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## Instruments to measure the inpatient hospital experience: A literature review

Kelly J. Edwards

*St Vincent's Private Hospital Sydney, University of Tasmania, Australia*

Kim Walker

*St Vincent's Private Hospital Sydney, University of Tasmania, Australia*

Jed Duff

*St Vincents Private Hospital, Sydney, University of Tasmania, Australia*

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### Cover Page Footnote

The authors would like to thank St Vincent's Private Hospital Sydney, the University of Tasmania and Professor Jose Aguilera Director of Nursing and Clinical Services at St Vincent's Private Hospital Sydney, NSW Australia. This work was (partially) supported through an Australian Postgraduate Award (APA).

## Instruments to measure the inpatient hospital experience: A literature review

Kelly Edwards, *St Vincent's Private Hospital Sydney, University of Tasmania, Australia, kelly.edwards@svha.org.au*  
Kim Walker, *St Vincent's Private Hospital Sydney, University of Tasmania, Australia, kim.walker@svha.org.au*  
Jed Duff, *St Vincent's Private Hospital Sydney, University of Tasmania, Australia, jed.duff@svha.org.au*

### Abstract

Healthcare professionals worldwide are increasingly broadening their focus to include the experiences of patients and their family members as a means of assessing quality patient centered care. This paper seeks to identify and discuss instruments specifically designed to measure the inpatient hospital experience. A literature search focusing on pre-identified instruments as per the Health Foundation's Helping Measuring Patient Centered Care database of measurement instruments (de Silva, 2014) and additional health databases (CINAHL, ERIC, EBSCO, HaPI, MEDLINE, PubMed and Psych INFO) was undertaken. Thirteen relevant instruments and seventeen associated studies (regarding instrument development and or validation) were identified. These instruments provide generalizable but less descriptive experience data, are predominantly based on post hospital discharge data and do not have identified feedback to staff mechanisms. Further research is warranted to co-develop an inpatient hospital experience instrument, designed to capture real time descriptive data with a corresponding feedback process to frontline clinicians. Ideally such an instrument could be designed using a participatory research methodology, whereby patients, friends, family and healthcare clinicians are equal co-developers.

### Keywords

Patient experience, measurement, patient centered care, patient-centered outcome research

### Acknowledgement

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Healthcare professionals worldwide are increasingly broadening their focus to include the experiences of patients and their family members, as a means of assessing quality patient centered care. Prior to 1995 experience research consisted of small scale studies using predominantly qualitative methods<sup>1</sup>. Today with substantially larger sample sizes, methods are mostly quantitative<sup>1,2</sup>. Government mandates and experience dependent remuneration schemes have further propagated an abundance of quantitative experience surveys particularly in the hospital sector. In recent years developments in the science of measuring patient experience have been made, and as such a range of approaches are available to measure experience<sup>3</sup>. These fall broadly into survey, patient feedback processes or narrative methods (interviews and patient stories)<sup>4,5</sup>. Approaches can further be divided into generalizability and the depth of information provided<sup>5</sup>. The Health Foundation<sup>5</sup> contend that these strategies for measuring

