inpatient survey, the national schizophrenia audit survey or a previous local survey in the last 12 months were excluded to try and avoid patients receiving multiple surveys.

10.2.2 Method used for data collection

Through discussion with the pilot site it was agreed that a paper-based survey mailed out to patients home addresses would be the most appropriate method. Two mailings were carried out, the reminder mailing being sent to non-responders only after four weeks.

10.2.2.1 Use of staff and patient information sheets

It was agreed that two posters would be drafted: for staff at the CMHTs and for patients displayed in clinic waiting areas and the day hospital.

10.2.3 Sampling

There were around 800 patients in each CMHT (600 in clusters 4-17). There was concern that patients with schizophrenia may receive more than one survey; there was a National audit planned for August which would coincide with selection of patients for this project fieldwork. Sampling to avoid administering surveys to patients receiving the nation audit was considered. The national audit samples n=200 patients from ICD10 codes.

Consideration was also given to exclude patients who had been selected for the recent National Community Mental Health survey.

A pilot sampling strategy was carried out prior to fieldwork to identify the number of potential participants' who had not been included in a) the National Schizophrenia audit and b) the NHS Community Mental Health Service User Survey. Furthermore, patients were excluded from the following criteria

- MH clusters 1, 2, 3, 10, 18, 19, 20 and 21
- Patients been seen by services for less than 12 months
- Patients from out of area
- Current inpatients

A random sample of n-250 patients from nine of the CMHTs, with a predicted 20% response rate would result in an achieved sample of 200. This was considered acceptable for the pilot. Following the pilot of the sampling strategy the following were selected. Table 15 outlines the sampling from each CMHT.

Table 15: Sampling numbers

| Team | Area | Sample |
|--------------------------|------------------|--------|
| Bucks North West | Aylesbury | 100 |
| Bucks North East | Aylesbury | 150 |
| Bucks South East | Amersham | 80 |
| Bucks South West | Amersham | 120 |
| Oxon City East | Oxford City | 170 |
| Oxon City West | Oxford City | 170 |
| Oxon South West | West Oxfordshire | 170 |
| Bucks Assertive Outreach | Bucks | 20 |
| Oxon Assertive Outreach | Oxon | 20 |
| | | 1000 |

10.2.4 Questionnaire content

Patients discharged from hospital were likely to receive multiple services. There was concern that it would be difficult to identify the services on which patients would be basing their views. It was suggested to have sign-posts in the survey to each service (like the

Picker inpatient survey) but this was considered burdensome and lengthy which could impact on response rates. The trade-off between service-lines and global ratings were acknowledged. An important issue for patients with mental health problems was whether care coordination was working well for them. Patients should know who their care coordinator or keyworker is. The following were identified as additional questions:

- Do you know who your care coordinator/keyworker is
- How helpful were they in coordinating your care?
- If you used another service in addition to CMHT was there a discussion to update your care plan?

Changes were made to the survey to capture terms meaningful to mental health service users. For example, '*mental* health condition' was added; removing healthcare from 'staff' items.

It was agreed that a list of services would be included at the front end of the survey those that patients were likely to access. These would include those provided by the trust and also third sector organisations. It was noted that social services are integrated within the trust. The following services were suggested:

- Community Mental Health Teams (CMHTs) for example: psychiatrist, community psychiatric nurse, social worker,
- Crisis team
- Inpatient
- Day hospital
- Drug and alcohol services
- Complex needs service
- Psychological therapist
- Voluntary organisations

An overall rating scale was suggested for each service. In addition to this, text boxes could be inserted throughout the survey to capture patient's specific comments. A member of the local PPI group was consulted about the content of the questionnaire.

10.3 Delivery / implementation

10.3.1 Administration

A random sample of patients from the electronic register was selected. Fieldwork commenced in August 2013 and the closing date for non-responder reminders set as October 2013. The response rate for the survey can be seen below.

| | | |
|------------------------------|--|----------------------------|
| Dates of Fieldwork: | First mailing | 14 th August |
| | Reminders for non-responders | 14 th September |
| Response Rate: | Initial Mailing | 1000 |
| | Total Returned completed first mailing | 149 |
| | Total returned | 263 |
| Overall Response Rate | | 26% |

10.3.2 Costs and economic considerations

It was noted that identifying and screening patients and practical aspects of posting surveys was labour intensive. Payment was agreed to cover costs to administer the surveys. Costs are detailed below.

Table 16: Fieldwork costs

| Fieldwork activity | Cost |
|---|-----------------|
| Printing and packing | £748.00 |
| Delivery of questionnaires to Oxford Health | £33.40 |
| Postage for mailing | £727.00 |
| Data entry | £653.25 |
| Invoice for Norfolk administration | £360 |
| Total | £2521.65 |

10.4 Reporting

Results were presented in a report with sections as follows-

- Demographic description of responders
- Services accessed and ratings
- Overall responses
- Responses by CMHT
- Responses by cluster (non-psychotic and psychotic)
- Free text comments by cluster (non-psychotic and psychotic)

10.4.1 Key results

Most of the responses to items in the survey were positive and in many cases at the highest rating. 60% of participants found it very easy or easy to get the care they needed when they wanted; 9% found it very difficult. 61% had been given the right amount of information about their condition but 25% felt that they had not been given enough.

Over 80% had been involved in decisions about their care and had opportunities to discuss worries and fears. Three-quarters of participants had reported that they had one person who coordinated their care; just over half reported that they were helpful and kept them informed.

Discussions related to using other services and updating care plans was not completed by 30% of participants, 23% did not know this information and 19% stated that this did not happen. Generally though, participants responded that the different people caring for them worked well together.

Over half of respondent's family and carers had been offered involvement in their care; 12% did not want them involved.

90% of participants reported that staff had responded to their individual needs and 88% reported they felt safe. Confidence in staff and being treated with kindness and understanding was reported by over 85% of participants. Care was perceived to be helpful by 80% of participants; equally, services helped participants better understand and manage their condition.

A third of participants rated their care overall as excellent; 46% as good. Only 6% reported very poor experiences.

10.4.1.1 Services accessed

The questions relating to services accessed and overall ratings were not completed consistently by a large proportion of participants. In some cases ratings have been provided but the box was not ticked as having accessed these services. While we can be confident that if they have rated the services they have clearly accessed or used it, what we cannot be sure of is if people had accessed the service but not provided a rating. Ratings for each service were mostly good or excellent.

10.4.1.2 Patients' experience by county, cluster and team

There was very little difference in experiences by **county** with the minor exception for question 3 where 31% of patients from Bucks reported not being given enough information about their condition compared to 19% in Oxon.

There were no striking differences in patients experiences based on mental health **clusters** of psychosis and non-psychosis.

Patient's experiences by **team** were slightly variable but overall positive. There was a very slight trend of patients from Bucks South East to report less positive experience compared to other teams. This was not significant, but responses at the highest range were less than other teams especially for question 17 evaluating patients overall ratings of experience. However, Bucks South East was the only team where 100% of patients reported having one person who manages or coordinates their care (Question 5). It should be noted that there were only ten participants who responded to the survey from this team; there were around 40-50 responses from other CMHTs.

10.4.2 Free text comments

Participants from all of the CMHTs report descriptive accounts of excellent services and care from specific healthcare professionals including psychiatrist, CPNs, social workers and support staff. Many report good access to the crisis team and staff being responsive to their

needs. Some staff were described as caring, supportive, respectful, non-judgemental, understanding and knowledgeable about them and their condition. Some found care and support effective in preventing hospitalisation and helping them manage their condition.

There were a number of comments about poor care and services. In a few cases, participants expressed anger and frustration related to lack of understanding of their condition by healthcare professionals and unresponsiveness to crisis and needs. Some reported lack of consistency of care from different staff and lack of referral to specialist services.

Generally there were no specific differences in comments from the different mental health clusters. The only specific comments from the psychotic group that were striking were related to feelings of suspicion about the purpose of the survey and concern that their answers would be linked to them as individuals.

10.5 Dissemination

The dissemination meeting to discuss results was attended by the project team members but included other stakeholders'.

10.5.1 Success of the method

10.5.1.1 Response rate

Staff were not surprised by the 26% response rate and thought this was typical of surveys for mental health patients. The response rate for the national community mental health service user survey at the trust was 34%. It was noted that there were differing response rates from specific CMHTs; this was thought to reflect the different populations they serve. City West CMHT covered more affluent areas whereas City East CMHT was more diverse-university students and people with chronic illnesses.

Staff were thoughtful about different methods of feedback from patients to maximise responses. Different methods are trialled and deployed across the trust to collect feedback tailored to different settings and patient groups to encourage patients to tell them about their experience eg handheld tablets, kiosks, on-line surveys on the website and via iPads, postal surveys, patient groups, patient interviews, talking mats.

10.5.1.2 Quantitative results

The tables of results were thought to be confusing as it was not clear the number of participants' from each team. The charts were revised post meeting to indicate these. The results per team were thought to be useful specifically the free text comments. The results were disseminated to each team. The trust has found patient feedback is most effective when it can be broken down to team level.

Staff were interested in exploring whether patients accessing several services report a better or worse experience. Additional analysis was conducted. This was carried out post meeting and with discussion with the Quality lead and project team at Oxford. Further analyses were carried out to examine experiences of multiple service users. Further discussions were related to identifying how each of the patients rated their overall experience with the services (CMHTs, Crisis Team, Psychological Therapies, Day Hospital, Drug and Alcohol, Complex Needs Service, Inpatient wards and Voluntary organisations) to identify if a patient has a poor experience with one service did this affect their experience of the other services. The

questionnaire asked service users to rate the individual services that they used. These ratings were compared to the overall rating provided at the end of the questionnaire. For example for the Community Mental Health Teams (CMHTs) 78% of people who rated their overall experience as Excellent also rated the CMHT as Excellent.

While this was considered to provide more detailed information, analyses at an individual patient level was not deemed to be appropriate. It was accepted as a limitation of the analytical approach.

10.5.1.3 Qualitative comments

Staff thought the free text was informative and useful to feedback to teams. However, it was noted that some of the named services were removed. It was acknowledged that individual names of people should be excluded but it named services should be reports. This information was provided post-meeting.

10.5.1.4 Friends and Family Test

At the time of fieldwork, the FFT was not required for the trust, however the same model introduced for acute hospitals was rolled out across the 10 Community Hospital wards and three Minor Injury Units. Staff thought that it was a worthy question but concerns raised about the feasibility of introducing it using the same model as the acute hospitals for all community based services.

10.5.1.5 Key Themes

The findings were thought to support the results from the 2013 NHS community mental health service user survey and also the local monthly survey started from Oct 2013; experiences were consistent and provided additional weight to the evidence. The key areas for improvement being consistently feedback are: patients feeling involved in decisions, patients experience of care review meetings, not receiving enough information and wanting more involvement of their families and carers.

10.6 Sharing of results and what next

Overall the survey was thought to be useful but it was nevertheless felt that a pathway approach (inviting respondents' to provide more global responses to services) would only be useful if methods could also be developed to highlight experiences of specific services so that feedback can be acted upon. The trust also piloted a survey locally for Stroke patients and found challenges with receiving feedback about services which are not provided by the trust.

In 2014/15 the trust is planning to learn from the experiences in 2013/14 to trial further methods for asking patients for feedback along their journey through services, with the aim to reduce duplication of surveys and work using a whole system approach. The trust is interested to learn and hear about the experiences from the other pilot sites in the collaboration.

The report was considered very helpful in this format and was shared with the Heads of Service and Service Managers. The services mostly commented on how helpful it has been to have a team level breakdown presented in a visual way using bar charts. The results and common themes from the survey were discussed with the Team Managers, Clinical Leads and Consultants in each Community Mental Health Teams (CMHT).

11 Nuffield Orthopaedic Centre

11.1 Context / background

This pilot site represents a service hosted in an orthopaedic NHS hospital. The service primarily is a referral 'hub' from primary care to secondary services. It provides triage, diagnostics and treatments.

