

Use of Patient-Reported Data within Acute Healthcare Context

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Patient-reported outcome measures (PROMs), patient-reported experience measures (PREMs) and patient satisfaction surveys provide important information on how care can be improved. The Hospital Consumer Assessment of Healthcare Providers and Systems tool (HCAHPS) was used most frequently for measuring patient satisfaction. Where reported, data were applied to improve patient-centred care and utilization of health resources. Gaps in the use of patient data within hospital services are noticeable. Engaging management and improving staff capability are needed to overcome barriers to implementation.

Keywords: PREMs ; PROMs ; patient satisfaction ; patient-reported data

1. Introduction

Delivering individualized patient-centred care is a valuable characteristic of high-quality health care services. To address this goal, many organisations collect patient-reported experience measures (PREMs), patient-reported outcome measures (PROMs) and patient satisfaction questionnaires. These measures can be powerful tools for system change, as they provide patient-specific information to health professionals and organizations. Incorporating PROMs and PREMs data into patient care has been directly associated with improved care and improved effectiveness of treatments ^[1]. PROMs and PREMs enable patients to report on their quality of life, daily functioning, symptoms and other aspects of their health and well-being. Health services can also use this type of data to assist in measuring organizational performance and to determine the services and care that patients require and request ^[1].

Patient-reported experience measures (PREMs) are collected directly from patients, pertaining to their individual and unique experiences within the health service or their condition ^[2], while PROM data can relate to the patient's perception of the impact of their condition (e.g., symptom severity, pain scales, function and/or health-related quality of life) or their interaction and satisfaction with the health service. Patients can input information on both disease-specific and general measures of function and health, which can be tracked over time ^[2]. Both PROMs and PREMs data can be obtained through questionnaires and/or surveys, with the aim of the collected data being used to initiate or support quality improvement activities and changes in health care ^[3]. Incorporating PROMs and PREMs data into clinical practice has the potential to narrow the gap between the clinician's and patient's views of the care provided and help tailor individualised care plans to meet the patient's preferences and needs ^[4]. Evidence also exists identifying positive associations between patient safety and patient experience ^[1].

2. Concept 1: Geographical Contexts of Included Studies

A total of 24 (27.9%) studies were from the United States of America ^{[5][6][7][8][9][10][11][12][13][14][15][16][17][18][19][20][21][22][23][24][25][26][27][28]}, 15 (17.4%) from the United Kingdom ^{[3][29][30][31][32][33][34][35][36][37][38][39][40][41][42]}, 8 (9.3%) from Canada ^{[43][44][45][46][47][48][49][50]}, 6 (6.9%) from the Netherlands ^{[51][52][53][54][55][56]}, 5 (5.8%) from Australia ^{[57][58][59][60][61]}, 4 (4.6%) from Nigeria ^{[62][63][64][65]}, 2 (2.3%) from Hong Kong ^{[66][67]}, 3 (3.5%) from Ireland ^{[68][69][70]}, 3 (3.4%) from India ^{[71][72][73]}, 2 (2.3%) from Italy ^{[74][75]} and 2 (2.3%) from Greece ^{[76][77]}. Single studies (1.2%) were reported from Sweden ^[78], Germany ^[79], China ^[80], Denmark ^[81], Ethiopia ^[82], Pakistan ^[83], Uganda ^[84], Finland ^[85], Ghana ^[86], Tanzania ^[87], Saudi Arabia ^[88] and New Zealand ^[89]. One study was reported from across both Australian and New Zealand hospitals ^[90].

