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# Proposed Patient-Inclusive Methodology for Developing and Validating Patient Experience Surveys

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**Abstract**

*Patient experience while using telehealth services impacts patient care, and health system incentives and reimbursement. Therefore, the patient experience should be continuously improved, which requires evaluation. Surveying patients is integral to this process. Ideally, patient experience surveys used to evaluate telehealth services should cover patient experience sub-themes, be validated, and minimize bias. This paper evaluates how current validated patient experience surveys cover patient experience sub-themes, and how many are telehealth-specific. We collected 11 validated patient experience surveys. We then extracted five themes and 114 sub-themes of the patient experience. We evaluated survey questions against patient experience sub-themes. We found that current validated patient experience surveys cover, at most, 20.2% of patient experience sub-themes, with the most common sub-themes being "Psychosocial Needs" (81.8%) and "Information: Treatment" (72.7%). We cross-referenced validated patient experience surveys against validated telehealth-specific surveys. Only one validated patient experience survey (PEQ) was also telehealth-specific.*

***Keywords:***

Telehealth, Patient Satisfaction

## Introduction

Patient experience is an essential contributor to the quality of patient care. Patient experience scores also affect incentives and reimbursements. Therefore, it is important to define what "patient experience" is before we measure it. Key themes and expert consensus have led to the development of several definitions for "patient experience." Key patient experience themes include personal interactions, organizational culture, patient and family perceptions, and across the care continuum. Other important aspects that impact patient experience include meeting emotional needs such as confidence, integrity, pride, and passion, and maintaining patient expectations. Patient experience also affects the positive realization of patient expectations and patient/family-centered care [1]. One of the most popular definitions of patient experience was produced by the Beryl Institute, which defines patient experience as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care" [2].

As telehealth services continue to grow, we must be able to evaluate the patient experience while using those services. This will help guide improvements in patient experience, facilitate meeting patient needs and expectations, and thus improve patient care and health system reimbursement.

Surveys can measure patient experience. Survey strengths include confidentiality, independent assessment of clinicians and patients, pre-existing scales which allow cross-study comparison, low cost relative to sample size, result generalizability, and the ability to validate surveys, thus ensuring accurate measurements of desired constructs [3].

However, surveys have limitations, and inappropriately constructed surveys may exhibit various biases and technical issues. Therefore, it is recommended that scientifically validated surveys be used to assess telehealth services [3]. Validated surveys have been evaluated to ensure that their questions achieve face validity, usefulness, construct validity, convergent and discriminant validity, and content validity. Additionally, that the overall survey instrument achieves reliability and internal consistency [3]. Validated surveys ensure that survey measurement of constructs is accurate, dependable, and reliable [3, 4].

For patient experience using telemedicine services to be accurately evaluated, validated surveys should be used. However, those surveys should also comprehensively collect all the sub-themes that contribute to patient experience. In addition, telehealth services introduce a unique patient care scenario, and therefore patient experience surveys used to evaluate telehealth services should be validated for telehealth services specifically. This paper evaluates current validated patient experience surveys for coverage of established patient experience sub-themes and validation specifically for telehealth services.

## Methods

Our objectives were to determine how completely current validated patient experience surveys cover patient experience sub-themes, and to determine how many were telehealth-specific. To identify patient experience sub-themes, we used guidelines from the UK National Clinical Centre [5]. We collected validated patient experience surveys from a recent systematic review [6]. We also collected telehealth-specific surveys from a different systematic review [7].

We constructed a table that associated key patient experience themes and sub-themes with survey questions. Survey questions were paired with patient experience sub-themes based on clinical experience and whether the survey questions contained specific terms. A physician reviewed the association between sub-theme and survey questions. This resulted in a matrix containing patient experience sub-themes, and surveys and their survey questions. Data analysis was then performed on the matrix to evaluate how completely survey questions incorporated the identified patient experience sub-themes.

To evaluate which validated patient experience surveys were validated specifically for telehealth, we cross-referenced the collected validated patient experience surveys against established telehealth-specific validated surveys.

## Results

We extracted the five themes and 114 sub-themes from the UK National Clinical Centre guidelines on patient experience [5]. We then collected 11 validated patient experience surveys identified in a recent systematic review [6], and extracted their survey questions. The extracted data were arranged into a 114x11 matrix of patient experience sub-themes versus surveys and survey questions. Data analysis was then performed on the 114x11 matrix to evaluate how completely survey questions covered the identified patient experience sub-themes.

In reviewing the 11 validated patient experience surveys, we found that surveys only covered, at most, 23 out of the 114 patient experience sub-themes (20.2%). Of the covered sub-themes, "psychosocial needs" under the theme "Essential Requirements of Care" was the most covered (81.8% of surveys), followed by "Information: Treatment" under the theme "Enabling Patients to Actively Participate in their Care" with a focus on "Information" (72.7% of surveys), further followed by "Pain," "Relationship with Healthcare Professional," "Explanations" and "Individualized Approach" (63.6% of surveys).

*Table 1– Survey Coverage of Patient Experience Sub-theme*

| **Survey** [8-18] | **Number of Covered Sub-themes** | **Percent of Sub-themes** |
|---|---|---|
| HKIEQ | 23 | 20.2% |
| NHSIP | 22 | 19.3% |
| SIPES | 22 | 19.3% |
| QPP | 18 | 15.8% |
| PEQ | 15 | 13.2% |
| QPPS | 13 | 11.4% |
| HCAHPS | 12 | 10.5% |
| PPE-15 | 11 | 9.6% |
| I-PAHC | 10 | 8.8% |
| PPQ | 9 | 7.9% |
| NORPEQ | 5 | 4.4% |

We then collected 12 telehealth-specific validated surveys specified in a recent systematic review [7]. We cross-referenced this list against the 11 previously identified validated patient experience surveys. Only the PEQ survey was both a validated patient experience survey and validated specifically for telehealth services.

