Patient-Reported Experience Measures (PREMS)

A Scoping Document to Inform the Evaluation of the NHS Vanguard Sites
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Section 1: Introduction

There is increasing awareness of the importance of incorporating the patient perspective and their experiences into evaluations of the healthcare system, particularly in terms of the assessing the quality and safety of the services provided. In the UK context the Care Quality Commission (CQC) and the National Institute for Health and Care Excellence (NICE) have jointly produced a Quality Standard providing guidance for commissioners on improving the quality of patient experience for those using NHS services (Appendix A). The 14 quality statements listed in this guidance very much echo the NHS Patient Experience Framework covering areas such as coordination of care, integrating patient preference into treatment options, provision of information, communication, education, as well as physical comfort and emotional support (Appendix B).

However, despite these initiatives there is no consensus as yet in terms of a widely accepted definition of quality of care other than it is a multidimensional concept with varying interpretations depending on the context. At this point it is worth noting the distinction between patient satisfaction and patient experience. Patient satisfaction may be defined as the gap between expectations and experiences. This concept has been frequently criticised as patients commonly report high levels of satisfaction with the quality of service provided (irrespective of the actual quality) due to a “gratitude bias” and other factors (Beattie et al., 2015). Service evaluations based on patient satisfaction ratings may consequently provide a false impression, and are therefore lacking in validity and utility. Patient experience on the other hand reflects patients’ interactions with healthcare systems and the degree to which their needs are met. A commonly used acronym in this context is STEEEP referring to Safety, Timeliness, Effectiveness, Efficiency, Equity and Person-Centeredness. For instance, did the patient receive the results of a particular diagnostic test? Beattie and colleagues (2015) have described the distinction between satisfaction and experience as:

“asking patients whether or not, or how often, they have experienced certain care processes, rather than [...] rating aspects of care or treatment” (p. 2)

Capturing patient experiences in healthcare systems may contribute to the monitoring of quality and safety, development and improvement of services, as well as benchmarking hospital performance and monitor effectiveness of interventions. However, in order to do so the data generated through patient experience needs to be valid, reliable and useful in practice. One way of collecting these data is through patient-reported experience measures (PREMs). These measures (typically, validated questionnaires or surveys) provide an objective way of enabling patients to describe their experiences of the (quality of) care received from their own perspective. PREMs, like their close cousins PROMs – patient-reported outcome measures which capture patients’ ratings of their symptoms, functioning, quality of life – come in a number of guises including general or generic measures not specific to any particular medical condition or context, to those measures that are designed to measure the experiences of patients with certain medical conditions (e.g. arthritis, Bosworth et al., 2015) or particular healthcare settings (e.g. community services, Teale & Young, 2015).

There is, as a consequence of this, a large number and wide variety of PREMs that have been (and are still being) published covering a range of healthcare services. However, the coverage is very patchy with some clinical areas having a number of well-established PREMS, and others few if any. One patient setting that has received a great deal of focus in terms of the patient-experience (and PREMs) is the quality of in-patient care.
This paper will describe in more detail a number of PREMs used to collect the patient experience of the quality of care received in hospital both nationally (UK) and internationally. It also describes those few instruments that have been or are being developed in areas such as community and long-term care.
Section 2: Patient-Reported Experience Measures (PREMs): Inpatient Survey

A recent systematic review (Beattie et al., 2015) identified 11 PREMs used to assess the patient experience of hospital quality of care. These 11 instruments have been described in more detail below. As part of their review the authors also conducted an evaluation of each instrument, assessing the psychometric properties (validity and reliability), as well as a rating in terms of cost efficiency, acceptability and use in decision-making. A modified version of this evaluation is shown in Table 2.1. Beattie et al. (2015) concluded that all the instruments reviewed displayed good properties in respect of the criteria evaluated. Furthermore, although no single instrument could be described as being fit for all purposes (which to a large extent depend on context of use); some recommendations could be made about which instruments to use in certain cases. For instance, they recommend the CAHPS is used for “high stakes purposes”, such as public league tables or research, although they do caution that its use in these context would be resource intensive. On the other hand, the QPPS, PPE-15 or I-PAHC could be used to measure local quality improvements.

2.1 Consumer Assessment of Healthcare Providers and Systems (CAHPS) – Hospital Survey

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) – Hospital Survey is a 27-item instrument covering 7 domains: Care from nurses, Care from doctors, Hospital environment, Patient experiences in hospital, Discharge, Overall hospital rating and General questions (covering patient’s overall health, education, ethnicity and language spoken at home). The majority of response categories are 4-point Likert scales (e.g. Never, Sometimes, Usually, And Always). The aim of the instrument is to capture patient experiences of hospital care. Although the early validation studies demonstrated good internal reliability and consistency (Keller et al., 2005) others have demonstrated that the instrument does not capture all the domains of interest to patients (Sofaer et al., 2005).