3. Concept 2: Characteristics of Included Studies

3.1. Study Populations and Settings

The population sizes for the single studies included ranged from 7 participants [30] to 2,648,275 [27]. The majority of studies ($n = 28$; 32.5%) were undertaken in general acute hospital inpatient units [5][6][8][10][11][16][19][20][21][24][25][28][32][34][35][47][54][59][66][67][71][74][76][77][78][80][83][86], while 12 studies (13.9%) were reported more specifically as being set within the Emergency Department [12][13][14][18][42][43][49][56][68][70][73][75] and 8 studies (9.3%) were relevant to surgical settings [9][15][17][22][37][48][69][89]. Thirteen studies (15.1%) were undertaken in outpatient clinics [23][27][33][45][50][62][64][65][72][82][85][87][88]. Three studies (3.4%) reported on inpatient and outpatients as participants [55][63][84] and three studies (3.4%) included data collected from health professionals [30][31][38]. Nine studies (10.4%) took place within oncology, haematology or palliative care inpatient or outpatient units [7][26][30][31][36][44][46][79][81]. Single studies reported on patients undergoing colonoscopy [58] and haemodialysis [39], and one research reported on two patient groups with rare diseases of sclerosing cholangitis and kidney disease requiring transplant [38]. Some studies reported mixed settings/patient groups.

3.2. Study Design, Methodology and Data Collection Methods

Seven systematic research [3][29][40][41][51][52][57] were included as they contained aspects that pertained to the use of PREMs or PROMs data in practice and/or barriers and facilitators to the implementation of the collected data. **Table 1** provides a summary of these research. It is important to note that some of the included systematic research included studies of paediatric populations and/or settings other than hospitals. One systematic research protocol was also included in the selection [60], and the researchers were contacted to see if the research was completed, but no data were available at this time. The research aims to examine factors influencing the fidelity of implementation of PROMs data and is ongoing.

Table 1. Characteristics of systematic reviews relevant to the topic.

Author	Country of Origin	Number of Included Studies	Type of Review and Primary Focus	Summary of Results (Pertaining to Implementation)
Bastemeijer, et al., 2019 [51]	Netherlands	21	Systematic review (SR) of studies that reported on quality improvement activities in hospital settings based on patient experience data; barriers and promoters also reported on	Quality improvement (QI) strategies included staff and patient education, audit and feedback processes, clinician reminders, organisational and policy change. Barriers pertain to data collection, lack of time and scepticism regarding the benefits of change. Organisational support staff and patient involvement were reported as facilitators
Boyce et al., 2014 [29]	UK	16	Qualitative synthesis examining the experience of health professionals using PROM data to improve care quality	Barriers to and facilitators of the use of data were reported under four themes, summarised as practical, attitudinal, methodological and impact categories. Infrastructure, timing and workload must be considered prior to collecting PROM data to ensure the use of findings. Including staff in the planning stage may improve engagement, attitudes and subsequent use of data. Interpretation of PROMs data varies, which requires further consideration
Foster et al., 2018 [40]	UK	6 systematic reviews	Systematic review of systematic reviews	Time and resources needed for preparing and designing processes for implementing PROMs and changes relating to PROMs data. Recommendation for 'leader' to facilitate the implementation of strategies based on feedback. Contextual considerations and staff training are needed. Gaps identified in factors that influence the implementation of PROMs

Author	Country of Origin	Number of Included Studies	Type of Review and Primary Focus	Summary of Results (Pertaining to Implementation)
Gleeson et al., 2016 [3]	UK	11	SR of how PREMs are collected and used to inform QI projects in hospitals; barriers to and facilitators of using patient experience data also reported	Patient experience data mostly collected via surveys. Difficulties noted in evaluating any changes from implementing the results of experience data into practice. Formal staff training suggested for the analysis of data and implementation of subsequent QI projects, as a lack of confidence in interpreting data was seen as a major barrier
Graupner et al., 2021 [52]	Netherlands	22	SR of the effectiveness of PROMs on patient outcomes, patient experiences and process indicators in cancer care. Fifteen studies compared PROMs with no PROM	Feedback to health professionals and patients from collected PROM data led to improvements in symptom management, communication between patients and healthcare providers, as well as HRQoL and patient satisfaction. Results were not statistically significant due to small samples
Greenhalgh et al., 2017 [41]	UK	36	Two realist syntheses; one to develop a classification and taxonomy of programme theories with the development of a logic model on the collation, interpretations and use of PROMs data. The second synthesis explored how PROMs data work in practice in detail, including (but not limited to) an analysis of barriers and supporters of the implementation process and unintended consequences	PROMs data that were deemed to be clear and credible, focused on patient care improvement and that were timely, were more likely to be used to develop improvement strategies. System-wide approaches were then needed for implementing improvement strategies. PROMs were a beneficial method for patients to raise concerns, but improvements in communication with health care providers were less overt. The reviews highlighted challenges with moving beyond collecting PROM data to effectively using results for any change in practice
Ishaque et al., 2019 [52]	Australia	22 studies included with 25 comparisons	SR of RCTs comparing the effectiveness of PROM with no PROM, with outcomes including health care processes, health outcomes and satisfaction with care	Improvements noted in clinician/patient communication and decision making; however, many studies focused on statistical significance, rather than highlighting clinically meaningful changes in outcomes or care processes. Some, but not all, studies implemented strategies based on PROMs use. Methodological limitations noted within studies