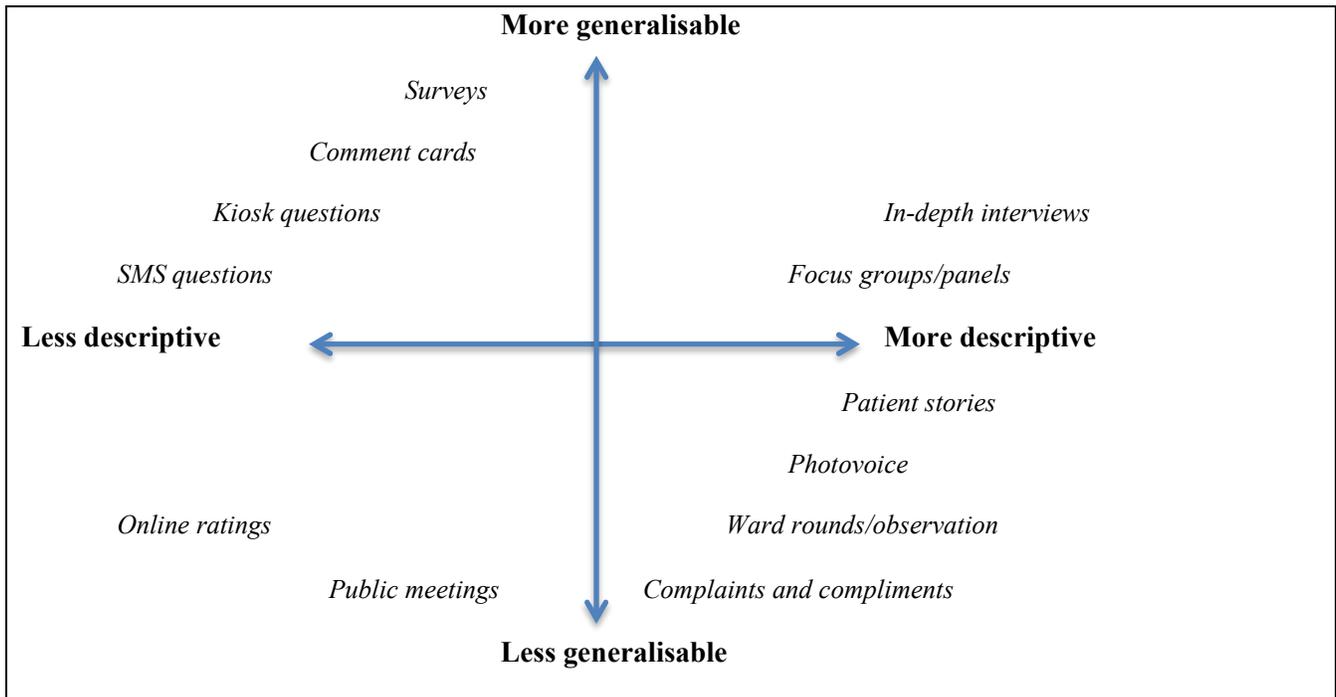
patient experience are on a continuum (See Figure 1). Meaningful measurement of experience however, is intrinsically problematic given its multifaceted and subjective nature and as such no gold standard measurement instrument exists. The main purpose of this paper is to identify published instruments designed specifically to capture experience data of the hospital inpatient.

### Method

#### Search Strategy

A three-stage search strategy was used. Stage one focused on pre-identified instruments as per the Health Foundation's *Helping Measuring Patient Centered Care* database of measurement instruments<sup>6</sup>. The Health Foundation<sup>7</sup> has produced a database of commonly used validated tools for measuring patient centered care, based on screening over 200,000 studies published between 2000

**Figure 1 The Health Foundation (de Silva 2013) Examples of methods used to measure patient experience of health services**



and 2013. Using the ‘category’ filter, instruments used to explore specifically ‘experience’ were identified.

The following databases were then searched for additional instruments published between 2000 and 2015:

- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Education Information Resources Center (ERIC)
- EBSCO
- Health and Psychosocial Instruments (HaPI)
- Medical Literature Analysis and Retrieval System (MEDLINE)
- PubMed
- Psychology and Behavioural Sciences Collection (PsychINFO)

With the following search strategies:

((T1 experience AND ((patient or person or family) AND (centered))) or ((MH ‘patient satisfaction’) OR (MH ‘Patient attitudes’) or ‘patient experience\*)) AND (Patient satisfaction OR patient experience\*) AND (reliabil\* OR validat\* OR development) OR (questionnaire\* OR survey\* OR tool\* OR instrument\*)

OR

TI((reliabil\* OR validate\* OR development)) AND ti((experience\* OR satisfaction)) AND (questionnaire\* OR survey\* OR tool\* OR instrument\*)

Finally, articles regarding development or validation of each identified instrument were then searched using the above search strategies limiting results to studies published between 1990 and 2015.

