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

Briefing

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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.

Final report

An electronic copy of the final report can be obtained from www.pickereurope.org. Alternatively, contact info@pickereurope.ac.uk for any queries.
1. Briefing document

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.

This briefing document reports the lessons learned from our work with the seven pilot sites and case study site involved in the study. The findings have implications for health policy and practice, and these are summarised on page 9 of this briefing.

1.1. Research design

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

1.1.1 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\(^1\) was chosen as the working definition for use in this project.

A standard questionnaire to assess the domains in the framework, plus the principles of 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’. Service lines were considered to be specialised clinical areas with specific functional and operational remits. Several competing definitions of ‘pathways’ were considered, and a taxonomy was developed. For this project, pathways were considered as a metaphor for the patient journey – rather than planned sets of services or clinical processes.

1.1.2 Phase 2 – field testing

In phase 2, different approaches to measuring patient and service user feedback of pathway and service lines were employed at seven pilot sites, with varying results.

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.

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The pilot sites were:

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

### 1.1.3 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 lessons to emerge from this phase provide evidence of the factors which influence the success of patient experience initiatives in NHS organisations and it is these key findings which we provide detail on in this document.
Key Findings

1.1  Context

In the majority of the sites we engaged with 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’, retrospectively, and after discharge. The level of activity seen demonstrates the importance that NHS organisations place on patient experience initiatives and this should be commended.

It was striking how varied the technologies used to monitor patient experience are. A range of techniques such as hand held devices, comment cards, and personal interviews were used to capture patient experience in real time. Organisations had diverse solutions to resourcing this work: some used staff directly employed for this purpose, whilst others used external agencies or volunteers to encourage patients to give their feedback. Similarly a diversity of approaches were used to follow-up with patients after using services, including telephone interviews, postal questionnaires, and consultation events.

The use of a suite of approaches to obtaining patient feedback is extremely beneficial for reaching different target audiences and for providing rich information. There is no single ‘best’ method that is superior and NHS organisations should not limit themselves to one method – particularly if multiple methods can be used to complement one another by soliciting different types of feedback or engaging different audiences. However, there are risks that multiple local collections could create avoidable duplication and so an organisation-wide strategy is important.

1.2  Facilitating service improvements

It was equally apparent that efforts were made in each of the sites to disseminate evidence from the monitoring of patient experience and to facilitate service improvements in the light of evidence. In most cases, service feedback was gathered in silos: collections were specific to particular services rather than being implemented consistently across a range of them. In the best examples, patient experience evidence was reported directly back to the staff providing the relevant service, and mechanisms were in place to support service-level improvements by the same staff. Staff at the particular services clearly expected to identify specific improvements in the light of evidence reviewed. These arrangements maximised the likelihood that staff would pursue improvements based on evidence from users.

Being able to see feedback at a service level was incredibly important to sites. When thinking about new local collections, NHS organisations should be mindful of the ability to explore results at a sub-organisational level.

1.3  Testing the new model

This research demonstrated that trusts looking to undertake patient experience surveys should consider the appropriateness of the items on the questionnaire and the format in which it is delivered. For organisations looking to work with social care service users it might
be necessary to make even more adaptations to available questionnaires in these two aspects.

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 or service for which they were responsible.

The majority of sites accepted the questionnaire as sufficiently promising, and distinct from their existing approaches. All but one site, the adult social care service, accepted the core questionnaire in terms of domains of focus with very minor modifications. The modifications in some cases resulted in 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.

Organisations providing both health and social care services should take care when collecting feedback from different services and sectors; it should not be assumed that the same question set will be suitable for all. However, it is also important to note that increased tailoring leads to an increase in the cost of survey development and project management. As the number of areas of focus increases the cost of a fully tailored survey could become prohibitive making such an approach a less viable option.

There is a clear trade-off between the value of local tailoring and the cost associated with this.

1.4 Methodological considerations

The study raises a number of methodological issues familiar in the field of patient experience surveys, and provides a few lessons on best practice for implementation.

1.4.1 Quantitative and qualitative feedback

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. 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.

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. Indeed, mixing quantitative and qualitative feedback is perhaps the most obvious and best example of how different data collections can complement one another within an organisational-level strategy.