## Discussion

Patient experience is an essential indicator of healthcare quality and is directly related to healthcare reimbursement. For example, in 2015 Medicare paid hospitals $4.2 million based on HCAHPS measures of patient experience [19]. In our review of validated patient experience, surveys only covered up to 20.2% of all sub-themes which impact the patient experience. In addition, only 1 of those validated surveys, the PEQ, was specifically validated for telehealth services [7].

Currently validated patient experience surveys do not cover all patient experience sub-themes. Only 1 survey is specifically validated for telehealth services. We recommend creating new validated patient experience surveys that cover all patient experience sub-themes for telehealth services more completely.

Survey developers should consider underutilized patient experience sub-themes during development. While many of these sub-themes can be determined by reviewing the literature on patient experience sub-themes, we also recommend engaging with providers and patients to expand patient experience sub-themes further. Focus groups can help identify candidate sub-themes [3], as can patient and provider interviews. Over 40 years ago, Dr. Warner Slack once said, "The basis for our use of computers in medicine is the thesis that the largest and least used provider of healthcare is the patient" [20]. Patient experience should be respectfully and meaningfully assessed through the lens of the patient.

Once patient experience sub-themes are selected, questions can be collected from currently validated patient experience surveys. New survey questions may be constructed or produced by modifying previously validated survey questions if no previously developed questions are acceptable.

Questions in a survey should be evaluated for relevance to the desired patient experience sub-themes, bias, readability, responsiveness to change, clarity, consistency, and sensitivity to difficult topics [3]. Some questions should be phrased positively, while others should be phrased negatively to decrease the "halo effect" [4]. It is recommended that recall questions be avoided on surveys because respondents have limited ability to recall the past [4], though this may be difficult when evaluating patient experience. Questions should offer logically distinct response options and an option for non-response [21].

Survey questions use a five-point Likert scale for scoring. The scales should be scored in the same direction to make sense when summed [4]. Once previously validated, modified, and new survey questions are prepared, they may be added to an extant survey, or combined into a new survey instrument [3]. The modified or new survey instrument should then be validated [3].

Validation involves two pilot studies and a final validation study. The initial pilot study assesses survey questions' face and content validity, survey item usefulness, removal of items that perform poorly, and ensures that the survey evaluates all relevant constructs [3]. After editing the survey, the second pilot study reevaluates the above qualities [4], and helps refine wording and layout [22]. The validation study should establish the construct, convergent, criterion-related, and discriminant validity of questions [3]. The validation study also assesses the survey instrument for test-retest reliability, parallel forms reliability, internal consistency reliability [3], and psychometric properties such as Cronbach's alpha [4]. The validation study should be performed on a large population similar to the population that will be surveyed by the validated instrument [3].

Survey administration should be planned. Surveys can be administered as self-completion questionnaires or via interviews [4]. During the pilot and validation studies, consideration should be given to sampling frame and strategy, sample size, administration methods, means to improve response rate, disclosures to participants, and data management and analysis decisions [4]. The feasibility of survey administration should be assessed, including considering the number of times the survey will be administered, and how respondent anonymity will be maintained [4]. Data entry methods should be contemplated before data collection. Double data entry is recommended to reduce error. Data storage should be secure and adhere to regulations, including patient privacy regulations [4].

Validated surveys of patient experience do have some limitations. Surveys not validated in diverse populations and varied locations may lack generalizability [23]. Non-experiential factors, like health outcomes, may complicate patient experience evaluation, and preconceived expectations of healthcare may bias survey results [24]. Patient experience being understood as a separate metric from patient satisfaction

is a relatively new concept, and some instruments may have been developed with a limited distinction between the two [24].

This paper evaluated current validated patient experience surveys for coverage of patient experience sub-themes, evaluated which validated patient experience surveys were also validated for telehealth services, and put forth a method to develop more complete patient experience surveys. However, our review had limitations. We limited our sub-themes to those accepted by the NHS. However, more sub-themes may exist, and current sub-themes may lack granularity or clarity to categorize survey questions accurately. Moreover, we focused on 114 sub-themes. While possibly exhaustive, focusing solely on sub-theme completeness may not be the best strategy when surveying patients when balanced against ease of survey implementation or survey completion rate by patients. We limited our validated patient experience surveys to those found via a single systematic review from 2015 [5] though others may exist now and older surveys may have been updated. While our study found that current validated surveys did not cover many patient experience sub-themes, more research is required to determine which sub-themes were most associated with patient experience.

## Conclusions

Patient experience is a valuable indicator of healthcare quality and is associated with millions of dollars of healthcare reimbursement. Despite this, only 20.2% of patient experience sub-themes are evaluated by current validated patient experience surveys. In addition, only one validated patient experience survey is also validated specifically for telehealth services. To improve the telehealth patient experience, more comprehensive, validated patient experience surveys should be developed specifically for telehealth services. We have proposed a patient-inclusive method for developing and validating patient experience surveys for telehealth.

Future work includes involving patients in the co-design process to expand and more accurately define patient experience sub-themes, determine which sub-themes are most associated with patient experience while using telehealth services, and develop a more comprehensive patient experience survey validated specifically for telehealth services.

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