2.2 Quality from the Patients’ Perspective (QPP) and QPP – Shortened (QPPS)

The Quality from the Patients’ Perspective (QPP) is a 68-item instrument covering four domains: medical-technical competence (e.g. physical care, medical care, pain relief), physical-technical conditions (e.g. access to equipment, food and drink received), identity-oriented approach (e.g. usefulness of information received on results, self-care, examination) and socio-cultural atmosphere (e.g. ability to talk to doctors and nurses in private, how relatives were treated). The QPP was designed on the basis of a theoretical model of quality of care incorporating the patient perspective (Wilde et al., 1993). Early validation involved in-depth patient interviews and demonstrated high levels of content validity. The QPP has also been shown to have good internal reliability, construct and criterion validity (Wilde et al., 1993). A shortened version – the QPPS – has subsequently been developed (Larrson and Larsson, 2002). The QPPS is a 24-item questionnaire covering the same domains as the QPP. An early study demonstrated good internal consistency for the instrument. The short form has, for instance, been used to evaluate patients’ perceptions of their healthcare providers’ services (Wilde-Larsson & Larsson, 2009).
2.3 Picker Patient Experience Questionnaire (PPE-15)

The Picker Patient Experience Questionnaire (PPE-15) is a fifteen item questionnaire covering eight domains: Information & education, Coordination of care, Physical comfort, Emotional Support, Respect for patient preferences, Involvement of family & friends, Continuity & transition, and Overall impression. The response options vary with 8 items having 3 categories (e.g. “Yes, always”, “Yes, sometimes”, “No”), 4 items having 4 categories (an additional item, e.g. “I didn’t have any anxieties or fears”), and the other items having 5 or more response categories. The PPE-15 was derived from a larger 40 item questionnaire and is aimed at use as an in-patient questionnaire of patient experiences of their care. The initial development with a large sample of respondents demonstrated a high level of construct validity and internal consistency (Jenkinson et al., 2002). The PPE-15 has been used in the NHS, for instance, to evaluate patients emotional care received during hospitalisation (Murrells et al., 2013).

2.4 NHS Inpatient Survey (NHSIS)

The NHS Inpatient Survey (NHSIS) has been administered to patients by acute trusts since 2002. The aim of the survey is to collect information on patients’ perception of care received. The survey covers a number of domains including: admission to hospital, the hospital and ward, medical staff, care and treatment, operations / procedures, and discharge. The survey is sent to patients after their discharge from hospital. Validation of the survey has been limited (Boyd, 2006).

2.5 Scottish Inpatient Patient Experience Survey (SIPES)

The Scottish Inpatient Experience Survey (SIPES) is routinely used in the NHS Scotland to collect information from patients on their experiences of hospital admission following discharge (postal survey). There are 68 questions covering aspects of admission such as: the hospital and ward, care and treatment, operation and procedures, staff and discharge. There has been extensive validation conducted on the survey including patient interviews, cognitive testing, and stakeholder consultations. The survey has been shown to have good internal consistency (Scottish Government, 2010, 2012).

2.6 Hong Kong Inpatient Experience Questionnaire (HKIEQ)

The Hong Kong Inpatient Experience Questionnaire (HKIEQ) is a recently developed 58-item survey with 9 domains covering areas of care such as, access/choice/cooordination, communication and information, privacy, involvement in decisions, physical comfort and pain relief, hospital environment and facilities, involvement of family and friends, self-care support, care of healthcare professionals (Wong et al., 2013). The early developmental study demonstrated the instrument had good psychometric properties with high levels of internal consistency and reliability, and good content, structural and cross-cultural validity (Wong et al., 2015).

2.7 Patient Experience Questionnaire (PEQ)

The Patient Experience Questionnaire (PEQ, Pettersen et al., 2004) was developed from a large sample of respondents to capture patients’ experiences of quality of hospital care. The instrument consists of 35 questions which are scored on a 1 (negative) to 10 (positive) anchored rating scale (i.e. the extreme scores contain an “anchoring”
description such as “Not particularly satisfied (1)” and “Completely satisfied” (10)). These are summed to produce scores on 10 scales: information about future complaints, nursing services, communication, information about examinations. Contact with next-of-kin, doctor services, hospital and equipment, information about medication, organisation, and general satisfaction.

