

Mapping the Evolution of Patient Experience Research in Contemporary Healthcare: Concepts, Measurement Approaches, and Emerging Directions

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Abstract

Patient experience has become a prominent dimension of healthcare quality, yet the field remains conceptually and methodologically heterogeneous. Research has moved beyond global satisfaction ratings toward multidimensional accounts of communication, relational quality, continuity, organizational processes, accessibility, shared decision-making, digital encounters, and equity. At the same time, patient-reported experience measures, qualitative inquiry, journey-based methods, and technology-enabled feedback systems capture different parts of the construct and are not interchangeable. This scoping review maps how contemporary patient experience research has evolved, how patient experience has been defined and differentiated from related constructs, how it has been measured, which populations and settings have been represented, and which conceptual and methodological priorities are emerging. The review was designed using scoping-review methodology and PRISMA-ScR-compatible reporting principles. Evidence was organized across conceptual definitions, theoretical domains, measurement approaches, patient-reported experience measures, qualitative and mixed methods, digital and real-time measurement, population and setting coverage, geographic and equity representation, and emerging research directions. Measurement evidence was interpreted with attention to construct validity, psychometric maturity, contextual transferability, and the distinction between patient experience, satisfaction, participation, healthcare processes, and clinical outcomes. The mapped literature indicates a transition from broad service ratings toward increasingly differentiated accounts of what patients encounter, interpret, value, and report across healthcare journeys. Contemporary research gives greater attention to relational processes, care coordination, patient knowledge, organizational context, digital modality, accessibility, cultural and structural conditions, and patient partnership. Measurement approaches have simultaneously diversified, with disease- and setting-specific patient-reported experience measures, qualitative journey methods, virtual-care instruments, near-real-time feedback systems, and equity-oriented measures. However, theoretical grounding, psychometric completeness, population representation, and cross-setting comparability remain uneven. Patient experience research is evolving from a largely evaluative measurement field toward a more explicitly conceptual, contextual, and participatory field. Future progress depends less on identifying a single universal measure than on clarifying what aspect of experience is being measured, for whom, in which healthcare context, at what point in the care journey, and for what decision or improvement purpose. Stronger construct discrimination, accessible co-production, contextual validation, and integration of structured and interpretive evidence are central priorities.

Keywords: Patient experience, Patient-reported experience measures, Healthcare quality, Person-centred care, Measurement validity, Health equity

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Introduction

Patient experience has moved from a peripheral indicator of healthcare acceptability to a prominent component of healthcare-quality assessment. Yet its increased visibility has not produced corresponding conceptual uniformity.

Contemporary research describes patient experience through factors operating at multiple levels, including individual expectations and needs, interpersonal communication, relational trust, care coordination, physical and organizational environments, and broader system conditions [1]. The result is not one singular construct observed through different instruments, but a family of related experiential phenomena whose meaning changes according to the level, setting, population, and stage of care under study.

Care journeys further complicate this picture because what patients report is rarely confined to an isolated encounter. In elective perioperative care, for example, experience spans preparation, communication, expectation management, procedural care, recovery, and transitions between professionals and services [2]. Such evidence supports a longitudinal understanding in which experience is generated across linked encounters rather than solely at the point at which a questionnaire is administered.

Measurement research has evolved alongside this conceptual expansion. Surgical evidence demonstrates the coexistence of patient-reported experience measures (PREMs) and qualitative studies, while also showing that psychometric evidence is uneven and that structured instruments do not necessarily capture all domains identified through patients' narratives [3]. This distinction matters because increases in measurement activity can otherwise be mistaken for conceptual convergence. A field may accumulate more instruments while remaining uncertain about what, precisely, each instrument represents.

This review therefore treats patient experience research as an evolving knowledge domain rather than simply a collection of satisfaction surveys or PREMs. Its central concern is how concepts, measurement strategies, contexts, and emerging research priorities have changed together. The review separates descriptive evidence from the synthesis developed here and avoids treating patient experience, satisfaction, participation, healthcare processes, organizational performance, and clinical outcomes as interchangeable endpoints.

Review objectives and questions

The review was designed to answer five linked questions. First, how has contemporary patient experience research changed in its conceptual emphasis and methodological organization? Second, how is patient experience defined, and where does it overlap with or diverge from

satisfaction and related constructs? Third, which approaches are used to measure experience, and what forms of validity or interpretability do they provide? Fourth, which populations, healthcare settings, geographic contexts, and equity-relevant conditions are represented or underrepresented? Fifth, which emerging directions appear most consequential for conceptual development and measurement.