The site chosen is a typical example of an innovative form of managing musculoskeletal care pathways and such hubs are being piloted elsewhere in the NHS, partly in order to more effectively manage elective services.

11.1.1 Structure

The 'Hub' is located at the acute trust and runs 2 satellite clinics at neighbouring towns. It is funded by the PCT but staffed by specialists at the trust. Patients are referred by their GP, seen at the 'Hub' and then either treated or managed within the Hub services or referred to musculoskeletal services. Decision about surgery or other forms of management can be made in the Hub or in secondary services for example Osteoarthritis knee clinic.

There are about 100 patients referred to the Hub per month; 5-10% are referred back to their GP without further assessment. 70% are seen in the clinic from the Hub and of these, 50% have surgery. This process aligns with the 18 week pathway. A decision aid for surgery is currently being developed. The service including two satellite clinics is provided at the Nuffield Orthopaedic Centre which has strong links with the University of Oxford, Institute of Musculoskeletal sciences and Botnar Research centre.

11.1.2 Current and past arrangements for patient experience feedback (as of December 2013)

The Friends and Family Test was implemented in April 2014 and the trust participates in the NHS Adult Inpatient Survey. Local collections include 'realtime' feedback via iPads- '*How are we?*'. In addition, interviews have been conducted with samples of patients at the 'Hub'. Findings include patients often thinking they have been referred to secondary care. There has been an assumption that patients don't like waiting for surgery but feedback suggest that delays are acceptable to patients if appropriately managed and explained.

11.1.3 Current arrangements for action planning and quality improvement (as of December 2013)

The Nuffield Orthopaedic Hospital is one of many hospitals in the Oxford University Hospitals NHS Trust. A range of priorities are outlined in the annual Quality Accounts which apply across the trusts.

11.1.4 Project team

The project was led by a Clinical Director of Services and supported by the Musculoskeletal Triage Manager. Information sheets about the project were distributed to other staff at the 'Hub'.

11.2 Planning

11.2.1 Agreeing the approach

Two meetings were held prior to fieldwork to determine the form, focus and purpose of the survey to be jointly carried out by the research team and the local site. Given that the hub was a recent innovation the opportunity to carry out a survey independent of the service providers was considered a positive opportunity. It was decided that the most useful form of a survey was to gather patients' feedback following their appointment at the hub (at all three sites).

11.2.2 Method used for data collection

It was agreed that a paper-based survey handed to patients during their appointment would be the most appropriate method. Patients would be encouraged to complete the survey prior to leaving the hospital but a pre-paid envelope would be included should they wish to return the survey by post. All staff were encouraged to administer the survey packs and this extended to staff taking surveys with them to the satellite clinics. No reminders were sent to non-responders.

11.2.2.1 Personalised letters

Covering letters to the survey were personalised with the Clinical Director's electronic signature.

11.2.2.2 Use of staff and patient information sheets

It was agreed that two posters would be drafted: one for staff at the clinic to inform them about the study and one for patients. The poster for patients was used to inform them of the forthcoming survey. This was displayed in the waiting area of the clinic.

11.2.3 Sampling

The intention was for the survey pack to be given to all patients attending the clinic over a period of four weeks. To maximise sample size, it was suggested to include patients at the above mentioned satellite clinics. An achieved sample of 200 was required but it was anticipated that a larger number could participate; there were about 100 patients referred and seen at the clinics per month. 500 surveys were prepared in total for the 3 clinics.

11.2.4 Questionnaire content

The core questionnaire developed for the study was considered suitable by the team. It was modified only to sign-post the patient to the survey relating to their appointment at the 'Hub'. The Friends and Family Test was also included as requested by the project team.

11.3 Delivery / implementation

11.3.1 Administration

During initial fieldwork it became apparent that there were very few returns. In response the Clinical Director ensured that staff were aware of the survey and encouraged recruitment. Fieldwork commenced in September 2013 and completed at the end of December 2013; a pragmatic decision was taken to end fieldwork to keep within the main project deadlines.

| | |
|------------------------------|------------|
| Surveys provided | 500 |
| Total returned from Nuffield | 138 |
| Total returned from Banbury | 0 |
| Total returned from Bicester | 9 |
| Total Returned completed | 147 |
| Overall Response Rate | 29% |

The final response rate should be treated with caution as it is not clear how many surveys were actually administered.

11.3.2 Costs and economic considerations

Table 17: Fieldwork costs for Nuffield Orthopaedic Centre

| Fieldwork activity | Cost |
|----------------------------|----------------|
| Printing and packing | £400.77 |
| Delivery of questionnaires | £25.05 |
| Data entry | £116.89 |
| Total | £542.71 |

11.4 Reporting

A report was generated and covered:

- Demographic description of responders
- Overall ratings for each question
- Friends and Family Test
- Free text comments

11.4.1 Key results

A few key results from the survey are detailed in this section.

Over 60% of responses were in the highest positive categories for most items. Patients felt they were given the right amount of relevant information, were involved in decisions, were encouraged to talk about their worries and fears and were treated with kindness and understanding. Patient also reported similar positive experiences related to coordination of care, physical needs being met and had confidence in staff. This was also supported in the free text comments. Furthermore, 72% of patients found the care they received helpful in dealing with the problem(s) they attended for.

Less than half of patients had a family member or carer to be involved in their care but of those that did, 18% stated that they were involved. Patients reported problems with the appointment system. This was illustrated in the free text comments.

11.4.1.1 Friends and Family Test

The FFT, Net Promoter Score was 46 as illustrated below:

Table 18: Results for 'How likely are you to recommend our department to friends and family if they needed similar care or treatment?'

| Q14. How likely are you to recommend our department to friends and family if they needed similar care or treatment? | Number | % |
|---|-----------|------------|
| Extremely likely | 77 | 52% |
| Promoters | 77 | 52% |
| Neither likely nor unlikely | 8 | 5% |
| Unlikely | 0 | 0% |
| Extremely unlikely | 1 | 1% |
| Detractors | 9 | 6% |
| Net Promoter Score (Promoters minus Detractors) | 46 | |

11.5 Dissemination

11.5.1 Success of the method

11.5.1.1 Participation rate

Staff noted the lower than anticipated participation rate (29%). It was acknowledged that some staff did not engage with administering the surveys to patients. Some patients were also keen to leave the clinic as soon as their appointment was completed and therefore did not complete the survey on site. Very few returns were received from the satellite clinics (Banbury=0; Bicester=9). It was noted that there was considerable burden on administrators who went to the satellite clinics. They were not able to provide support to patients to complete the surveys and there was no area for patients to complete the surveys.

11.5.1.2 Patient experiences

Overall scores were positive and correlated with other patient experience feedback in the past. It was noted that patients did experience difficulties with the 'Choose and book' system of appointments. For those who did complete the survey in the clinic, there were no complaints about the content of length of the survey. It was thought that an online version of the survey may have increased participation rates.

11.6 Action planning

11.6.1 Satellite clinics

It was agreed that more support and resources would need to be available for patient experience collections to be successful at these clinics.

11.6.2 'Choose and book'

It was noted and acknowledged that the 'choose and book' system was confusing for patients. Furthermore, different locations available for surgery added to the confusion for patients when choosing the location for their appointment.

11.6.3 Collaboration with Clinical Commissioning Groups and GPs.

It was thought that there needed to be better communication and collaboration with CCGs and GPs. It seems that there are some patients who are referred to the 'Hub' who do not need secondary services. Experience with working with CCGs suggests that there is some scepticism about providers' collection of patient feedback and more support for an independent view.

11.6.4 Friends and Family Test

The Net Promoter Score generated from the results of the FFT was noted but it was difficult to extrapolate from the results as there was no comparator. It was thought to be use a useful and powerful indicator for the trust.

11.7 Sharing of results and what next

The results were presented by the research team to the site collaborators, particularly the Clinical Director of Services. The main conclusion of the meeting was that having an independent assessment of an innovative service had been invaluable.

Hubs to manage patient pathways for musculoskeletal services are potentially controversial given that they manage demand from primary care services for access to elective surgery. The largely positive responses observed in the survey provided some reassurance of the acceptability to patients of this innovation.

The main action for the site arising from the survey was to intensify efforts to communicate to GPs and CCGs about how the hub worked so that patients received accurate information about accessing appointments and how the hub would help them.

12 Northumbria Healthcare NHS Foundation Trust

The seven sites described so far in the report were involved in the project as pilot sites, where new survey collections were rolled out as part of an intervention to assess the impact of collecting patient experience along pathways or within service lines. Initial research to select potential pilot sites quickly identified Northumbria Healthcare NHS Foundation Trust as a trust whose own local work on patient experience was far more comprehensive than is currently typical for the acute hospitals sector. Indeed, some of the existing work in the trust appeared analogous to the service line approach being tested.

The trust were therefore approached as a potential pilot site, and were keen to participate. Ultimately this did not prove feasible given the respective timetables and requirements of the project and of the trust. Nevertheless, detailed discussions were held with the trust's Director of Patient Experience both at the start of phase two of our project and during the evaluation. During this time, the trust had undertaken work of its own that provides a useful and informative addition to evidence from the pilot sites we work with. We therefore present a description of the trust's work and experiences as a case study to accompany the other pilots.

Evidence in the case study is drawn from two interviews with the trust's Director of Patient Experience, Annie Laverty, in August 2012 and March 2014, as well as from additional materials provided by the trust.

12.1 Context / background

Northumbria Healthcare NHS Foundation Trust is a large multi-service organisation providing a combination of acute hospital, community health services, and adult social care across a large and diverse geographic area. The trust's area of operations spreads from the Scottish border to North Tyneside, covering both highly rural areas in the north and heavily populated towns further south. The trust employs almost 9,000 staff and runs three general hospitals as well as six community hospitals.

Internally, the organisation has five business units (eg medicine and emergency care; community; child health; etc). Each are very autonomous but all are expected to (and do) buy into the corporate vision set by the board and senior leaders. A centralised patient experience team supports all business units and is led by a board-level Director of Patient Experience – the first at the trust, and one of very few such roles in England – who has been in post since December 2009.

12.2 Measuring patient experience

Like most trusts, Northumbria have been measuring patient experience for many years, including as part of the NHS Patient Survey Programme established in 2002. Although the trust had been doing their own work previously, they note a change in their focus from 2009 – moving away from 'measurement' alone to concentrate on 'measuring and improving'. A key principle is that the team "never measure anything if we don't have the resource to improve it". In line with this, a £100k spend on measurement in 2009 had been halved by 2012 and the £50k savings spent on improvement work.

In spite of these changes, the trust was nevertheless able to conduct a range of patient experience data collections, including:

- A large-scale **postal survey** with regular mailings to recent patients. This included approximately 12,000 inpatients and 8,000 outpatients a year and used questions from national surveys. Results were reported at organisational level on a monthly basis (to the trust's board) and an on an annual basis to individual consultants, who were presented with their own personal results. Results for individual consultants are also published in part – albeit that only results for the top 20 consultants are published. However, results for all consultants are used as part of their appraisals, and the trust's CEO writes to individual consultants each year to draw attention to their results.
- A programme called “**two minutes of your time**”: very short surveys including a mix of qualitative and quantitative items given to people on the day of their discharge from hospital. Around 6-7,000 responses were received annually via this approach. The trust noted that results were very positive and commented that this reflected a halo effect at the point of discharge – but the results were nevertheless considered useful for comparing between wards.
- A regular programme of **near real-time feedback** collecting, as of August 2012, an average of around 600 responses per month (7,200 per year). Perhaps unusually, given that most 'near real-time feedback' is focussed on electronic solutions, this involved face-to-face interviews. Thirty wards were included across five sites in 2012; by Spring 2014 this had been extended to 37 wards over seven of the organisation's ten sites. Each ward would be visited for one day twice each month, and fifty per cent of the patients on the ward would be interviewed by members of the patient experience team.
- One example of a **pathways survey** (covering people treated for a hip fracture). Keen to understand people's experiences of different service after suffering a hip fracture, the trust had completed a small study. This used an independent cross-sectional surveys approach equivalent to the one we piloted in Sheffield Teaching Hospitals NHS Foundation Trust. In Northumbria's case, patients were interviewed at one of three stages of care: A&E, acute wards, or discharge and community rehabilitation. Results were presented as comparative data for each setting. Although the survey was small and include only a low number of patients, the trust noted that getting feedback had been more manageable in acute settings as opposed to community settings.