Of the primary studies, eleven (12.7%) used qualitative methods [32][33][38][39][43][44][47][59][68][81][89], with one of these studies reporting an ethnographic approach [81]. Fifty-six studies (65.1%) reported using quantitative methods [5][6][7][8][9][10][11][12][13][14][15][16][17][18][19][20][21][23][24][25][26][27][28][34][35][37][42][45][46][48][49][50][54][55][56][58][62][63][64][65][66][67][69][70][71][73][74][75][76][77][78][79][80][82][83][84][85][86][87][88][90].

Eleven of the included research (12.7%) used mixed methods for their studies [22][30][31][36][67][75][76][82][83][85][86]. Two of the quantitative studies (2.3%) reported specifically on using the Kaizen Lean methodology [49][69], which is based on the principles of process standardisation for quality improvement. Six studies (6.9%) examined various factors influencing patient satisfaction [24][27][70][73][80][84] and five other studies (5.8%) explored predictors of patient satisfaction [9][82] and/or correlations with other outcomes [15][34][48] (e.g., adverse events). Researchers also included one clinical trial protocol [39], as it outlined a prospective study that specifically examined the use of collected PROM data, as well as barriers and facilitators related to the data and preferred methods of feedback from both patients and physicians.

Regarding the data collection methods, surveys or questionnaires were the most popular method, as reported in 65 (75.5%) studies [5][6][7][8][9][10][11][12][13][14][15][16][17][18][19][20][21][22][23][24][25][26][27][28][30][31][34][35][36][37][42][44][45][46][48][49][50][54][55][56][58][62][63][64][65][66][67][69][70][71][73][74][75][76][77][78][79][80][82][83][84][85][86][87][88][90]. Focus groups were utilized in 6 (6.9%) studies [31][39][59][68][81][86] and interviews (including semi-structured interviews) were reported in 15 (17.4%) studies as data collection methods [22][30][32][36][38][39][43][47][68][72][75][76][82][83][89].

3.3. Measurement Tools Used in Included Studies

The Hospital Consumer Assessment of Healthcare Providers and Systems tool (HCAHPS) was the most frequently used tool for measuring patient satisfaction, used either in its entirety or parts thereof [6][8][9][10][13][14][15][16][17][19][21][22][24][28][48]. Other frequently used tools included Press Ganey surveys for measuring patient satisfaction [22][27][28][56][59] and versions or variations of the 15-item Picker survey [35][36][45][66][75].

Validated scales were used to collect PROM data, particularly within oncology studies [26][30][31][46] and studies of renal patients [39][90] or those with rare diseases [38]. Most studies used non-validated tools that were developed by the researchers based on the literature and/or previous research. Three studies reported on the development and psychometric properties of a new patient-report measurement tool [23][42][67].

4. Concept 3: Application of PREMs/PROMs Data to Clinical Practice

Of the 86 included research, only 22 primary studies reported on ways in which the collected data were used in practice, which are discussed in more detail below. Each of the six included systematic research included some detail pertaining to the application of data to clinical practice (refer **Table 1**). Two systematic research (total of 33 included studies) [31][51] addressed quality improvement programs arising from collected PROMs/PREMs data. One additional study [37] was reporting on an aspect of a larger PhD thesis, which examined a new model of care for supplying patient medication at discharge. Collected PROM data were used to support the new model. Roberts et al. [60] reported ongoing work to examine factors that influence the fidelity of the implementation of PROMs in routine patient care.