These questions are necessary because contemporary mapping studies continue to demonstrate extensive variation in instruments and conceptual foundations. In oncology, for example, a recent scoping review identified numerous distinct tools and found that explicit theoretical foundations were frequently absent [4]. Instrument proliferation therefore cannot by itself be interpreted as maturation of the field.

The review accordingly maps not only what has been measured but also the relationship between the construct claimed, the measurement mode used, the patient or population represented, the context of care, and the inference ultimately made. Where the reviewed literature establishes only associations, descriptive patterns, feasibility, or preliminary psychometric evidence, this review retains those limits rather than converting them into causal or universal claims.

Materials and Methods

Scoping review design

A scoping-review design was selected because the questions concern concept clarification, evidence mapping, measurement diversity, population and setting coverage, and research gaps rather than estimation of a pooled intervention effect. PRISMA-ScR provides the appropriate reporting framework for transparent presentation of identification, selection, and synthesis processes in reviews of this type [5].

The conduct framework was aligned with updated methodological guidance for scoping reviews, emphasizing explicit review questions, transparent inclusion logic, structured evidence charting, and a synthesis appropriate to heterogeneous evidence [6]. Scoping reviews are particularly suited to questions that seek to examine how a field is conceptualized, identify the forms of evidence available, and determine where knowledge remains incomplete [7].

Eligibility criteria

Eligible evidence was defined conceptually around research examining patient experience in healthcare delivery, including its definition, determinants, measurement, methodological development, setting-specific application, digital adaptation, equity implications, or patient-partnership implications. Evidence addressing satisfaction alone was considered relevant only where it helped clarify historical evolution or construct boundaries.

Eligible designs included empirical quantitative and qualitative studies, mixed-method studies, instrument-development and validation studies, systematic and scoping reviews, and methodological or conceptual studies directly relevant to the review questions. Evidence was interpreted according to design rather than treated as methodologically equivalent. Cross-sectional associations were not interpreted as longitudinal or causal effects, and qualitative findings were not translated into prevalence statements.

The publication window was restricted to 2017–2026 for the included evidence set. Particular attention was given to recent work because the review concerns contemporary evolution, while earlier studies within the window were retained when necessary to identify historical measurement patterns or methodological foundations.

Information sources

The evidence base was assembled from peer-reviewed journal literature spanning patient experience, healthcare quality, nursing, health-services research, patient education, equity, measurement science, surgery, oncology, critical care, digital health, and person-centred care.

A limitation of the evidence base must be stated explicitly. A complete source-by-source bibliographic export containing database-specific retrieval totals was unavailable. Consequently, database-level retrieval counts cannot be reconstructed here without introducing unsupported numbers. This affects quantitative PRISMA-ScR reporting but does not justify reverse-engineering review-selection counts from the final citation set.

Search strategy

Search concepts were organized around combinations of patient experience, patient-reported experience measures, satisfaction, experience measurement, psychometric properties, qualitative patient experience,

care journey, digital or virtual care, real-time feedback, equity, diversity, vulnerable or underrepresented populations, co-production, and patient partnership.

Methodological searching additionally covered scoping-review conduct, PRISMA-ScR reporting, and measurement-property evaluation. Searches were iteratively refined to capture construct-focused, setting-focused, measurement-focused, and population-focused literature rather than privileging a single terminology family.

Because exact database-export counts were unavailable, the search strategy is reported descriptively rather than accompanied by invented record totals.

Evidence selection

Selection was based on direct relevance to at least one prespecified review domain: conceptual development, measurement methodology, psychometric evidence, qualitative or mixed-method experience research, digital measurement, setting or population coverage, equity representation, or emerging patient-partnership approaches.

Potentially relevant papers were excluded from the evidence set when they were merely adjacent to patient experience, did not provide sufficient construct or measurement relevance, fell outside the publication window, or could not satisfy the bibliographic and journal-quality requirements used for the evidence set.

Numerical screening and exclusion totals are not reported because they were not recoverable from source-level screening records. The review therefore does not equate its 36 references with a PRISMA-ScR included-study count.

Data charting

Evidence was charted according to source design, population or evidence unit, healthcare topic, country or setting, focal construct, relevant intervention or contextual condition, measurement or operationalization, mapped experience domain, principal finding, heterogeneity, equity or contextual modifiers, quality information where reported, limitations, and role in the synthesis.

This structure was intended to prevent conceptual slippage. For example, a measure of satisfaction with virtual care was not automatically coded as equivalent to a multidimensional measure of virtual patient experience, and an association between patient experience and service utilization was not interpreted as evidence that

experience directly causes clinical or utilization outcomes.

Conceptual and measurement coding framework

Measurement evidence was coded separately from conceptual evidence. Instrument development, reliability, validity, responsiveness, cognitive testing, content relevance, and contextual validation were distinguished rather than collapsed into a binary judgment of whether a measure was “validated.”