The trust's view is that none of these approaches give the whole picture on their own: hence the approaches are intended to be complementary. Additionally, it was noted that some of the trust's collections include items asking people for their consent to be recontacted about their experiences. This allowed follow-up with patients to learn more about their stories. Accordingly, the trust acknowledged the role of patients as “witnesses”; an often untapped resource for understanding and improving.

12.3 Reporting

The trust had a sophisticated approach to reporting patient experience data. In particular, this included a microsite on the trust's intranet that made patient experience data accessible to all staff. This redacted identifiable information on patients but otherwise retained praise

for named members of staff. As well as making the data available openly, the trust sought to 'push' results to staff via targeted e-mails, making individual wards or units aware when new data about them was available. The trust noted that, having done this for some time, it was increasingly the case that these e-mail notifications would prompt conversations about quality and improvement between front-line staff and the patient experience team.

Wherever results were reported, the trust sought to tailor feedback to different audiences. For example:

- Board level data focussed on quantitative data – “it has to be numbers” and the volume of data is important.
- For clinicians, particularly doctors, it was again the case that high-volume data was valued. It was felt that they would not have accepted the various measures otherwise.
- At ward level, qualitative feedback is important. Ward managers look at the broad shape of trend graphs then look at the written comments.

For quantitative data, the trust had sought to set its own standards to help people to understand results. For near-real time feedback, in particular, the trust has gradually adopted a standard for scores: all should be greater than nine out of ten. This helps as an independent, free-standing marker – clinicians know what they are aiming for and don't need external data to benchmark their own performance on an everyday basis. It is used as “a trigger: not for blame but for talking about what's wrong”. The trust took 18 months from implementing this standard to most wards meeting it: a strong focus on improvement in the interim helped.

12.4 Service improvement

As described above, the trust stressed that their corporate vision of patient experience is about both measurement and improvement, and that their guiding principle was that the team “never measure anything if we don't have the resources to improve it”. Broadly speaking, the trust's approach to service improvement was rooted in an organisational development approach that looked at the 'health and wellbeing of services themselves.

Where a ward is performing poorly on patient experience measures, the patient experience team investigate the ward's own 'health and wellbeing' in terms of factors like staff experience and morale, clinical standards and so on. This becomes part of a discussion or intervention with the ward. Initially some wards were “nervous” about this, but most now “see patient experience information as indispensable” – and the trust stated that the level of staff engagement with patient experience had been “beyond expectations”. The trust felt that maintaining a consistent focus and clear principles has helped: another principle being that they “measure to improve, not to punish”.

In keeping with this ethos, the trust also had some resource available for individual teams or wards with ideas about new approaches for improving patients' care or experiences. Teams were able to request support from this fund and receive support quickly if ideas were considered useful.

Reviewing the trust's progress in 2014, it appeared that good progress had been made. The trust were able to demonstrate statistically significant improvements in the majority of their key measures on year-on-year comparative results.

12.5 Barriers and enablers

The trust considered their own programme of work in Northumbria to have been highly successful, and with evidence to support this: not only have they consistently achieved some of the most positive results of any trusts in national surveys, but they have shown significant improvement locally in recent years. We discussed the factors that affected their ability to improve in terms of patient experience.

- Senior level support, particularly from the CEO, board, and non-executive directors, was seen as crucial: all had “really got behind” data on patient experience.
- Organisationally, the trust is heavily invested in clinical leadership: one third of the executive team members were actively involved in clinical care. There is, consequently, “a sense that clinicians are in charge”.
- Collecting information in large volumes was seen as important in convincing people of the value and importance of data. This was especially true of consultants, who wanted to see confidence intervals around survey estimates and so on.
- A consistent, evidence-based approach was another factor seen as helpful in convincing staff of the value of the collection. It was noted that “focussing on a handful of measures driven by what matters to patients really resonates with staff”, and that the selection of measures used had remained fixed from 2010 to 2014.
- The trust was already a relatively high performer on patient experience before embarking on some of its bigger projects like individual consultant reporting. They expressed a view that such reporting may have been a challenge if they were a lower performing organisation.

12.6 North Cumbria University Hospitals NHS Trust

From April 2013, Northumbria became a ‘buddy’ for the neighbouring North Cumbria University Hospitals NHS Trust. Earlier that year North Cumbria had been identified as one of fourteen NHS trusts to be included in Professor Sir Bruce Keogh’s review of organisations with higher than expected mortality rates over a two-year period. Following the publication of the review’s final report, in July 2013, the trust was placed into special measures²⁶.

Prior to entering this ‘buddy’ arrangement, North Cumbria collected patient experience data from national surveys, complaints, and serious untoward incident (SUI). They also collected near real-time feedback locally using an informal CAPI (computer assisted personal interviews) approach, wherein volunteers from a ‘Patient Panel’ interviewed current patients using tablet computers such as iPads. This approach differed from the near real-time feedback collections in Northumbria, particularly in the use of volunteers, and this would have raised challenges around comparability. With the start of the buddy arrangement, there was a desire to transition towards a common platform. Northumbria’s patient experience team worked with North Cumbria’s board to secure funding for a new patient experience function, including a small team of staff with modest bandings and the same

²⁶ Keogh, B. (2013). *Review into the quality of care and treatment provided by 14 hospital trusts in England*. NHS England: London.

combination of methods used in Northumbria. The aim was, in short, to replicate Northumbria's approach as far as possible in a more challenging environment. A particular barrier was that in 2012 North Cumbria had "amongst the least happy staff, as evidenced by the NHS Staff Survey" and had had a series of changes to management teams in preceding years.

Encouraging staff engagement, which had proven easier than expected in Northumbria (see 12.4 above), was therefore important. To do this, Northumbria's team sought input from staff at North Cumbria on the questions to be asked in new collections, and shared all results in real time. They also stressed that not all of the new programmes required input from staff locally, which was considered helpful. The key factor in engaging front-line staff, though, appeared to be rapid sharing of feedback: results from the near real-time feedback collection described in 12.2 above, for instance, were returned within 24 hours where possible and supplemented by weekly reporting (promoted via newly established regular ward meetings). Results, although showing clear room for improvement, were used to celebrate success wherever possible. The reaction to this was very positive, particularly as there was a sense that at least some staff were expecting patients' responses to be a source of criticism. For example, one ward manager had been reluctant to hand out feedback cards, but started to do it when they read the comments and saw the gratitude of patients.

12.7 Conclusions

We discussed the learning points from the trust's programme of work, and particularly their own conclusions about what worked. Ultimately it was felt that it was particularly important and beneficial:

- to "measure the right things" and to *keep* measuring them – rather than to "chop and change" items or approaches regularly;
- not to focus purely on comparisons. Although there is competition in the NHS (within as well as between organisations), the trust's view was that the key thing to focus on was *improvement* rather than relative performance;
- to have organisational stability: the trust had had the same chief executive for ten years and the same director of patient experience since 2009. This was considered "absolutely critical" to enabling the strategic development of an approach.

Additionally, we note that:

- An important mechanic in manufacturing service improvement within the trust appears to be a habit of using patient feedback as the basis for discussions about improvement. The patient experience team facilitates this and it appears that the use of a consistent and focussed approach has encouraged the front-line to pay attention to and act on results.
- Some of the initiatives running successfully in Northumbria could conceivably be seen as challenging in other trusts – particularly the reporting of results about individual consultants, for example. Staff buy-in and support appears to have been important in allowing these approaches to flourish, and a positive and improvement-focussed approach appears to have encouraged that.

- There was a sense the trust's programme of work had not happened overnight. New programmes had been tested in small numbers of location and had gradually developed over time following a coherent long-term strategy. Successful programmes had been rolled out more widely but only when resources were available to make proper use of them. It was felt that "starting small and going incrementally has been so important" in building a successful programme.

13 Phase 3 – Evaluation

This section reports the lessons learned from the seven pilot sites and one case study. The overall aim of the project had been to develop and test a new model of assessing patient experience and to evaluate whether and how pathway and service line focussed approaches to assessing patients' experiences added value to standard organisational surveys.

13.1 Context

One of the most important early lessons learned by the research group was that in almost all sites there was a considerable amount of regular, locally initiated activity occurring to monitor patient experience and – wherever possible – to act upon evidence to improve services. Most services provided in the sites collaborating with the research team were the subject of regular monitoring, with multiple strategies of obtaining patients' feedback both in 'near real-time', when patients were in hospital and retrospectively, following up by a range of methods after discharge or use of the service by patients.

It was also striking how varied the technologies used to monitor patient experience are. A range of techniques such as hand held devices, comment cards, interviews were used to capture patient experience in real time, with diverse strategies of own employed staff, external agencies and volunteers to engage patients to complete assessments.

Similarly a diversity of approaches were used to follow-up of patients after their use of services: telephone interviews, postal questionnaires, and consultation events were all mentioned. Even with the naturally more limited resources available to the West Norfolk primary care practice, there was evidence of diverse approaches and techniques used either by the practice itself or in collaboration with the local COPD service team, on a more occasional basis, to obtain feedback on people's experiences of COPD services.

It was equally apparent that efforts were made in each of the sites to disseminate evidence from monitoring of patient experience and to facilitate service improvements in the light of evidence. Very rarely did it appear that action stopped at obtaining patient feedback. Typically, collated patient experience is regularly fed back to the most immediately relevant staff, whether ward or clinic staff, or relevant team in the community. Typically other higher level audiences in the clinical directorate or trust also receive the same regular aggregated evidence. In some cases sites sought to tailor the information being presented to different audiences, but this was not always the case.

Most importantly, almost all the sites had clear mechanisms intended to ensure that evidence from patient feedback is coherently overseen by staff with responsibility for the issue and is strategically taken account of by the organisation. Approaches include having staff employed to lead on patient experience or engagement, supported by and interacting with multi-disciplinary patient experience groups, with trust or board level patient experience strategies. In most sites, regular meetings of relevant staff to review patient experience evidence were being held. Just as importantly staff clearly expected to identify specific improvements in the light of evidence reviewed. These arrangements seem intended to ensure that mechanisms are in place to ensure the visibility and significance of patient experience and to maximise the likelihood that actions to improve are pursued in the light of evidence from users. Again, the Norfolk practice was the smallest organisation with least scope for staffing patient experience, but nevertheless did have an active Patient

Participation Group. At the other end of the spectrum, Northumbria Healthcare NHS Foundation Trust had the largest patient experience team of the sites we worked with, complete with a board-level director.

The majority of the existing arrangements observed in the sites could be considered to be related to service-lines in approach and functioning. That is, patient experience was gathered in relation to specific services, fed back to providers of those services, and higher level review and decisions about actions focused on specific services. In most cases, these approaches existed for silos: collections were specific to particular services rather than being implemented consistently across a range of them. Evidence from patient experience most relevant to staff providing a service was made available through diverse strategies and mechanisms were in place to take service-level improvements by the same staff.

This contrasts with the nationally initiated approaches to monitoring also taking place across health and social care. The nationally coordinated programmes, the responsibility of the Care Quality Commission, monitor patients in the different hospital, community, primary care, social care settings. This body of evidence is collected at quite aggregated levels and intended audiences are higher level regulators and providers. Whilst recognising the importance of the nationally coordinated programme, the sites less commonly referred to their results in relation to services. Although there is evidence that the national adult inpatient survey, for example, is reliable for specialties at suborganisational level²⁷, pilot sites were generally not using it in that way. An exception were Northumbria Healthcare, who had extended the collection of some questions from the national surveys to a much larger sample locally: results were broken down suborganisationally, even to the level of individual consultants, and the use of a large sample was seen as important in assuring staff of the credibility of that exercise.