1.4.2 Response rates and population profile

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 mental health conditions), or logistic challenges of delivery of surveys to patients.

Knowing the demographic profile of a local population is generally easy; understanding the best ways to engage with them is the real challenge. With any large scale collection 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 an organisation level, only a limited amount of tailoring can feasibly occur: tailoring to increasingly small population groups will necessarily mean that increasing levels of effort result in diminishing returns.

It is of interest that by far the highest response rate was observed in a primary care setting where the survey was sent out with a personalised letter, with signatures of the practice GP and nursing staff in addition to information posters displayed in the practice highlighting the survey. Whilst it is not reasonable to generalise from one case study, and there are significant confounding factors in the demographic differences between populations, it is reflective of best practice in survey delivery.

1.4.3 Population size

When looking across the pathways and service lines evaluated in this research the volume of users varied considerably.

Population size influences the way in which data can be collected, and it also has an influence on the timeframe from which participants may be selected. 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 necessitates a much longer sampling period for smaller services. This is particularly challenging when pathways studied are narrowly defined; such is the variety of ways in which individuals with different conditions may progress through health and social care services, that the true ‘population size’ for any individual pathway tends towards one.

The variation in population size influenced the approaches taken with each site and is an important factor for NHS organisations to take into account when planning patient experience collections that look across pathways and service lines.

1.4.4 Method of delivery

The majority of sites actively considered a range of methods for delivering the proposed survey. Most sites were familiar with and sometimes had extensive experience of using alternative technology such as hand-held devices, comment cards and telephone surveys. 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.
1.5  Resourcing

Resourcing was one of the biggest challenges facing the majority of sites in their work on collecting and using patient experience data. The primary issue encountered was that any resources needed to carry out patient experience initiatives had to be planned prior to their undertaking: there was very little spare capacity to support new initiatives. Invariably, the research team found that pilot sites had very limited financial flexibility around patient experience activity. Whilst all pilot sites could readily identify areas in which they wanted more patient experience information, it was evident that they would need resources to enable implementation of 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.

Limited resources means that it is incredibly important that NHS organisations make the best use of patient survey collections, from design to action planning. The findings identified in this research highlight the many considerations organisations should pay attention to in planning and implementing collections. Fundamentally, organisations should ensure that their full range of patient experience activities are aligned with one another and are planned as part of a clear overall strategy.

1.6  Staff engagement

The level of staff engagement and leadership provided from the site-based project teams impacted the success of the patient experience initiatives. Members of the project teams whose sites had experience of implementing local collections were not only more engaged and committed to the project, but were able to identify potential challenges and inform the methodology.

This research demonstrates that having staff who are engaged in and understand the importance of listening to patients aids successful patient experience initiatives. This demonstrates the need to support organisations that are new to listening to patients’ views to ensure that they make the right choices regarding methodology and resourcing.

1.7  Policy implications

Several developments in health and social services may reinforce the need for more pathway-oriented intelligence on patient experience. On the one hand commissioning will increasingly evolve away from inputs in terms of services and towards evidence in terms of outcomes, safety, and experiences. Commissioning will increasingly need to focus upon patients with 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 patients with 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 patients’ 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.

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 need to ensure best use of local findings.

### Implications for national policy

- A pathway approach to collecting patient experience feedback along ‘patient journeys’ is feasible at a local level but does not prove practicable for roll out at a national level. 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. Approaches to measuring care along pathways may therefore be more suited to highly tailored local projects than national collections.

- Organisations placed great value in being able to see results at an individual service line level. The ability to provide sub-organisation reporting is an important consideration for national patient experience collections.

- The resources to measure and improve people’s experiences remain tight – even in larger NHS trusts. There was limited flexibility around addressing local priorities and this may be a barrier to services wishing to make use of patient experience information.

### Implications for local providers

- The use of an organisation wide strategy to data collection and improvement is important to ensure that multiple methods can be used to complement one another.

- When designing data collections NHS organisations should be mindful of the ability to explore results at a sub-organisational level.

- 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. Our questionnaire, free to use by the NHS, provides a tool to evaluate performance against key domains of care.

### Implications for commissioners

- The ability to pin-point data to specific services or user groups is important to allow commissioners to better evaluate services.