2.8 Norwegian Patient Experience Questionnaire (NORPEQ)

The Norwegian Patient Experience Questionnaire (NORPEQ, Oltedal et al., 2007) is an 8-item instrument design to measure patient experiences of hospital care. The instrument consists of 6 item assessing patient experience (information on tests, staff interested in problem, professional skills of nurses/doctors, nursing care, and understanding doctors) and two additional items measuring global satisfaction and perceptions of incorrect treatment. Each question is rated on a five-point scale (“not at all”, “to a small extent”, “to a moderate extent”, “to a large extent”, “to a very large extent”). The initial validation study demonstrated that the NORPEQ had a good internal reliability and test-retest reliability (Oltedal et al., 2007). The NORPEQ has been used recently in a multi-national study to evaluate hospital quality management strategies (Groene et al., 2015).

2.9 In-Patient Experiences of Health Care (I-PAHC)

The In-Patient Experiences of Health Care (I-PAHC, Webster et al., 2011) is another recently developed instrument that measures patient experiences with hospital care. The 5 domains covered by the I-PAHC include: communication with nurses / doctors, physical environment, pain management, and medication communication. The instrument consists of 25 items; 17 items relate directly to the patient experience (rated either on a 4-point (Never, Sometimes, Usually, Always) or 2-point scale (Yes / No). Other items cover ease of navigation around the hospital, patient rating of the hospital (0 – Worst Hospital to 10-Best hospital), whether patients had to pay for their admission, and their educational level. The instrument has been shown to have high levels of internal reliability, as well as good construct validity.

2.10 Patient Perceptions of Care (PPQ)

Finally, the Patient Perceptions of Care questionnaire (PPQ, Rao et al., 2006) is a 16-item instrument designed to measure in- and outpatients’ perceptions of care. It consists of five subscales: medicine availability, medical information, staff behaviour, doctor behaviour and clinic infrastructure. These can be summed to produce an “overall perceived quality” of care score ranging from 1, lowest quality rating, to 5, highest quality rating. There are also 3 general patient satisfaction items. All items are rated on a 5-point Likert scale, ranging from 1 (“completely disagree”) to 5 (“completely agree”). The initial validation of the instrument showed good internal reliability, and a high degree of content and structural validity.
Table 2.1: Summary of properties of the 11 in-patient PREMs

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Purpose</th>
<th>Validity</th>
<th>Reliability</th>
<th>Other</th>
<th>Total (out of 32)</th>
<th>Rating (out of 100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PPE-15</td>
<td>National performance indicators</td>
<td>11</td>
<td>4</td>
<td>7</td>
<td>22</td>
<td>69</td>
</tr>
<tr>
<td>NORPEQ</td>
<td>Cross-national comparisons</td>
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<td>5</td>
<td>10</td>
<td>21</td>
<td>66</td>
</tr>
<tr>
<td>PPQ</td>
<td>Local quality improvement</td>
<td>8</td>
<td>4</td>
<td>9</td>
<td>21</td>
<td>66</td>
</tr>
<tr>
<td>CAHPS</td>
<td>National comparisons</td>
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<td>8</td>
<td>7</td>
<td>20</td>
<td>63</td>
</tr>
<tr>
<td>I-PAHC</td>
<td>Quality improvement</td>
<td>8</td>
<td>3</td>
<td>9</td>
<td>20</td>
<td>63</td>
</tr>
<tr>
<td>QPP</td>
<td>Quality improvement</td>
<td>8</td>
<td>4</td>
<td>6</td>
<td>18</td>
<td>56</td>
</tr>
<tr>
<td>PEQ</td>
<td>Quality improvement</td>
<td>6</td>
<td>4</td>
<td>7</td>
<td>17</td>
<td>53</td>
</tr>
<tr>
<td>QPPS</td>
<td>Quality improvement</td>
<td>4</td>
<td>4</td>
<td>8</td>
<td>16</td>
<td>50</td>
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<tr>
<td>HKIEQ</td>
<td>National comparisons</td>
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<td>4</td>
<td>6</td>
<td>16</td>
<td>50</td>
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<tr>
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<td>National comparisons</td>
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<td>1</td>
<td>8</td>
<td>13</td>
<td>41</td>
</tr>
<tr>
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<td>National performance indicators</td>
<td>4</td>
<td>2</td>
<td>6</td>
<td>12</td>
<td>38</td>
</tr>
</tbody>
</table>

Key:
Validity: Content/theoretical development; construct; criterion.
Reliability: Internal consistency; other reliability.
Other: Cost efficiency; acceptability; use in decision-making.

1 Adapted from Beattie et al. 2015.
Section 3: Patient-Reported Experience Measures in Other Contexts

One particular area of potential interest to the Vanguard sites where there have been recent developments is long-term and community care. Teale & Young (2015) report the early development of a PREM to assess users’ experiences of bed-based (e.g. community hospitals) and home-based (e.g. hospital-at-home) services. The authors identified 15 items drawn from the 2008 Picker Adult Inpatient Survey bank (from which the PPE-159 was also derived), which were then completed by over 6000 users in the two types of services. This resulted in 2 questionnaires: an 8-item instrument for use in bed-based services, and a 12-item instrument for use in home-based services. The items shared by both PREMS comprised: staff information, user involvement in goal setting, whether their questions were answered, confidence in staff, involvement in discharge decisions, home circumstance considered, information for family, and being treated with dignity. The additional items for the home-based PREM included: awareness of goals, aware of how to contact staff, additional equipment requirements, and discharge.