**Selection Criteria**

Titles and abstracts were initially considered using a modified version (see Table 1) of Beattie and colleagues<sup>8</sup> ‘Inclusion Selection Questions’ for instruments to measure patient experience of healthcare quality in hospitals.

Only primary, peer-reviewed studies (print, online, journal or report) in English, which directly reported on the development and or validation of a patient reported hospital experience instrument published in a print, online journal or report were included. General research regarding experience and what matters to patients and their family members was not included, as the focus was on instruments for measurement rather than findings using the measurement.

Studies primarily concerned with specific events or issues (such as patient discharge or safety) were not included. Studies examining measurements for specific specialist areas within the hospital setting were included. The reason for inclusion is based on the aim of identifying measurement instruments regardless of the patient’s reason for admission. Instruments designed specifically for

**Table 1 Inclusion Selection Questions**

1. Does the study report the development and/ or validation of Patient Reported Experience Measure instrument?	Yes Go to question 2	No Reject
2. Is the context a hospital setting or intended for use in a hospital setting?	Yes Go to question 3	No Reject
3. Is the population adult inpatient, or adult inpatient family member?	Yes Go to question 4	No Reject
4. Is the study measuring the patient, family member perspective of the patient's experience of care?	Yes Go to question 5	No Reject

participants with intellectual disabilities or psychiatric disorders were excluded based on the assumption that these have likely been developed for their specific needs.

## Results

Thirteen relevant instruments and seventeen associated studies (regarding development and or validation) were identified (See Table 2). Two instruments were developed in the United States (HCAHPS, PAQS-ACV), one in Hong Kong (HKIEQ), one in Ireland (INPQCS), five in the United Kingdom (NSNS, NHS NAIS, PPE-15, howRwe, ICE) one in Australia (PEECH), one in Norway (PEQ), one in Sweden (QPP) and one joint development in Norway, Sweden, Iceland and Denmark (NORPEQ). The number of participants in each study ranged from 25 (HIEQ) to 19720 (HCAHPS).

Instrument development consisted primarily of literature reviews, focus groups followed by item generation, pilot testing and appraisal. The theoretical or guiding principles were only identified for eight of the thirteen instruments ((The Institute of Medicine for HCAHPS, Picker domains for HKIEQ and NHS NAIS, Grounded theory for PEECH, PAQS-ACV, QPP, Patient Centered Care for PPE-15 and the concept that all patients want high quality service from staff and the organisation as a whole for howRwe). All studies included patients only as participants and intended users of the instruments. The aims of all studies were to develop, test and or report on a patient experience approach. Patients and or family members were involved in the development of at least eleven instruments (HCAHPS, HKIEQ, INPQCS, NSNS, NHS NAIS, PEECH, PEQ, PAQS-ACV, PPE-15, QPP, howRwe).

All but three instruments (PEECH, ICE & NORPEQ) were developed and tested using mixed method approaches. Qualitative methods were predominantly used for item generation (interviews and focus groups) with quantitative and qualitative methods used to test and analyse the instruments. All instruments identified are survey based providing predominantly quantitative data with items ranging from four questions (howRwe) to ninety-five (INPQCS). Two instruments include comment

sections (HKIEQ and NHS NAIS), and two included comment sections for each item (PEECH and howRwe).

Eight instruments used a paper based only survey mode (NSNS, NHS NAIS, PEECH, PEQ, PAQS-ACV, PPE-15, QP and NORPEQ). Two instruments use a telephone only mode (HKIEQ and INPQCS). The HCAHPS instrument uses four modes (Mail only, telephone only, mail with telephone follow-up, and interactive voice response (IVR) mode). HowRwe is designed for use with multiple modes - paper, touchscreen device (such as kiosks, smartphones and tablets), web browsers, and telephone. Touchscreens were used for testing. It is not clear from the literature what mode one instrument was tested using (ICE). None of the articles identify a corresponding feedback mechanism (that is how the information provided by the instrument is to be fed back to clinicians).