A more visible national initiative for the sites with which we worked was the Friends and Family Test, a nationally mandated initiative launched at exactly the time of the current study. The Friends and Family Test meant a change in priorities for a number of the acute trust pilot sites and limited their capacity to take on new data collections. This was especially evident in the two acute trusts taking part in the research. For example, Sheffield Teaching Hospitals NHS Foundation Trust's volunteer workforce and handheld devices were committed to collecting data for the Friends and Family Test, ruling out this approach. Only one pilot site, Nuffield Orthopaedic Centre, chose to include the Friends and Family Test in their questionnaire to align with current collections in the trust in accordance with policy.

Generally, however, the Friends and Family Test and its very high level support gave added weight to the importance of patient experience as an issue. Also occurring during the time of our fieldwork, the other national level development with the same consequences was the final report of the public inquiry into Mid Staffordshire NHS Foundation Trust²⁸.

The array of local initiatives and the impact of national developments makes formal evaluation of the impact of the research group's new model and piloting with collaborating

²⁷ Sullivan, P. J., Harris, M. L., Doyle, C., & Bell, D. (2013). Assessment of the validity of the English National Health Service Adult In-Patient Survey for use within individual specialties. *BMJ Quality & Safety*. doi:10.1136/bmjqs-2012-001466

²⁸ Francis, R. (chair). (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London: The House of Commons.

sites very difficult. However, it is possible to look for themes and trends in how the sample of very different sites applied the new model and developed service line- or pathway-focused approaches to monitoring and responding to patient experience. In terms of the two overarching goals for the project, the first was to test the model of patient experience developed by the research group.

13.2 Testing the new model

When approaching the sites for collaboration, it was made clear that the overall purpose of the collaboration was to test whether a new questionnaire could be used to develop a more strategic understanding of patient experience along either service-line or pathway perspectives. Sites had first to assess the new questionnaire and then jointly agree a reasonably challenging context in which to test it in order to understand an important patient group for which they delivered services.

The majority of sites accepted the questionnaire as sufficiently promising and distinct from their existing approaches. All but one site accepted the core questionnaire in terms of domains of focus with very minor modifications. The modifications might be the addition of small numbers of additional questions relevant to their particular services, or more commonly modifications of actual format on the page to enhance readability. Using Homerton University Hospital NHS Foundation Trust as an example of modification of items, the Speech and Language Therapy Service added questions relating to communication and swallowing whilst the Acute COPD Early Response Service added questions focusing specifically on flare-ups (or exacerbations). As an example of modification of format, the South Coast Stroke Service were keen to employ an easyread format that they had developed and found acceptable in previous related surveys of individuals who had had stroke.

In addition, some sites were concerned that the generality in which items were expressed would mean that it would not be possible to attribute patients' expressed experiences to specific sources – ie particular providers. In such cases, for example, the South Coast Stroke Service, the questionnaire was further modified to invite respondents to cite specific services as particularly good or bad in relation to their answers to individual items. Broadly, the questionnaire was considered by sites to offer a sufficient range and appropriate focus of items.

The one exception was the preference of collaborators from the Staffordshire and Stoke on Trent Partnership NHS Trust to work with a local adult social care survey questionnaire that the Partnership Trust had been developing with local public and staff involvement. Not surprisingly, although it contained topics in common with the research team's instrument, such as information and involvement in decisions, certain key topics such as use of aids and home support were unique to the finally agreed survey in this pilot. This suggests that further work would be needed to produce a single overarching questionnaire that would equally fit both health and social care services.

13.3 Service-line sites

Sites were free to choose how they wished to work with the research team and the specifics of each pilot were negotiated. As discussion reached agreement over time, it became apparent that sites were choosing more service-line or pathway oriented approaches (the

language of these two approaches seemed too abstract to shape choices from the beginning). Fortunately the two approaches were tested by sufficient numbers of sites.

One of the sites testing a service line approach was Homerton University Hospital NHS Foundation Trust. The surveys that emerged examined patients' experiences of four very different services provided by the Trust, with the content and conduct of the surveys overseen by clinical leads for each of the three services and overall coordination provided by the Trust lead for patient experience. This corresponds closely to the 'bottom up' model for service line measurement outlined in section 3.1.2 above. Overall results were found helpful in confirming evidence from other patient experience initiatives and the ability to compare services directly across largely standardised items provided fresh evidence to the group. A similar logic operated in the Staffordshire and Stoke on Trent Partnership NHS Trust where the project group identified two specific services for which they wanted to see comparative evidence to assist in overall planning of their social care services.

The Nuffield Orthopaedic Centre pilot was considered an example of service line use of patient experience, but to some extent the distinction between service line and pathway breaks down. Musculoskeletal hubs have been developed in the NHS to improve management of elective services in this area of healthcare. In that sense hubs are introduced into a complex existing array of care pathways from primary to community and secondary services. However, as the vast majority of referrals for musculoskeletal conditions are now funnelled into a single service – the hub – it was possible to develop a fairly simple service line survey of how patients experienced the new service. In some ways this reflects a possibility flagged in our initial scoping work: that services with an effective focus on integration may appear (or become) effectively seamless to patients.

Overall the service line sites illustrated fairly simple ways in which information about patient experience can in many ways be considered like other data – whether that be financial, clinical, or patient safety related – that can be readily provided for teams or directorates responsible for delivery of specific services. A focus on suborganisational reporting of comparable patient experience data could provide useful management and improvement data, particularly alongside these other types of information. The evidence from the current research usually complemented other evidence of patient experience.

13.4 Pathway sites

Four sites developed plans for a patient experience survey that would explore pathway-focused approaches. Three sites elected to explore how a single survey of a patient group might throw important light on patients' experiences across a range of services: the South Coast of England Stroke Network, the West Norfolk Primary Practice (COPD survey) and the Oxford Health NHS Foundation Trust (and its focus on community services for individuals with severe mental health problems). From the outset discussion with all three sites recognised that a single survey would be a challenging vehicle with which to capture the range of patients' experiences of a wide range services. The sites were all willing to experiment to see what might be revealed.

The fourth site willing to test a pathway was the Sheffield Teaching Hospitals NHS Foundation Trust who elected to examine with the research group services for hip fracture. However, as will be discussed below, the project team reached the conclusion that the kind of single retrospective survey explored by the other three 'pathway' sites would not work and

instead opted for a series of cross-sectional surveys of specific services that taken together would provide evidence of patients' experiences across pathways. This approach may be considered hybrid, having elements of service line and pathway focus: each individual cross-section covers a service, but taken together they address a pathway of care. A similar approach had been trialled on a small scale in the case study site, Northumbria Healthcare NHS Foundation Trust, who looked at people's experiences of hip fracture treatment via a co-ordinated set of cross-sectional surveys. In that case, it was found to be useful but challenging to implement, particularly for community services.

The South Coast of England Stroke Network chose to focus on patients six months after their discharge from care for their stroke, particularly given that this was the time at which a new review of patients was to be instituted. In terms of reviewing patient experience, it was felt that most patients were likely to have experienced a wide array of services by the six month stage. The survey jointly developed by the research and site project team aimed to ask patients to report their experiences within one questionnaire, largely based on the template questionnaire developed by the research team. It was however recognised that this approach would not be able to attribute particularly good or bad experiences to particular services. The solution adopted was to use comment boxes in which patients could identify and describe specific experiences of particular services. On balance this approach to capturing patient experiences across multiple pathways was considered useful by the project team. The local CCG would consider repeating a similar survey. However it was agreed that the capacity to 'drill down' to attribute views expressed to specific services would still need further development.

A similar discussion and outcome occurred in the discussion with the West Norfolk Primary practice who decided to work with us on a pathway approach to understanding the experiences of their patients with COPD. It was recognised that a series of separate surveys of this patient group for each of the services they had used was likely to be highly burdensome to respondents, logistically difficult to administer and resource intense. Rather, as happened with the stroke project, it was agreed that a single overarching survey was preferable, not least because it would provide preliminary evidence of the numbers of their patients using each of the various COPD-related services available. The same compromise was reached that regular comment boxes throughout the questionnaire would be used to encourage respondents to identify good or bad experiences in relation to specific services.

The same issues were discussed by the project team for the Oxford Health trust wanting to review patient experiences across the array of different services whilst recognising that a series of separate surveys was not feasible for a finite population of users. This project arrived at a different solution. Whilst applying the same core instrument as had been used in most of the other sites, that is requiring respondents to report on their experiences across services received, in this case, in the last year, it was decided that it was feasible and informative to ask patients to provide a single rating of each of the nine specific main services they had made use of in the previous year.

Overall, novel strategies for tackling patients' experiences where they experienced multiple services and care pathways yielded modest success. There was widespread and understandable desire on the part of service providers to clarify the impact that specific services had upon patients' reported experiences. In the case of the Sheffield pilot (and the Northumbria case study) of hip fracture, this resulted in a decision to carry out multiple cross-sectional surveys of all the different services that contribute to patient care. In the

case of the other sites testing pathway-oriented approaches, a range of strategies had to be added into the survey either to provide freetext space for respondents to volunteer information about specific positive or negative experiences or the more globally oriented survey questions had to be supplemented by a series of specific ratings of particular services in the Oxford Health survey of severe mental health. The practicality and suitability of single retrospective versus multiple independent cross-sectional samples was related to the nature and size of the patient population, and this is further addressed in 13.7.1 below.

13.5 Methodological considerations

The study raises a number of methodological issues familiar in the field of surveys of patient experience.

Firstly, it was clear that collaborators in the sites valued having a combination of structured (quantitative) and qualitative feedback. Both kinds of evidence appeared equally valued. The various modifications of the standard patient experience survey developed for the purposes of this study were able to incorporate space and opportunities for extended freetext comment. It was clear that in most sites there was significant prior experience of obtaining both kinds of evidence and both approaches were equally valued, providing complementary insights into strengths and weaknesses of services.

Secondly, a risk familiar to all surveys arose across a number sites – that of poor response rate. Where lower response rates were recorded these were generally not considered surprising by the collaborating sites, being variously interpreted as reflecting background social and demographic factors of the local population, specific difficulties of some patient groups included in studies (for example patients with severe mental illness), or logistic challenges of delivery of surveys to patients.

It is of interest that by far the highest response rate was observed in a primary care setting where the survey was sent out in a personalised letter, with involvement by signature of the practice GP and nursing staff and notices in the practice highlighting the survey. The study does not make it reasonable to generalise from one case study, and there is a significant confounding factor in the demographic differences between populations. However it is an interesting example of monitoring of complex care pathways for a complex long term condition and comes closest of all the sites to being a true population-based approach to monitoring of a patient group's pattern of service experiences.

A third familiar methodological issue was considered in all sites: the method of delivering the survey. The majority of sites actively considered a range of media for delivering the proposed survey. Most sites were familiar with and sometimes had extensive experience of using alternative technology: hand-held devices, comment cards, telephone surveys, and several other approaches. In every case, it was mutually agreed that new technologies would not assist the planned survey and conventional postal survey methods were used. This was invariably a pragmatic choice based on the need to agree and deliver a survey within the time and resources available for the research project. A postal survey was by far the easiest and most reliable method to implement in a short period of time, particularly because it provided the easiest way of adding capacity (or 'scaling up' collections) without significant investment or burden.

13.6 Resourcing

The research team found without exception that there was very limited financial flexibility around patient experience activity in the pilot sites. Whilst all pilot sites could readily identify areas they wanted more patient experience information on, it soon became evident that the sites would need resources to enable them to implement new collections.

In the smaller pilot sites such as the West Norfolk primary care practice, resources were needed to support admin staff to process the surveys. In the larger pilot sites staff resources were present but were at capacity. In most cases pilot sites required additional funding to cover the time spent by staff to implement the survey. Costs varied depending on sample size and method.