The most frequently reported utilisation of the collected data was to improve communication between patients and health care staff. Two studies [13][18] reported on the use of the AIDET (Acknowledge, Introduce, Duration, Explanation, Thank you) communication framework, with results from their studies highlighting improvement in patient satisfaction scores after implementing the framework. Real-time feedback was reported on as a way to also improve patient–physician communication [10].

Four qualitative studies reported perspectives on the use of collected data [38][39][43][81]. Thestrup Hansen et al. [81] conducted an ethnographic study which explored patients' perspectives on the use of PROMs data in haematology clinics. Patients reported that undertaking a PROMs survey provided them with topics to discuss with a doctor; however, some reported being confused by the purpose and utility of the data. Aiyegbusi et al. [38] reported patient and physician perspectives on the use of PROM data, with both groups reporting communication benefits through using PROM data to instigate discussions on quality of life or symptom management. It was also reported that the use of PROMs data facilitated patient-centred care and patient involvement, although it was suggested by physicians that specific PROM tools were more effective than generic tools for their patient cohort who had rare diseases [38]. Dainty et al. [43] reported physicians' perspectives on the use of PROM data in the Emergency Department (ED) and identified tension between the dynamic and complex nature of the ED and the application of PROM data. More specifically, participants suggested that, as they often saw patients for short periods and frequently at times of crisis, there was preference for the use of objective data (e.g., detail on adverse events and readmission data). Concerns were voiced regarding the legal and ethical implications of using patient-reported data due to limited follow-up with patients. Other issues of the subjectivity and timing of collecting data were also seen as limitations to the application of PROMs in the ED; however, some participants suggested a benefit in using PROMs to facilitate communication between patients and physicians. The researchers highlighted the importance of physician involvement in planning and implementing PROMs in the ED [43]. Anderson et al. [39] reported a clinical trial protocol for a qualitative study on the use of PROMs in patients requiring haemodialysis. This is ongoing and will capture data on the use of electronic PROMs for this context.

Other applications of collected data included the establishment of a patient liaison program to monitor patients' satisfaction and improve care and patient flow within the emergency department [12][49], an increase in screening rates for patient distress within the oncology setting [26], the implementation of nursing care bundles [21], strategies for reducing noise levels within hospital wards [22] or improving cleanliness and waiting times in the outpatient department [87]. The implementation of specialist oncology nurses [30][31] or a nurse–midwife [25] to coordinate patient care and flow through different care settings was also reported on and evaluated using patient-specific or general satisfaction surveys. Additionally, data were used to reorientate care towards patient's centeredness to ensure that patients are the focus of their care and participate in their own goal setting [11].

Multifaceted interventions were reported on in two additional quality-improvement projects [5][19], whereby audit data were collected pre- and post-interventions, with improvement noted in both patient satisfaction scores and staff responses.

Improvements addressed (but were not limited to) patient–staff communication, patient discharge instructions, patient nutrition, staff availability and maintenance of patient dignity.

5. Concept 4: Facilitators and Barriers to Using Collected PREMs and PROMs Data

Several studies reported on barriers to and facilitators of collecting PROMs data; however, for this concept, researchers report on barriers to and facilitators of using or implementing collected PROMs/PREMs data in hospitals for changes in services or practice. Of the systematic research, Greenhalgh et al. ^[41] highlighted the distinction between individual PROMs measures (such as those for symptom reporting or pain scales) and measures that are used for service improvement or service quality measures (e.g., satisfaction scores). Boyce et al. ^[29] reported on sixteen studies in their research , exploring health professionals' experiences of using collected data, with the barriers reported on including inadequate resources and poor attitudes to PROM use. Although participants inferred benefit to the use of collected PROMs data for improving patient care, concerns were raised around patient privacy, confusion regarding the goals or aims of implementing PROMs data and limited managerial support to make changes. Incorporating clinicians at the planning stage of any PROM-based intervention was recommended to facilitate change ^[29].

Forster et al. ^[40] reported on six systematic research (118 total studies), with a focus on facilitators of and barriers to implementing patient-reported outcome measures for health services. Most of the included studies reported on challenges associated with collecting data, rather than the use of collected data, and the researchers recommended further research on how organisational culture impacts and supports changes in practice following the collection of PROMs data. Across the relevant studies, barriers and facilitators were reported under patient, staff organisational or data and intervention-related categories.

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