Data was designed to be collected during hospital admission for five instruments (NSNS, PEECH, PAQS-ACV, QPP and howRwe) and post discharge for the remainder (ranging from immediately post discharge to up to twelve months post discharge). Nine instruments provide the recipient with quantitative data (HCAHPS, INPQCS, NORPEQ, NSNS, PEQ, PAQS-ACV, PPE-15, QPP, and ICE), four provide quantitative and limited qualitative data (HKIEQ, NHS NAIS, PEECH, howRwe), with none providing qualitative data only. All instruments fall into the more generalizable, less descriptive approach (See Figure 2).

## Discussion

As the desire to practice patient centered care has gained prominence, numerous institutions are increasing their efforts to capture patient experience data. Most OECD (Organization for Economic Cooperation and Development) member and partner nations are endeavoring to obtain experience data at national, state or institution level <sup>1</sup>. Many hospitals outsource larger scale studies to companies such as Press Ganey, Gallup, Dr. Forster, and the Picker Institute, while others solely use in house approaches <sup>2</sup>. While thousands of studies are published regarding patient experience, often information

provided regarding the method of collection or instrument used is limited <sup>10</sup>. Despite this obvious real world practice of capturing experience data, there are very few validated and published instruments designed specifically to examine the hospital experience (thirteen), and even fewer designed to capture data during the episode of care (five).

Direct patient feedback is the core method for measuring patient experience <sup>11</sup>. The literature confirms the view that quantitative structured questionnaires or surveys are the most common approach published <sup>1,9,11-13</sup>. Such quantitative research however is not capable of providing rich and nuanced information regarding individual experience, and for this reason patient interviews are becoming increasingly popular as a means of obtaining qualitative experience data <sup>14-17</sup>. Cleary and colleagues <sup>18</sup> suggest qualitative research is in fact the optimal scholarly means of understanding patient experience, while Russell <sup>1</sup> purports information gleaned from surveys make them potentially ‘useless for improving patient’s experience’. Experiences cannot be reliably evaluated by using standard questions <sup>11</sup>, nor by solely focusing on individual aspects of the overall experience <sup>19</sup>. Accordingly experience data collection requires multiple approaches to enhance validity <sup>1</sup>. Many hospitals and larger institutions do use multiple approaches to collect data<sup>1</sup>. Despite this adoption of qualitative approaches and expert opinion regarding the

importance of qualitative approaches, it is difficult to understand why there are no published qualitative instruments. This view is echoed by de Silva <sup>5</sup> and Russell <sup>1</sup> who have identified research regarding the testing and validating of survey tools but very limited research on qualitative techniques.

While four instruments (HKIEQ, NHN NAIS, PEECH, howRwe) do contain comment sections (providing limited qualitative data) all instruments identified are considered to be less descriptive and more generalizable. Such surveys are not suitable for those with low literacy, and as such have the potential for self-selection bias <sup>11</sup>. Surveys have also tended to reflect concerns of administrators, often representing manager or clinician agenda <sup>11</sup>. Six instruments were developed using patient focus groups, however the resulting surveys of this type can only represent the issues identified by patients other than those completing the questionnaire. As such survey approaches cannot provide in depth data nor are they well suited to cover sensitive issues <sup>5</sup>. Despite these limitations most hospitals continue to use standardised surveys as they provide administrators with the benefit of allowing for comparison and benchmarking against other institutions <sup>20</sup>. This is potentially of limited value to the individual patient or the health care provider caring for them.