It was evident that there was very little or no financial capacity in the pilot sites for doing more with patient experience that wasn't already planned for by the organisation, particularly in light of recently added national demands such as The Friends and Family Test. In one site, for example, plans to use tablet computers handed out by volunteers as a means of administering the collection had to be suspended because of demand to use this resource, previously deployed on locally prioritised collections, for the newly introduced Friends and Family Test.

A somewhat different approach to resourcing patient experience work had been visible in the case study site, Northumbria. In that case, dedicated funding had been made available "on the basis of rock-solid board support" and thanks to an organisational ambition to excel in patient experience. The trust felt that making resources available was fundamental to the values of the modern NHS, noting that "saying we can't afford to measure is like saying we can't afford to know how people think".

13.7 Local variation and national context

The sites we worked with varied considerably in their baseline state regarding the work they were undertaking and their operational readiness for patient experience feedback and research. This was related, although not intractably, to organisation size and resourcing.

In all pilot sites, national policy and top-down changes impacted organisations' measurement and improvement activities. The most noticeable changes in external context to impact on participating organisations were the Health and Social Care Act (2012), the introduction of the Friends and Family test, and the final report of the public inquiry into Mid Staffordshire NHS Foundation Trust. The passage of NHS reforms via the Health and Social Care Act has impacted particularly on the commissioning landscape, with the move from primary care trusts (PCTs) to clinically led commissioning groups (CCGs). Meanwhile, both the introduction of the Friends and Family Test and publication of the Francis Report have led to a shift in culture, with a renewed emphasis on obtaining patients' experiences of care in all organisations.

The structural implications of the Health and Social Care Act (2012) are widely reported and well known; it is beyond our scope to recite them here. However, there have been particular implications for the delivery of patient experience work locally. In some cases teams of staff with particular knowledge of or interest in patient experience have been separated. One site noted that their new commissioners post-reforms had less experience and understanding of patient experience issues, and were thus less willing to consider novel approaches.

The Friends and Family test meant a change in priorities for a number of the acute trust pilot sites and limited their capacity to take on new data collections, this was especially evident in the two acute trusts taking part in the research. For example, Sheffield Teaching Hospitals NHS Foundation Trust's volunteer workforce and handheld devices were committed to collecting data for the friends and family test ruling out this approach.

Only one pilot site chose to include the friends and family test in their questionnaire, Nuffield Orthopaedic Centre, to align with current collections in the trust in accordance with policy.

13.7.1 Population size and profile

Pilot sites took this research as an opportunity to explore areas not directly targeted by a national data collection, specific areas of interest, and, in some cases, areas the sites have had difficulty evaluating previously. It is clear that the makeup of pathways and services is a product of local circumstances, which are characterised by considerable variation. The services and pathways evaluated differed considerably and focusing on local pathways and services required a narrow, tailored focus. Population size, nature, and profile were two of these variants.

13.7.2 Size

When looking across the pathways and service lines evaluated in this research the volume of users varied considerably. This was particularly evident with Homerton University Hospital NHS Foundation Trust where the surgical rehabilitation service saw 60 users in three months compared to the sexual health service which saw over 2,000 users in the same period.

The variation in population size influenced the approaches taken with each site; approaches suited to larger populations were not necessarily suitable for smaller ones and vice versa. For example, a hand-out approach to data collection as seen with the hip fracture pathway would not be practical for surveying a census of users of the much higher-volume sexual health service at Homerton University Hospital NHS Foundation Trust.

Not only does population size influence mode, it also has an influence on the timeframe from which participants are sampled. For quantitative reporting of results, a minimum number of responses is generally required to ensure that the confidentiality of individuals is protected. Moreover, service providers are generally not familiar with adjustments to accurately reflect the reliability of estimates based on small groups of people (eg the finite population correct for estimates from simple random samples), so data from smaller services can appear with wide confidence intervals and lack perceived credibility. Getting a sufficiently large sample size for quantitative reporting can, then, necessitate a much longer sampling period for smaller services.

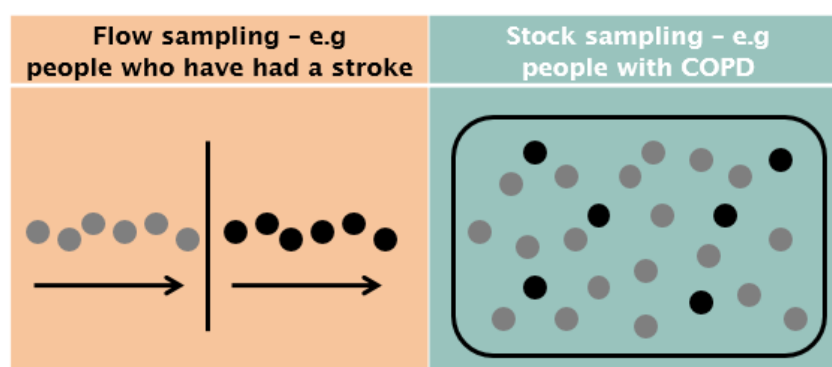
Another factor to influence sampling is the movement and interaction people have with health services and how this differs between conditions. A fundamental and important distinction exists between groups of patients and service users that exist as enduring populations versus those that are defined purely by their entrance to or exit from services. Stock and flow sampling is a good a way to demonstrate this influence²⁹. A flow sample

²⁹ Lancaster, T., & Chesher, A. (1981). Stock and flow sampling. *Economics Letters*, 8(1), 63–65.

consists of people moving through a care pathway or accessing a service, becoming eligible to be included in a survey by their entrance or exit to or from a particular service – eg by being discharged from hospital or attending a fracture clinic. With stock sampling you are selecting from an existing population of people whose eligibility is independent from their service utilisation. This is particularly likely to be the case for studies focussing on particular conditions: for example, all people QOF registered with COPD as was the case with the West Norfolk Primary Care Practice.

This distinction between stock and flow sampling is illustrated in figure 8, below. In this illustration, individual units – or patients – are represented with dots. Black dots are selected; grey dots unselected. In the flow sampling scenario, people are selected as their own pathway of care takes them through a particular ‘turnstile’ event. In the stock sample, people are selected at random from within an existing but finite population.

Figure 8: Illustration of stock and flow sampling



Stock and flow sampling are an important consideration in any patient experience survey, as the choice of one or other of these methods within a given study can have different implications for the representation of different patient groups. But it is particularly important when planning studies that look across pathways or service lines, because stock and flow approaches intuitively lend themselves to the planning of these studies. Stock samples are a natural way of defining groups for pathway studies because they are independent of individual services; flow samples make sense for service line measurement because they restrict eligibility to people who have passed through the service line’s care. Awareness of these issues is therefore important in planning such studies.

Population size and sampling frame are key considerations when implementing a data collection and from this research we have seen that one sample size does not fit all. With this in mind, and whilst it would not be appropriate to recommend one particular sample size or time frame for service line and pathway collections, this research reinforces the need to consider the number of users when measuring patient and service user experiences. Central to the implementation and use of any survey is the construction of a sampling frame as it determines the population to which results can be generalised. For a service line or pathway data collection at a national level the same sampling frame would need to be used for all services (or all pathways) to ensure that results could be comparable between organisations; it is clear that this would be difficult to design and implement.

13.7.3 Profile

Another of the variants to influence approaches taken, and the success of these, was population profile. Knowing the demographic profile of a local population is generally easy; understanding the best ways to engage with them is the real challenge.

For example, the Homerton Trust in London received response rates which seemed very low for this type of survey (see section 8), but was actually relatively normal for the trust. Homerton staff had identified poor response as an anticipated problem prior to fieldwork. In the National Inpatient Survey the trust only achieved a response rate of 30% which is quite low compared to other trusts and indicative of the trouble they have accessing patient feedback.

There are a variety of factors responsible for this that Homerton staff are trying to overcome. The demographic profile of the trust is disproportionately young and often service users do not speak English at all. Furthermore, many service users are illiterate in their native language and live in very transient and socially deprived communities. These factors combined hinder the trust's ability to seek written feedback or contact patients via post.

At Sheffield Teaching Hospitals NHS Foundation Trust the average respondent age was 83: unsurprising given the nature of the pathway, hip fracture. Because of this, the questionnaire was tailored with a larger font to accommodate those with poorer eyesight. Not only did the population profile influence the approach taken to questionnaire design but it had an effect on the success of the hand-out methodology; targeting frail patients in the first stage of acute care post-operation resulted in a selection bias.

For this research we were able to explore and implement quite specific approaches to collecting patient and service user feedback within each of the pilot sites. But this luxury is contrary to the requirement for consistency and standardisation in larger (or national) surveys involving multiple organisations. With any large scale national survey the demography of respondents will be mixed and an approach suited specifically to one group, such as older people, may not be suited to another. Because of this, at a national level, only a limited amount of tailoring can occur. There has to be a certain level of generalizability making some of the specific approaches taken with pilot sites in this research unsuitable for a national collection.

13.8 Adaptation versus standardisation

As mentioned in section 3.1.1 the research team felt that for a service line approach to data collection to be feasible it would need to be sufficiently generic that it can be applied locally without extensive remodelling to suit the local operating context.

Through discussions with pilot sites it soon became evident that it would be impossible to establish a 'one-size-fits-all' approach to measuring along pathways and service lines. This was the case with all aspects of design from sampling, questionnaire, fieldwork methodology to reporting. The need to understand and reflect local and condition specific considerations was evident.

Pathways collections using independent cross-sections (as seen with the hip fracture pathway) or retrospective measures (as seen with the stroke pathway) are viable, but depend on setting. A flexible approach is required and due to the variation between pathways and service lines it is important organisations do not take an existing model of

collecting patient experience and transfer it directly to another pathway or service without considering whether any alterations in design are required. Alterations in design might be required due to:

- Organisation specific service designs.
- Population size and profile.
- Data collection activities already underway at organisation.

13.9 The use of a generic survey instrument

The core questionnaire developed in phase one of the research was viewed positively by the pilot sites and ensured that all domains of the NHS Patient Experience Framework were covered. However, in all cases some amount of tailoring was required to ensure that local priorities were covered – be it modifications to format such as the design of an easy read version or the inclusion of questions specific to the particular pathway/service.

Tailoring the design of the questionnaire to each setting made it possible to ensure that the questions asked were those of the greatest relevance to the service and its patients/service users. Additional questions fell into three groups: condition-specific, service-specific, and target-specific.

Using Homerton University Hospital NHS Foundation Trust as an example the Speech and Language Therapy Service added questions relating to communication and swallowing whilst the Acute COPD Early Response Service added questions focusing specifically on flare-ups (or exacerbations).

However, there is a major disadvantage to this approach: increased tailoring leads to an increase in the cost of survey development and project management. For example, if Homerton University Hospital NHS Foundation Trust wanted to carry out a survey in each of their service lines, not just the four selected for this research, they would face the prospect of liaising with 50+ services all with different wants and needs. As the number of services increases the cost of a fully tailored survey becomes prohibitive making such an approach a less viable option for the trust.

This issue is not confined to service line approaches alone. If an organisation wished to look at a range of pathways using a cross-sectional design within each pathway it could lead to specific questions being added at each selected point within each pathway. Again, as the number of pathways and cross sections increases so will the cost and burden on staff.

Consequently, whilst there is definite merit in designing tailored questionnaires to gather detailed information on different types of services or stages in a pathway, our view is that this is most appropriate when done on a bespoke basis to provide a detailed investigation of a particular area. For the broader purpose of providing high-level feedback on patients' experiences of a range of different services within organisations, we believe that the costs and limitations of developing a series of tailored surveys outweigh the benefits. In other words, there is a clear trade-off between the value of local tailoring and the cost associated with this. Tailoring becomes less practical as the range of services and size of collection increases, such that more generic approaches should be favoured for larger collections.

13.10 Analysis and presentation of results

When deciding how to present results to the pilot sites there were two main considerations; audience and sample size & response rate and an unexpected finding, the importance of freetext comments.