In a slightly different, but nevertheless relevant, context Dutch healthcare organisations have a statutory obligation to collect client experience data. Since 2006 there have been a number of “Consumer Quality indices” (CQ-index) developed for different contexts with the Dutch healthcare system (e.g. sheltered accommodation, accident and emergency departments, general practice), and all of these PREMs have been based on the CAHPS described above. Triemstra et al. (2010) describe the development of the CQI for use in long-term care, such as nursing and residential homes. This work has resulted in three PREMs for use in somatic care wards (residential care, 81 items), psychogeriatric care (residential, 72 items) and home-based care (117 items). The domains covered by the 3 PREMs include: care plan & evaluation, shared decision-making, communication and information, physical & mental well-being, competency and safety of care, (safety of) living environment, participation and autonomy, and continuity of care.
Section 4: Discussion and Conclusion

There are a wide variety of PREMs available for different medical conditions and healthcare contexts. Some of these PREMs are well-established and thoroughly validated; others are still under early development. One area that has received considerable focus is the quality of care in hospitals. Beattie et al. (2015) have recommended a number of PREMs, such as the QPPS and PPE-15 for use with in-patients (or patients following discharge).

Although specific items may differ between different healthcare services or medical conditions, there appears to be a great deal of agreement between the various PREMs. The common themes that transcend the different contexts appear to be:

- Communication (with staff) and information (test results, examinations);
- Care received (both nursing and clinical);
- Physical and emotional support;
- Shared decision-making;
- Consideration of family / home environment;
- Hospital or ward environment.

Given these overlapping or common domains where no PREMs are as yet available for a particular context it may be possible to adapt and/or amend existing instruments for use in the Vanguard sites. For instance, the choice of PREMs may be considered within the development phases of evaluations at the Vanguard sites. The local context and requirements will determine whether existing validated instruments are suitable for the intended, whether they need to be adapted or indeed whether new PREMs need to be developed.
References


APPENDIX A

NICE Quality Statements

Statement 1. Patients are treated with dignity, kindness, compassion, courtesy, respect, understanding and honesty.

Statement 2. Patients experience effective interactions with staff who have demonstrated competency in relevant communication skills.

Statement 3. Patients are introduced to all healthcare professionals involved in their care, and are made aware of the roles and responsibilities of the members of the healthcare team.

Statement 4. Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.

Statement 5. Patients are supported by healthcare professionals to understand relevant treatment options, including benefits, risks and potential consequences.

Statement 6. Patients are actively involved in shared decision making and supported by healthcare professionals to make fully informed choices about investigations, treatment and care that reflect what is important to them.

Statement 7. Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported.

Statement 8. Patients are made aware that they can ask for a second opinion.

Statement 9. Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.

Statement 10. Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety.

Statement 11. Patients experience continuity of care delivered, whenever possible, by the same healthcare professional or team throughout a single episode of care.

Statement 12. Patients experience coordinated care with clear and accurate information exchange between relevant health and social care professionals.

Statement 13. Patients’ preferences for sharing information with their partner, family members and/or carers are established, respected and reviewed throughout their care.

Statement 14. Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs.
APPENDIX B
NHS Patient Experience Framework

NHS Patient Experience Framework
In October 2011 the NHS National Quality Board (NQB) agreed on a working definition of patient experience to guide the measurement of patient experience across the NHS. This framework outlines those elements which are critical to the patients’ experience of NHS Services.

- Respect for patient-centred values, preferences, and expressed needs, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making;

- Coordination and integration of care across the health and social care system;

- Information, communication, and education on clinical status, progress, prognosis, and processes of care in order to facilitate autonomy, self-care and health promotion;

- Physical comfort including pain management, help with activities of daily living, and clean and comfortable surroundings;

- Emotional support and alleviation of fear and anxiety about such issues as clinical status, prognosis, and the impact of illness on patients, their families and their finances;

- Welcoming the involvement of family and friends, on whom patients and service users rely, in decision-making and demonstrating awareness and accommodation of their needs as care-givers;

- Transition and continuity as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions;

- Access to care with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting time for an appointment or visit in the out-patient, primary care or social care setting.

This framework is based on a modified version of the Picker Institute Principles of Patient-Centred Care, an evidence-based definition of a good patient experience. When using this framework the NHS is required under the Equality Act 2010 to take account of its Public Sector Equality Duty including eliminating discrimination, harassment and victimisation, promoting equality and fostering good relations between people.

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