**Figure 2 Experience instruments identified to measure patient experience in hospital**

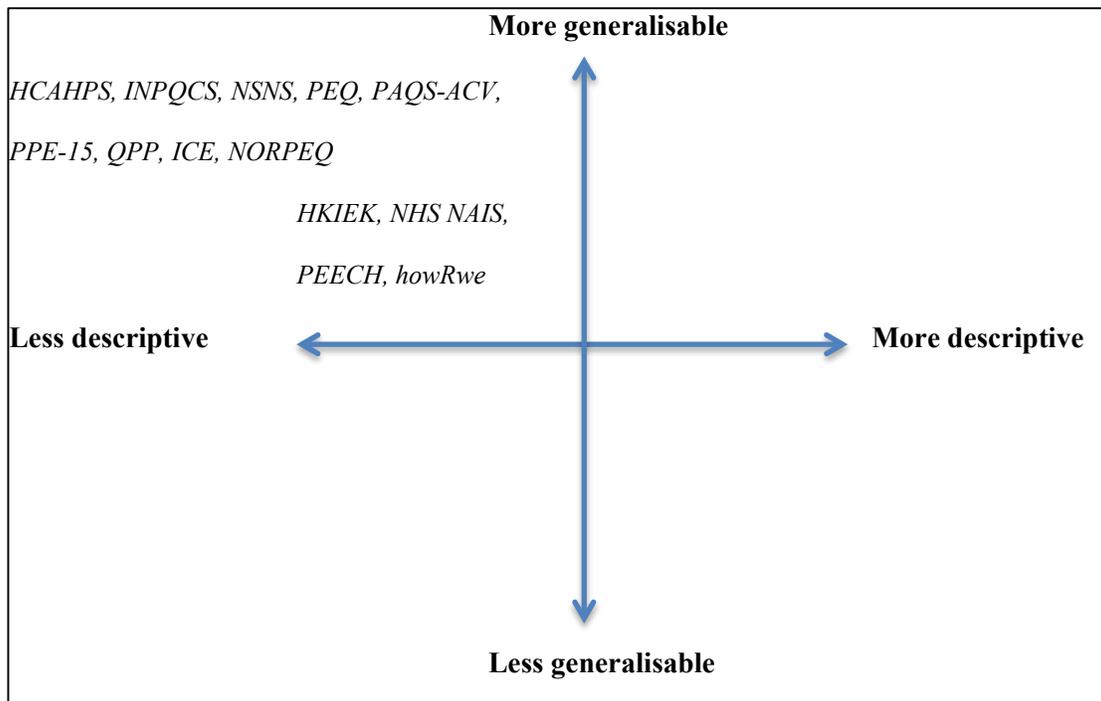


Table 2 Experience Data Collection Instruments and Associated Studies

Approach Name	Study Authors	Study Title
<b>Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)</b>	Giordano, Elliott, Goldstein, Lehrman & Spencer 2010	Development, Implementation and Public Reporting of the HCAHPS Survey
	Goldstein, Farquhar, Crofton, Darby, Garfinkel 2005	Measuring hospital care from the patients' perspective: an overview of the HCAHPS Hospital Survey development process
<b>Hong Kong Inpatient Experience Questionnaire (HKIEQ)</b>	Wong, Coulter, Cheung, Yam, Yeoh & Griffiths 2013	Validation of inpatient experience questionnaire
	Wong, Coulter, Cheung, Yam, Yeoh & Griffiths 2013b	Item generation in the development of an inpatient experience questionnaire: a qualitative study
<b>howRwe</b>	Benson & Potts 2014	A short generic patient experience questionnaire: howRwe development and validation
<b>Intensive Care Experience ICE questionnaire (ICE)</b>	Rattray, Johnson & Wildsmith 2004	The intensive care experience: development of the ICE questionnaire.
<b>Irish National Perception of Quality of Care Survey (INPQCS)</b>	Sweeney, Brooks & Leahy 2003	Development of the Irish National patient perception of quality of care survey.
<b>NHS National Adult Inpatient Survey (NHS NAIS)</b>	Reeves, Coulter, Jenkinson, Cartwright, Bruster & Richards 2002	Development and Pilot Testing of Questionnaires for use in the Acute National Health Service (NHS) Trust Inpatient Survey Programme
<b>Newcastle Satisfaction with Nursing Scale (NSNS)</b>	Thomas, Macmillan, McColl, Priest, Hale & Bond 1995	Obtaining patients' views of nursing care to inform the development of a patient satisfaction scale
	Thomas, McColl, Priest, Bond & Boys 1996	Newcastle satisfaction with nursing scales: an instrument for quality assessments of nursing care
<b>Nordic Patient Experiences questionnaire (NORPEQ)</b>	Oltedal, Garratt, Bjertnaes, Bjørnsdottir, Freil & Sachs 2007	The NORPEQ patient experiences questionnaire: Data quality, internal consistency and validity following a Norwegian inpatient survey
<b>Patient's Assessment of Quality Scale - Acute Care Version (PAQS-ACV)</b>	Lynn, McMillen & Sidani 2007	Understanding and Measuring Patients' Assessment of the Quality of Nursing Care
<b>Patient Evaluation of Emotional Care during Hospitalisation (PEECH)</b>	Murrells, Robert, Adams, Morrow, Maben 2013	Measuring relational aspects of hospital care in England with the 'Patient evaluation of emotional care during hospitalisation' (PEECH) survey questionnaire
	Williams & Kristjanson 2009	Emotional care experienced by hospitalised patients: development and testing of a measurement instrument
<b>Patient Experience Questionnaire (PEQ)</b>	Pettersen, Veenstra, Guldvog & Kolstad 2004	The patient experiences questionnaire: development, validity and reliability