13.10.1 Audience

As mentioned previously there were varying levels of familiarity and exposure to patient experience feedback at each of the pilot sites. Differences were seen not only between but within pilot sites.

The involvement of staff from different disciplines at each of the sites was essential for the planning and delivery of the collections but with it came the challenge of presenting results in a way that could be understood by all staff involved from patient experience leads to front-line nursing staff. At each of the pilot sites, staff involved with the research were asked how they would like their results presented and were able to ask for further analysis or changes in presentation once they had seen their report. Priorities were different for each of the sites and so the requests for further analysis varied. However, having the ability to drill down into the data further was important to all pilot sites.

This was particularly so for the staff at Oxford Health Foundation Trust. The staff involved in this research were a group very familiar with looking at experience data. They were keen to explore their results further and look at patterns in response specifically in relation to experiences with particular services and correlations with overall experience.

13.10.2 Size of response

Response rates influenced the analysis that could be carried out and is an important consideration when looking at developing a generic model for use across NHS organisations. Because of the variation in population size and responses seen between the service lines and pathways the prescription of one approach to analysis with the use of statistical testing could not be made.

Taking this into account, providing a standard template for analysis and presentation of results for service line and pathway approaches to data collection is challenging. Rather than prescribing one format it is more practical to provide a guide to data analysis which gives organisations suggestions on how they can look at their data.

13.10.3 Patient Comments

An unexpected finding from the research was the importance sites put on freetext comments. Freetext patient comments were largely thought to be a valuable source of qualitative information. Representatives from the Homerton Trust explained that patient comments are most useful when divided up by service line. This was not always possible, however, as some services had too few patient comments, and reporting them by service would have breached confidentiality. This was a common trend across sites- those with a sufficiently high volume of responses could use the comments to pinpoint service improvements, while those with a lower number of responses were only able to see trust-level aggregates of patients comments.

Although at a national level there is no exact way of reporting freetext comments in a uniform way, the underlying theme across trusts with regard to patient comments was that trusts found patient comments the most purely representative of the patient voice. Freetext allows

trusts to understand the things patients feel are important that they may not include in a survey. This type of feedback can promote person-centred improvement on very specific issues.

14 Conclusions

The current study provides further support for the view that, below the level of the national programmes of surveys of patient experience, there is already a very substantial level of local activity to obtain patients' experiences of specific services and to feedback this evidence directly to the relevant audiences of service providers. The sample of collaborating sites where this pre-existing activity was observed was diverse and extended well beyond larger acute trusts historically considered to be best equipped to develop and sustain regular monitoring of patient experience.

This array of activities to help the NHS to be sensitive and responsive to patients' experiences has been built upon a wide range of methods, not only to collect evidence of patients' experiences but also to report in accessible ways the evidence gained at a local level.

There are potential risks in this proliferation of approaches to monitoring patient experience, in that locally generated surveillance may not provide a complete picture of the full range of aspects of care that matter to patients. Moreover, they may create excess and unnecessary duplication whilst preventing comparability – and they still may not do justice to the complexity and diversity of journeys around services that patients, particularly with long term conditions, are required to make.

With this background, the current study was commissioned to examine whether a simple unified model of patient experience could be developed that might be relevant to different patients' experiences of a diverse range of local services. The project would also examine whether the model could be tested in terms of capacity to support emerging forms of service-line and pathway-focused management and decision-making about NHS services.

A core questionnaire was developed and tested that, with a small number of items, addressed all dimensions of the NHS Patient Experience Framework and related high level conceptual models of patient experience such as the Picker Institute's Principles of Patient-Centred Care. The questionnaire proved a robust basis for measurement when applied across seven very different environments of health and social care services. In the one pilot site that felt that it needed to work with the research group by means of an already existing, locally developed survey instrument, it was possible to cross-map key domains of experience. Importantly, it was possible to retain all of the content from the core instrument across settings whilst adding small numbers of additional items to reflect local priorities or adjusting the format to suit particular patient groups.

Consequently, we consider the development of a simple, unified, and conceptually grounded model of patient experience with broad applicability to have been a success. As established in phase one, there was good agreement across a range of frameworks on the dimensions of patient experience. Our own work to review existing measures and draw together a short instrument providing minimally sufficient coverage of these key dimensions results in a core questionnaire that could be widely and usefully applied. Moreover, the short instrument was sufficiently malleable that it could be usefully adapted and expanded to capture issues specific to particular conditions or services. Such adaptation frequently proved useful in the context of the pilots, where new resource was made available to support it. But it was equally clear that most NHS organisations have limited spare capacity to undertake this kind of work on their own, and thus there is a trade-off between the extent to which the core

instrument can be tailored and the purposes for and scale at which it can be used. Wider projects, such as national or regional collections, tend to be conducted with the aim of providing data for performance assessment or patient choice, and they thus require data from different organisations to remain comparable. In these cases, standardising on a core instrument without adaptation will generally remain the optimal approach.

A second aim of the project was to test the feasibility of measuring people's experiences along pathways and within service lines, and to assess how useful this proved. Initially, work was required to properly operationalise these concepts, particularly in terms of patients' perspectives of care and treatment. The terms 'pathway' and 'service line' are both open to multiple potentially conflicting interpretations. Moreover, common use of the term 'service line' within the NHS is closely linked to a health services management perspective, whilst 'pathways' – and particularly 'pathways of care' – can describe planned clinical or organisational systems. We sought both to understand these different interpretations and to look at how the terms and concepts could be understood by patients. For service lines, it was clear that patients should be able to reflect and report on their experiences with particular clinical teams – albeit with some caveats – and so we treated 'service lines' generically as defined sub-organisational functional groups. For pathways, we avoided clinically- or service-defined interpretations and used a broader definition of pathways as 'patient journeys'; a metaphor, essentially, for the range of experiences that any individual may have whilst traversing a health and social care system to receive care or treatment for one or more conditions.

These understandings of 'service lines' and 'pathways' had implications for measurement. Generally, it was more straightforward to apply the survey instrument to address service lines: or, in other words, to monitor the users of specific services and give feedback to providers of that service. In principle, such an approach should be achievable as a simple modification of traditional organisation-level patient surveys – for example by either a) selecting samples of patients from individual services and then aggregating these in a 'bottom up' fashion or b) simply increasing the organisational sample size until disaggregation to relevant service lines becomes possible. The former approach has clear advantage and was adopted in some of our sites. This generally worked well and was viewed favourably by professionals at the pilot sites.

More challenging were the pilots in which collaborating sites were willing to test the instrument in the context of patients using multiple services. These pilots were essentially testing whether a) patients could meaningfully report their experiences on the different domains of the questionnaire in relation to their own diverse pathways around services or b) whether inferences could be made about these pathways via a series of surveys confined to particular services. It was possible to use the new questionnaire in these more complex ways. Where a single group of patients reported on their experiences over time and with a range of services, it was felt essential to provide a range of mechanisms to allow patients to identify and comment on specific services. In other words, there was a demand for patients' responses to be attributable to particular services even when trying to take a patient's perspective on pathways.

Several developments in health and social services may reinforce the need for more pathway-oriented surveys of patient experience. On the one hand commissioning will evolve increasingly away from inputs in terms of services and towards evidence in terms of outcomes, safety, and experiences. Commissioning will increasingly be focused upon

complex and multiple long term conditions, particularly as an aging population drives an increase in the proportion of people with a range of conditions. On the other hand it is apparent that for many long term conditions there will be increasing provision of integrated or whole system services. A particularly important new policy lever will be the Better Care Fund, which moves £3.8bn of funding from the health service into a pool for shared health and social care services. Some of the funding for this is expected to be dependent on patient's reports about the co-ordination of services: potentially, this could influence thinking about the relative importance of attributability versus a 'big picture' view of user experience in the future.

There is growing salience, awareness and understanding of what matters to patients with corresponding expansion of activities and dedicated staffing to support monitoring, analysis and reporting of patient experience. Nevertheless all sites in the current study would have difficulty in carrying out and reporting, let alone sustaining repeated surveys of the kind summarised here. Additionally there are complex strategic choices at local level about which services and patient groups warrant more detailed monitoring and reporting of experiences. These problems raise complicated questions about where and how to deploy capacity to address patient experience, and suggest a need for further support for local users.

Mechanisms to more adequately capture and report evidence are only one part of the solution to raising the quality of patients' experiences of care and minimise major failures such as reported in the Francis enquiry. Additional major initiatives are required in relation to education, training and culture change. This study shows that it is possible to develop effective mechanisms to ensure that services at the local level are fully aware of what matters to patients, but further support may be needed to ensure best use of local findings.

14.1 Policy implications

Surveys of people's experiences have been an important part of health and social care policy for well over a decade. At the turn of the century, the NHS Plan (2000) set out a vision for patients to "for the first time... have a real say in the NHS" (p12), including via surveys that would be partly responsible for determining "the funding received by local NHS organisations" (p20)³⁰. This followed the introduction of the NHS national patient survey programme from 2002, which has now been running for over a decade with limited changes to its core approach. Meanwhile, the policy importance and stakes attached to patient experience have grown: key developments include Lord Darzi's 2009 review of quality, which enshrined patient experience as having equal importance to clinical effectiveness and patient safety³¹, and the Francis report into Mid-Staffordshire NHS Foundation Trust (2013)³², which highlighted the role of patient experience in compassionate care.

As noted in 2.1 above, one of the ambitions of the present research was to identify whether it might provide the basis for evolutionary developments to the way national surveys have historically been undertaken. In particular, we sought to assess whether service line

³⁰ Department of Health, the. (2000). *The NHS plan: A plan for investment, a plan for reform*. Department of Health London.

³¹ Darzi, A. (2008). *High quality care for all: NHS next stage review final report*. Department of Health: London.

³² Francis, R. (chair). (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London: The House of Commons.

measurement might provide an effective basis for suborganisational evaluation of the quality of care, and whether measurement along pathways might provide a more holistic view of the full range of services people experience. In setting out our conclusions from this work, we note several key implications for health policy:

- Despite the clear importance ascribed to people's experiences, and the wide consensus on this, resources to measure and improve people's experiences remain tight – even in larger NHS trusts. There was limited flexibility around addressing local priorities, particularly following the launch of the NHS Friends and Family Test.
- Local ownership of intelligence from patient experience collections was found to be important for the effective collection and use of results. Given the challenges around capacity and prioritisation outlined above, though, there would be benefit in exploring and pursuing new major initiatives in relation to providing education, training, and culture change locally.
- The NHS Friends and Family Test, whilst not the subject of this research, was noted to be useful in focussing attention on patient experience locally. However, it was also found to require considerable resources and quantitative data from the question used was generally not seen as beneficial: only one of our seven pilot sites chose to incorporate the question into their pilot. We note that a review of the Friends and Family Test is forthcoming.
- It is possible to adopt a simple, unified model of patient experience and to use this as the basis for measurement across a range of services. We endorse the National Quality Board's NHS Patient Experience Framework as an effective model, with the note that it may be useful to additionally include measures of people's experiences or perceptions of clinical effectiveness and safety to give a rounder view of care quality. Other patient experience frameworks, including the Institute of Medicine and Picker Institute frameworks, were generally more similar than different.
- Service line – or analogous – approaches appear a useful means of collecting suborganisational information. Such approaches can be managed relatively easily via traditional survey methods: the key is simply having the correct information to disaggregate results to appropriate service groups (or, indeed, to collect consistent data in a 'bottom up' fashion that takes suborganisational estimates as a starting point and aggregates up to organisational level).
- Pathway approaches, defined from the user perspective, are feasible but far more complicated to plan and administer than surveys focussing on particular services. A particular challenge is the small size of local 'pathways'; because of the wide range of long-term conditions and comorbidities that people may have, truly individual patient journeys tend towards a population size of one. This necessitates different and pragmatic approaches to measuring care along pathways and these may be more suited to highly tailored local projects.
- Where pathway surveys were completed, the overall results were welcomed as giving a 'big picture' of care – but providers remained most interested in results that could be attributed to particular services. Users of results valued comparability and consistency in the data collected.

- At present, it is not clear that there is sufficient demand to justify development of pathway surveys at a national level, nor the experience nor resource to enable effective service improvement based on them. This situation should be monitored, though, particularly as new policy levers such as the Better Care Fund encourage developments in the way providers and commissioners approach integrated care.

Our most immediate recommendation from the above is to investigate the potential of extending existing survey programmes to include suborganisational reporting, eg across service lines within organisations. This should be feasible and useful as a development of existing approaches and would add value for local users of survey data. Further research should audit NHS organisations on their views and preferences for suborganisational reporting – particularly to assess the suborganisational units where reporting would be most valuable.

15 Dissemination

The findings from this research will be disseminated in a number of ways. The dissemination activities presented below work to ensure the impact of the project.

15.1 Presentation to the collaborators and PPI panel

Preliminary findings from this research were presented to the project's collaborators and PPI panel at the end of February 2014. The collaborators and members of the PPI panel provided comment on the findings and these were considered when drafting this report.

15.2 Presentation to the project advisory group

Findings from this research were presented to the project's advisory group at the end of March 2014. The group provided comment on the findings which were taken into account by the project team when drafting this final report.

15.3 Picker Institute Europe and University of Oxford websites

This final report will be published on the organisational websites for Picker Institute Europe and University of Oxford. The questionnaire (generic and easy read) and associated guidance will also be made available. Once published on these websites we will carry out an email dissemination via specific groups.

The Picker Institute will also use its twitter account to promote the report, questionnaire and associated guidance.

15.4 Presentation at the European Care Pathways Conference 2013

Emerging findings from the research, particularly the conclusions of the scoping work in phase one, were presented in a plenary session at the European Care Pathways Conference in Glasgow on 21st June 2013.

15.5 Presentation at the International Forum on Quality and Safety in Healthcare

Findings from this research were presented at the International Forum on Quality and Safety in Healthcare in April 2014. The International Forum is jointly organised by the Institute for Healthcare Improvement (IHI) and BMJ and its aim is to improve health care and outcomes for patients and communities.

A poster presentation detailed the activities and evaluation undertaken at the two of the pilot sites; Sheffield Teaching Hospitals NHS Foundation Trust and a West Norfolk Primary care practice.

15.6 Publication in a peer reviewed journal

The research team intend to publish the findings from this research in a peer reviewed journal.

16 References

- Darzi, A. (2008). *High quality care for all: NHS next stage review final report*. Department of Health: London.
- Department of Health. (2000). *The NHS plan: A plan for investment, a plan for reform*. Department of Health: London.
- Department of Health. (2012). *NHS Outcomes Framework 2013 to 2014*.
<https://www.gov.uk/government/publications/nhs-outcomes-framework-2013-to-2014>;
retrieved 17th February 2014.
- Department of Health. (2012). *NHS Patient Experience Framework*. Department of Health: London. Retrieved from <https://www.gov.uk/government/publications/nhs-patient-experience-framework>.
- Doyle C. (2012). *Experience as an Aspect of Quality*. PEPP Patient Experience Excellence Framework.
- Ernst & Young, RAND Europe and the University of Cambridge (2012). *National Evaluation of the Department of Health's Integrated Care Pilots*. Cambridge: RAND Corporation.
- Foot, C., Sonola, L., Maybin, J., & Naylor, C. (2012). *Service line management: can it improve quality and efficiency?* The King's Fund, London.
http://www.kingsfund.org.uk/publications/slm_paper.html
- Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*.
<http://www.midstaffspublicinquiry.com/sites/default/files/report/Volume%201.pdf>; retrieved 26th February 2014.
- INVOLVE. (2012). *Briefing notes for researchers: public involvement in NHS, public health and social care research*. <http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf>; retrieved 3rd March 2014.
- Keogh, B. (2013). *Review into the quality of care and treatment provided by 14 hospital trusts in England*. NHS England: London.
- Lancaster, T., & Chesher, A. (1981). Stock and flow sampling. *Economics Letters*, 8(1), 63–65.
- Map of Medicine, 2012. *Map of Medicine*. [online] Available at:
<http://www.mapofmedicine.com/> [Accessed 11 July 2012].
- Monitor. (2010). *Service line management*. <http://www.monitor-nhsft.gov.uk/SLM>; retrieved 1st June 2012.
- National Institute for Health and Care Excellence. (2012). *Quality standard for patient experience in adult NHS services*. <http://publications.nice.org.uk/quality-standard-for-patient-experience-in-adult-nhs-services-qs15/introduction-and-overview>; retrieved 25th February 2014.
- NHS England. (2013). *Putting Patients First: The NHS England business plan for 2013/14 – 2015/16*. <http://www.england.nhs.uk/wp-content/uploads/2013/04/ppf-1314-1516.pdf>;
retrieved 25th February 2014.
- NHS Institute for Innovation and Improvement (2013). *NHS Patient Feedback Challenge*.
http://www.institute.nhs.uk/images/documents/Share%20and%20network/Patient_Feedback_Challenge/Programme%20Brochure.pdf; retrieved 20th March 2014.
- Nolan, M. R., Brown, J., Davies, S., Nolan, J. and Keady, J. (2006). *The Senses Framework: improving care for older people through a relationship-centred approach*. *Getting Research into Practice (GRiP) Report No 2*. Project Report. University of Sheffield.

Picker Institute, 1987. *Picker Principles of Patient-Centered Care*. [online] Available at: <http://pickerinstitute.org/about/picker-principles/> [Accessed 03 April 2014].

QIPP, 2012. *QIPP*. [online] Available at: <http://www.dh.gov.uk/health/category/policy-areas/nhs/qipp/> [Accessed 11 July 2012].

Robert, G., & Cornwell, J. (2011). 'What matters to patients'?. http://www.institute.nhs.uk/images/Patient_Experience/Final%20Policy%20Report%20pdf%20doc%20january%202012.pdf; retrieved 17th February 2014.

Staley K. (2009) *Exploring Impact: Public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh.

Sullivan, P. J., Harris, M. L., Doyle, C., & Bell, D. (2013). Assessment of the validity of the English National Health Service Adult In-Patient Survey for use within individual specialties. *BMJ Quality & Safety*. doi:10.1136/bmjqs-2012-001466

Thistlethwaite, P (2008). A practical guide to integrated working. Integrated Care Network.

Thistlethwaite P (2011). *Integrating health and social care in Torbay: Improving care for Mrs Smith*. London: The King's Fund.

Tourangeau, R., *Cognitive sciences and survey methods*. In T. Jabine, M. Straf, J. Tanur, & R. Tourangeau (Eds.), *Cognitive Aspects of Survey Methodology: Building a Bridge Between Disciplines*, pp. 73-100. Washington, DC: National Academy Press

Ware, J., Davies-Avery, A., Stewart, A. (1978). The Measurement and Meaning of Patient Satisfaction. *Health and Medical Care Services Review*, 1:2-15

World Health Organization. (2000). *The World Health Report*. Geneva: World Health Organization.

17 Appendix A: Patient and public involvement in this research

Patients and members of the public were actively involved throughout the research, and we are grateful for the helpful and insightful input provided by a number of contributors, particularly including the members of our PPI panel (see section 2.3.2 above). Involvement of patients and the public in this research is explained below under the three terms used by INVOLVE³³; involvement, participation and engagement.

Involvement: Where members of the public are actively involved in research projects and in research organisations.

In preparing the application for this research we recruited a patient with extensive experience of research engagement, and they provided comments on and contributions to our proposal.

In addition to this, members of the public were actively involved in this research through participation in the ‘Patient and public involvement (PPI) panel’. Please see section 2.3.2 for further details.

Finally, the project featured pilot site specific active involvement. At a few of the sites members of the public were involved as stakeholders contributing to discussions about the approaches to take to data collection.

Participation: Where people take part in a research study.

Members of the public took part in this research by helping test the core questionnaire to be rolled out in ‘Phase 2: field testing’. In addition to this, fieldwork in each of the pilot sites was dependant on patients and members of the public kindly opting to provide their feedback on their services or pathways. We are indebted to each and every respondent to the pilots.

Engagement: Where information and knowledge about research is provided and disseminated.

Picker Institute Europe and the University of Oxford will disseminate findings from this research to the public through their organisational websites and by using social media (such as the Picker Institute’s Twitter account).

³³ INVOLVE. (2012). *Briefing notes for researchers: public involvement in NHS, public health and social care research*. <http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf>; retrieved 3rd March 2014.

18 Appendix B: Surveys reviewed for question mapping exercise in phase 1

| Code | Survey |
|----------|--|
| INPC | NHS INPATIENT SURVEY-CORE 2011 |
| INPB | NHS INPATIENT SURVEY-BANK 2011 |
| GPC | NHS GP SURVEY (Y6W2)-CORE 2012 |
| OPC | NHS OUTPATIENTS- CORE 2011 |
| OPB | NHS OUTPATIENTS- BANK 2011 |
| AEC | NHS A&E-CORE 2012 |
| AEB | NHS A&E-BANK 2012 |
| LTC6 | LONG TERM CONDITIONS 6-QIPP-2010 |
| LWYLTC | LIVING WITH YOUR DIABETES AND OTHER LTCs- 2010 |
| NHS-C | NHS-CANCER |
| NHS-D | NHS-DIABETES-2006 |
| NHS-H | NHS-HEART CARE-2003 |
| NHS-MC | NHS-MIDWIFERY-CORE 2010 |
| NHS-MB | NHS-MIDWIFERY-BANK 2010 |
| NHS-S | NHS-STROKE-2005 |
| MHIP | NHS-MENTAL HEALTH ACUTE INPATIENT |
| MHCC | NHS-MENTAL HEALTH COMMUNITY-2011 |
| NAPT | NATIONAL AUDIT OF PSYCHOLOGICAL THERAPIES-2009 |
| IAPT | IMPROVING ACCESS TO PSYCHOLOGICAL THERAPIES: MID AND END OF TREATMENT PATIENT EXPERIENCE QUESTIONNAIRE |
| BTIP | BETTER TOGETHER INPATIENT-NHS SCOTLAND |
| BTGP | BETTER TOGETHER GP-NHS SCOTLAND |
| NHS-SC | NHS-SOCIAL CARE SURVEY |
| NHS-SCB | NHS-SOCIAL CARE SURVEY/INFORMATION CENTRE-BANK |
| OEQ | OUTCOMES AND EXPERIENCES QUESTIONNAIRE [OXFORD] 2012 |
| PEPP | PATIENT EXPERIENCE POLICY PROGRAMME 2011 |
| PAM | PATIENT ACTIVATION MEASURE |
| H-CAHPS | CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS-HOSPITAL SURVEY 2011 |
| CAHPS-SC | CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS-SURGICAL CARE SURVEY 2011 |

| | |
|------|--|
| CF | QUALITY OF HEALTH CARE SURVEY-COMMONWEALTH FUND 2006 |
| ECHO | EXPERIENCE OF CARE AND HEALTH OUTCOMES (CAHPS) |
| FAB | NATIONAL PAEDIATRIC TOOLKIT (FABIO THE FROG) |

19 Appendix C – Formatted generic questionnaire



Patient Experience Questionnaire

What is the survey about?

This survey is about your **experience as a user** of NHS health care services.

Who should complete the questionnaire?

The questions should be answered by the person named on the front of the envelope. If that person needs help to complete the questionnaire, the answers should be given from his/her point of view – not the point of view of the person who is helping.

Completing the questionnaire

For most questions please tick ☒ clearly inside one box using a black or blue pen. For some questions you will be instructed that you may tick more than one box.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please **do not** write your name or address anywhere on the questionnaire.

Questions or help?

If you have any questions, please call the helpline number given in the letter enclosed with this questionnaire.