<b>Picker Patient Experience Questionnaire (PPE-15)</b>	Jenkinson, Coulter & Bruster 2002	The picker patient experience questionnaire: Development and validation using data from in-patient surveys in five countries
<b>Quality from the Patient's Perspective Questionnaire (QPP)</b>	Larsson & Larsson 2002	Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire

The solution to obtaining richer data does not lie with more detailed surveys. While surveys tend to have positive response rates, length of survey can actually be a deterrent to completion thereby impacting response and value of

information<sup>21</sup>. The United Kingdom NHS NAIS survey for example has seen response rates decline from 64% in 2001<sup>22</sup> to 49% in 2013<sup>23</sup>. Shorter survey instruments reduce participant burden, which was a guiding driver

behind the establishment of the howRwe<sup>20</sup> and QPP instruments<sup>24</sup>. Not surprisingly however a comparison between PPE-15 and PEECH Instruments, found that the longer PEECH Instrument, provided more data regarding interpersonal aspects of quality care than the shorter Picker Institute Instrument<sup>25</sup>.

National, state and even hospital wide surveys usually provide non-attributable experience data. That is they don't necessarily reflect the care delivered by the provider or providers who were directly responsible for the experience<sup>26</sup>. The recent focus on improving experience<sup>27</sup> suggests that data collected at the episode of care and collected at individual team level may have the greatest impact on services<sup>1</sup>. Slow feedback to staff is also an ongoing criticism of patient experience surveys<sup>28</sup>. By the time frontline clinicians receive information, they may well argue that such practices have now improved<sup>29</sup>.

Collecting real-time data (when the patient is in the hospital) or near-time (immediately post discharge) is the most effective way to capture meaningful experience data<sup>1</sup> however only five instruments (NSNS, PEECH, PAQS-ACV, QPP, howRwe) are validated based on collection in real time, and one in near time (ICE). The leisure industry have been using real time methods to elicit data for decades however the healthcare industry has been slow to adopt this practice<sup>30</sup>. Timing of data collection is crucial as it provides the recipient with 'fresher' information<sup>30</sup>. Staff in particular perceive timely information as having greater validity<sup>30</sup>. Two studies which used the PEECH instrument – one administered while patient was in hospital<sup>31</sup> and one post discharge<sup>25</sup> found that differences in findings could be influenced by recall bias. Such recall bias is often an issue with data collected post discharge<sup>21</sup>. The United Kingdom Department of Health now requires all hospitals to collect 'real-time' or 'rapid' feedback from hospital patients<sup>32</sup>.

There are naturally ethical and validity concerns regarding real-time collection of data. There may be a tendency for patients to offer positive results regarding satisfaction for fear of jeopardising treatment<sup>1,4,33</sup>. Experience research however differs from satisfaction research in that it does not ask patients to rate their quality of care, rather it seeks to capture the patient's perception of what did or did not happen during an episode of care. Results from the NSNS found that answers did not differ between hospital and home, suggesting patients can be asked about their experiences before they leave hospital without biasing results<sup>34,35</sup>.

The perception of improving experience for other patients is also powerful incentive to offer truthful real time feedback, and we must not underestimate today's healthcare consumer<sup>30</sup>. The existence of online communities such as PatientsLikeMe and

HealthTalkOnline suggest that large numbers of the patient population are in fact willing to share their experiences<sup>36</sup>. The value of real time data also appears to be outweighing any ethical concerns, with more and more hospitals seeking real time data. In select United Kingdom hospitals experience trackers (hand held devices) are being used that allow patients to answer five multiple choice questions<sup>30</sup>. The Picker Institute's Frequent Feedback system also makes use of real-time hand held devices<sup>30</sup>. Customer Research Technology (CRT) provide a range of products to hospitals including hand held devices and touch screen kiosks for real-time purposes<sup>30</sup>. Other approaches available for real-time include; patient stories/interviews, paper based methods, stand-alone kiosks, telephone and online systems<sup>30</sup>. While the majority of instruments identified in the review are paper based, only five could be considered real-time instruments.

As patient centered care models and attention to patient experience show no sign of abetting, timely and effective feedback to those providing the care is imperative as 'we [healthcare clinicians] might think we are delivering care that looks like one thing, but in reality it is quite another'<sup>37</sup>. While most articles in this review did not discuss the importance of reporting or feedback to staff mechanisms, Picker state that reporting the findings to patients and staff is extremely important and suggest a collect, communicate, act strategy where results are readily available to staff<sup>38</sup>. Only one study discussed feedback to staff (INPQCS). The staff were informed of the interviews to be carried out in the INPQCS and were advised that they (staff) would have access to the information once collated, although methods of doing so were not discussed<sup>39</sup>.

There is little evidence available on how best to use and disseminate patient experience data<sup>11</sup>. Clinicians tend not to feel ownership of results from surveys; often claiming 'that doesn't happen on my ward'<sup>40-42</sup>. Yet none of the studies identified a preferred feedback to clinician mechanism. These clinicians are disproportionately responsible for day to day decision making that impacts the patient's experience yet survey results tend to be communicated to senior hospital administrators then trickle down slowly through the hierarchical channels<sup>42,43</sup>.

Commitment from every employee is required to optimise a patient's experience<sup>44</sup> however clinicians often report difficulty in interpreting quantitative results<sup>45</sup>. The Francis Inquiry into Mid Staffordshire NHS Foundation Trust reported that 'results and analysis of patient feedback including qualitative information needs to be made available to all stakeholders in as near-real time as possible'<sup>38</sup>. Experience feedback also needs to be ward specific, rapid, and staff need the opportunity to discuss the findings<sup>43</sup>. The instrument used should also only include

items which are under the day to day control of staff and management <sup>20</sup>. Given these findings it is difficult to understand why none of the experience instruments appear to have been designed with specificity, speed nor staff in mind.