**Taking part in this survey is voluntary.
Your answers will be treated in confidence.**

YOUR EXPERIENCE

1. How easy did you find it to get the care you needed when you wanted it?

- 1 ☐ Very easy
2 ☐ Fairly easy
3 ☐ Not very easy
4 ☐ Difficult
5 ☐ Very difficult

2. Were you given clear and understandable information about your *condition and treatment*?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I was offered information but chose not to take it

3. Were you involved as much as you wanted to be in decisions about your condition and treatment?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No

4. Were you given the opportunity to talk about your worries and fears with regards to your condition?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No
4 ☐ I had no worries or fears

5. Did the different people treating and caring for you work well together to give you the best possible care?

- 1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No, never
4 ☐ Can't remember
5 ☐ Not relevant

6. Did the healthcare staff offer your family, carers or friends the opportunity to be involved in decisions about your condition and treatment?

- 1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No, never
4 ☐ There were no family members, carers or friends available to be involved
5 ☐ I didn't want my family, carers or friends to be involved in decisions about my care and treatment

7. Did healthcare staff respond to your individual needs?

- 1 ☐ Yes, at all times
2 ☐ Yes, most of the time
3 ☐ Yes, some of the time
4 ☐ No, never

8. Did healthcare staff do everything they could to make you feel physically comfortable?

- 1 ☐ Yes, at all times
2 ☐ Yes, most of the time
3 ☐ Yes, some of the time
4 ☐ No, never

9. Did you have confidence and trust in the healthcare staff?

- 1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

10. How helpful has your care been in dealing with the problem(s) you sought help for?

- 1 ☐ Extremely helpful
2 ☐ Very helpful
3 ☐ Helpful
4 ☐ A little helpful
5 ☐ Not at all helpful

11. Have health services helped you to better understand and manage your own health?

- 1 ☐ Yes, definitely
2 ☐ Yes, to some extent
3 ☐ No

12. Overall, were you treated with kindness and understanding?

- 1 ☐ Yes, always
2 ☐ Yes, sometimes
3 ☐ No

13. Overall, did healthcare staff keep you informed about what would happen next?

- 1 ☐ Yes, completely
2 ☐ Yes, to some extent
3 ☐ No

ABOUT YOU

14. Who was the main person or people that filled in this questionnaire?

- 1 ☐ The **patient** (named on the front of the envelope)
2 ☐ A **friend** or **relative** of the patient
3 ☐ **Both** patient and friend/relative together
4 ☐ The patient with the help of a health professional

Reminder: All the questions should be answered from the point of view of the person named on the envelope. This includes the following background questions.

15. How many times have you used NHS services in the past 6 months?

- 1 ☐ Once
2 ☐ 2 or 3 times
3 ☐ 4 or 5 times
4 ☐ More than 5 times

16. Are you male or female?

- 1 ☐ Male
2 ☐ Female

17. What was your **year** of birth?

(Please write in) e.g.

| | | | |
|---|---|---|---|
| 1 | 9 | 3 | 4 |
|---|---|---|---|

| | | | |
|---|---|--|--|
| 1 | 9 | | |
|---|---|--|--|

18. Do you have any of the following long-standing conditions? (Tick **ALL** that apply)

- 1 ☐ Deafness or severe hearing impairment → Go to 19
2 ☐ Blindness or partially sighted → Go to 19
3 ☐ A long-standing physical condition → Go to 19
4 ☐ A learning disability → Go to 19
5 ☐ A mental health condition → Go to 19
6 ☐ A long-standing illness, such as cancer, HIV, diabetes, chronic heart disease or epilepsy → Go to 19
7 ☐ No, I do not have a long-standing condition → Go to 20

19. Does this condition(s) cause you difficulty with any of the following? (Tick **ALL** that apply)

- 1 ☐ Everyday activities that people your age can usually do
2 ☐ At work, in education or training
3 ☐ Access to buildings, streets or vehicles
4 ☐ Reading or writing
5 ☐ People's attitudes to you because of your condition
6 ☐ Communicating, mixing with others or socialising
7 ☐ Any other activity
8 ☐ No difficulty with any of these

20. To which of these ethnic groups would you say you belong? (Tick **ONE** only)

a. WHITE

- 1 ☐ English/Welsh/Scottish/Northern Irish/British
- 2 ☐ Irish
- 3 ☐ Gypsy or Irish traveller
- 4 ☐ Any other white background, write in...

b. MIXED / MULTIPLE ETHNIC GROUPS

- 5 ☐ White and Black Caribbean
- 6 ☐ White and Black African
- 7 ☐ White and Asian
- 8 ☐ Any other Mixed/multiple ethnic background, write in...

c. ASIAN / ASIAN BRITISH

- 9 ☐ Indian
- 10 ☐ Pakistani
- 11 ☐ Bangladeshi
- 12 ☐ Chinese
- 13 ☐ Any other Asian background, write in...

d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

- 14 ☐ African
- 15 ☐ Caribbean
- 16 ☐ Any other Black / African / Caribbean background, write in...

e. OTHER ETHNIC GROUP

- 17 ☐ Arab
- 18 ☐ Any other ethnic group, write in...

ANY OTHER COMMENTS

If there is anything else you would like to tell us about your experience, please do so here.

Was there anything particularly good about your hospital care?

Was there anything that could be improved?

Any other comments?

THANK YOU VERY MUCH FOR YOUR HELP

Please check that you answered all the questions that apply to you.

Please post this questionnaire back in the **FREEPOST** envelope provided.

No stamp is needed

20 Appendix D: Information sheet

Development of New Models for Collection and Use of Patient Experience Information in the NHS

Project management: Overall delivery is the joint responsibility of Picker Institute Europe and University of Oxford.

Aims

The New Models of Patient Experience project is a collaboration between Picker Institute Europe and Oxford University to develop and test mechanisms for measuring patient experience along pathways and within service lines. The project is funded by the Department of Health and runs over the period 2012-14.

The research team are looking for a small number of NHS sites (probably up to 10) who will be willing to be involved in the study.

What are the benefits of taking part?

Taking part in the project will provide participating organisations with a unique opportunity to contribute to and give feedback on the development of new approaches for measuring patient experience.

As part of the project, the Oxford team (the Picker Institute & the University of Oxford) will conduct ground breaking pilot surveys in up to ten NHS sites. Although the primary aim of the surveys will be to test and evaluate the methodologies used, the fieldwork will also generate a considerable volume of substantive data on patient experience in the pilot sites. The Oxford team will provide detailed results to pilot sites for their local use, at no cost to participating organisations.

There would be three stages of involvement for a collaborating site. The research team are conscious that involvement must be minimally disruptive.

Stage 1 - probably 2 meetings with relevant interested local staff

An individual or small group of individuals with an active interest or responsibility in patient experience would agree to meet with the Oxford team. The aim of this meeting would be to discuss the project. The Oxford team would explain its objectives. We would also hope to obtain a description of current and recent activities of the site in the area of patient experience. In this or subsequent meeting, there would also be a discussion of practicalities of stage 2 and whether a service line or pathway focused approach (or implementing both) would be the most appropriate for the site.

Service line approach

We want to include both organisations with and without service line management/reporting approaches implemented. Within the pilot sites we would not necessarily envisage covering all service lines, but would minimally include a sample of several different service lines. For example, service lines in an acute setting might include neurology, cardiac services, ENT,

and oncology. In a community setting this would be services like dental, and district nursing. The patient experience of each service line would be evaluated. Data collected could then be used for local reporting to provide highly precise performance assessment data and highly relevant data for local quality improvement.

Pathways

Ideally we would like to include a mix of more and less predictable pathways to test the suitability of our approach to cases where there may be differing levels of variation in patients' typical journeys. This will be done by purposive identification of relevant cases – most likely particular conditions. For example, stroke or MSK pathways are relatively predictable in that there are a number of common elements to the care of most individuals; long-term neurological conditions are far less predictable and may involve a diverse range of services.

Stage 2 - a survey run by Oxford group with some minimal help of local staff

The trust or site would work with the Oxford group over a period of approximately 3 months to carry out a survey of a group of patients for whom the site has provided care. The main responsibility of the site or trust would be to make available a means of contacting the patients.

Initial work would involve working with patient experience leads, clinical directors/leads & other managers to understand organisations' service configuration, current practices and structures. We want to test our approach and methods with organisations at different stages in implementing and using patient experience measures and so are keen to fully understand what work is underway in your organisation to collect and act on patient experience information.

Most aspects of the conduct of the survey – data collection and analysis would be the responsibility of the Oxford group.

Questionnaire

The team have developed a core questionnaire which they hope to roll out across pilot sites. This questionnaire has been developed with the NHS Patient Experience Framework in mind, with questions covering domains such as 'Emotional support', 'Co-ordination and integration of care', and 'Information, communication, and care'. If required, this questionnaire can be adapted to include questions of interest from the pilot sites and the survey can be carried out in a number of different possible ways in terms of medium and technology. The best survey medium to use (paper, online, handheld devices etc...) will be explored with the pilot site.

Stage 3 – feedback to site and interviews / discussions with key involved site staff

The survey results would be fed back to the participating site. A small number of individuals from the collaborating site would be willing briefly to discuss with the Oxford group their views of what has been learned from the survey, particularly, candid views about relevance of data to local agenda for quality improvement, meaningfulness and timeliness of the survey feedback. The Oxford group would provide feedback of lessons from the project as a whole.

A further output will be a final report looking at the evidence gathered from all pilot sites which will directly inform the policy approach to patient experience measurement of DH

and other key national stakeholders, including CQC and NICE. The report will provide a robust and evidence-based view of the feasibility and value of collecting patient experience feedback at service-line level and across pathways.

21 Appendix E: Equality and diversity

The research team recognise the importance of including the perspectives of a diverse range of people in research. In this section we detail the ways in which we have ensured not only diversity but worked for the inclusion of different groups.

21.1 Project management

The core project team consisted of researchers from Picker Institute Europe and University of Oxford. The team are experienced in qualitative and quantitative research, development, and thinking in patient experience, PROMs, and health surveys. In addition to the core team the advisory group and project collaborators ensured that the research benefited greatly from the input and experience of a range of different professionals and organisations.

21.2 Patient and public involvement

Patients and the public were engaged at different points in this research. The research team ensured that views from a diverse group of members of the public and patients/service users were heard.

Members of the PPI panel came from different backgrounds and had had very different experiences with the NHS (including A&E and maternity services). The team considered the views of the PPI panel as important as those from the collaborators and advisory group.

Members of the public recruited to test the core questionnaire represented a mix of ages, males and females, and had had different experiences with the NHS. The mix of conditions covered by the service lines and pathways in different parts of the country meant the inclusion of diverse populations in this research.

When planning the data collections at each of the pilot sites consideration was given to factors which may hinder response and ways that these could be limited such as the use of different questionnaire formats (larger font, easyread).

21.3 Pilot sites

21.3.1 Selection of sites

A key consideration of this research was to ensure the diversity of pilot sites recruited. To ensure broad coverage across a number of criteria the research team used purposive maximum variation sampling to select the pilot sites for inclusion in this project. Using this approach we were able to include a mix of pathways, sites covering different sectors, and a mix of urban and rural sites (important for providing a balance between a range of factors such as age and ethnicity).

21.3.2 Project teams at each site

The inclusion of a range of staff (for example practice managers, patient experience leads, and front line healthcare staff) in the design and implementation of the data collection at each site provided a great level of participation and engagement. As mentioned earlier in this report staff engagement was a key element in the success of the pilots.

Picker Institute Europe
Buxton Court
3 West Way
Oxford OX2 0JB

Tel: + 44 (0) 1865 208100
Fax: + 44 (0) 1865 208101

info@pickereurope.ac.uk
www.pickereurope.org

Charity registered in England and Wales: 1081688
Charity registered in Scotland: SC045048
Company limited by guarantee registered in England and Wales



The logo for the Picker Institute Europe, consisting of the word 'picker' in a bold, lowercase sans-serif font, with three small circles above the 'i', and 'Institute Europe' in a smaller, uppercase sans-serif font below it.