Systematic reviews, highlight the large volume of studies purporting to measure satisfaction, with or experience of specific aspects of care <sup>1,46</sup>. The volume of different measurement approaches however, makes it difficult to compare findings, which also explains why so few studies are then eligible for systematic reviews on issues regarding experience <sup>1,47</sup>. Hudon and colleagues <sup>47</sup> systematic review for example identified over 3000 articles regarding patient perceptions of patient centered care however only 26 articles met the inclusion criteria.

Similarly, one of the major criticisms of patient satisfaction surveys and surveys from a validity point of view is their lack of theoretical foundation <sup>24</sup>. Guiding theories or principals were identified in the associated experience instrument literature for only eight studies. HKIEQ and NHS-NAIS were based on Picker Domains (See Table 3). The Institute of Medicine (IOM) domains (See Table 4) were the guiding principles for the creation of the HCAHPS instrument. Patient centered care and the assumption that all patients want high quality service from staff and organisations as a whole were the basis upon which the PPE-15 and howRwe instruments were developed respectively. Only three instruments (PEECH, PAQS-ACV, QPP) mention the theoretical model upon which the instrument is based, all of which being

grounded theory.

The NHS recommends bringing staff and patients together to design improvements <sup>11</sup>, while Brown Davidson and Ellins <sup>30</sup> state that patients must be involved in the design of experience measure instruments. While all instruments involved participants in the development process at some stage it is unclear whether patients specifically were involved at every stage. ‘Authentic and genuine consultation with stakeholders’ is key to developing experience instruments <sup>18</sup> suggesting a participatory research methodology is well suited to developing such an instrument. It is interesting to note that while most instruments were developed with some stakeholder input, none identified as having been based upon a participatory research method.

### Conclusion

Current perspectives in healthcare suggest a fundamental tenant of patient centered care is patient experience. The future drive towards patient centered care suggests capturing patient experience data will take on even more importance over the coming decades. Progress has been made in the last decades regarding the science of measuring patient experience <sup>3</sup>. This review demonstrates that, while there are a numerous approaches available, there is not a large body of literature regarding instruments designed to capture experience data of the hospital inpatient, with no validated instruments designed to capture qualitative data. Only quantitative methods in the

**Table 3 Picker Domains of Patient Centered Care**

- |  |
|--|
| <ul style="list-style-type: none"> <li>• Respect for patients’ values, preferences and expressed needs</li> <li>• Coordination and integration of care</li> <li>• Information, communication and education</li> <li>• Physical comfort</li> <li>• Emotional support and alleviation of fear and anxiety</li> <li>• Involvement of family and friends</li> <li>• Transition and continuity</li> </ul> |
|--|

Source: Picker Institute <http://pickerinstitute.org/about/picker-principles/>

**Table 4 The Institute of Medicine Domains of Quality Healthcare**

- |   |
|---|
| <ul style="list-style-type: none"> <li>• Safe</li> <li>• Effective</li> <li>• Patient Centered</li> <li>• Timely</li> <li>• Efficient</li> <li>• Equitable</li> </ul> |
|---|

Source: Agency for Healthcare Research and Quality <https://cahps.ahrq.gov/consumerreporting/talkingquality/create/sixdomains.html>

form of surveys are represented in this review. This is not to say that qualitative methods are not being used in the healthcare arena or that there are a substantial number of studies using qualitative methods to capture experience data. It simply highlights the gap in the literature regarding validated qualitative instruments.

The instruments identified are able to provide generalizable but less descriptive data, which is predominantly collected post hospital discharge. While this appears to be common practice<sup>48</sup>, experience data needs to be captured as close to the experience as possible to exclude recall bias<sup>49</sup>. The lack of discourse surrounding instrument preferred feedback to staff mechanisms is also apparent. Further research is warranted to co-develop a patient experience instrument, designed to capture real time data with a corresponding feedback process to frontline clinicians. Ideally such an instrument could be designed using participatory research methodology.

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