This approach was informed by measurement-property guidance emphasizing structured evaluation of reliability, validity, and related properties rather than treating instrument availability as evidence of measurement adequacy [8]. For PREMs, construct definition was considered particularly important because measurement quality depends not only on statistical properties but also on whether the instrument captures the intended experiential phenomenon.

Conceptual coding distinguished patient-reported experience from satisfaction, participation, perceived service quality, relational processes, organizational characteristics, and downstream outcomes. The review also preserved differences among individual, relational, organizational, digital, structural, and equity-relevant levels of explanation.

Synthesis and presentation

Evidence was synthesized descriptively and interpretively rather than statistically pooled. The descriptive synthesis maps how patient experience has been defined, measured, and applied across populations and settings. The interpretive synthesis developed in later sections examines where these patterns suggest conceptual maturation, unresolved ambiguity, or new measurement requirements.

Where a relationship is well supported by the mapped evidence, it is described as evidence-supported. Where the review integrates separate findings into a new classification, architecture, or research priority, that synthesis is identified as proposed. This distinction is maintained especially for multilevel relationships, equity conditions, digital-transfer questions, and future measurement directions.

Results and Discussion

The reviewed literature demonstrates substantial expansion in the conceptual and methodological scope of

patient experience research. Earlier work within the review window often concentrated on instrument performance, service ratings, satisfaction, access, and associations between experience measures and organizational or utilization outcomes. More recent studies increasingly examine disease-specific experience, patient journeys, virtual-care encounters, near-real-time feedback, cultural responsiveness, equity-oriented measurement, accessibility, co-production, and patient partnership.

This evolution is not linear. Older approaches have not disappeared, and newer PREMs frequently coexist with satisfaction measures, qualitative narratives, organizational indicators, and service-level surveys. The field therefore appears better characterized by diversification than by replacement.

A second pattern is increasing specificity. Rather than assuming one patient-experience instrument can transfer unproblematically across healthcare contexts, recent work more often develops or tests instruments for particular clinical populations, care modalities, or groups whose experiences may be poorly represented by conventional surveys.

A third pattern is growing recognition that measurement architecture affects whose experience becomes visible. Language, disability, digital access, healthcare setting, cultural context, communication requirements, and structural disadvantage can influence both the experience of care and the feasibility or interpretation of experience measurement.

Evidence-selection reporting boundary

A numerical PRISMA-ScR flow cannot be presented because database-specific retrieval, deduplication, title/abstract screening, full-text exclusion, and final inclusion counts were unavailable. Reporting those numbers would therefore require fabrication.

Evidence selection

The evidence mapped for substantive synthesis includes conceptual and methodological scholarship, systematic and scoping reviews, quantitative observational studies, qualitative studies, and instrument-development or validation research. These designs contribute different kinds of knowledge. Reviews identify recurring themes and evidence gaps; validation studies address measurement performance in defined populations; observational studies describe associations; and

qualitative work provides contextual and experiential detail that may not appear in structured instruments. No numerical evidence-category distribution is reported because such frequencies would need to be calculated from the complete verified included-evidence ledger rather than from the reference list.

Publication and field evolution

The evolution of patient experience research can be understood as a shift in analytical emphasis rather than a clean sequence of replacement. Earlier PREM reviews already documented substantial methodological concern. In emergency care, for example, available PREMs showed variable and incomplete psychometric evidence, demonstrating that formal patient-experience measurement was established before measurement-property standards were consistently satisfied [9].

Digital-care research illustrates another early boundary. A systematic review of telehealth literature largely examined satisfaction, demonstrating that technologically mediated care was initially often evaluated through acceptability or satisfaction rather than through richer multidimensional experience constructs [10]. That history remains important because contemporary virtual-care PREMs should not be interpreted as simple continuations of older satisfaction studies.

Research also increasingly examined relationships between reported experience and healthcare-system outcomes. English primary-care data showed that some appointment-experience measures had small associations with emergency service use, while other experience measures were inconsistent [11]. Such findings

strengthened interest in patient experience as a system-performance signal but also showed why reported experience should not be assumed to function as a direct proxy for utilization or clinical outcome.

Organizational evidence further expanded the unit of analysis. Hospitals using more patient-facing care-coordination strategies reported more favorable experience outcomes in several domains [12]. Routine primary-care data similarly showed that measurable variation in experience could occur at organizational levels rather than being attributable only to individual patient characteristics [13].

Policy-level research extended this movement. Following implementation of state Caregiver Advise, Record, Enable legislation in the United States, several hospital-experience measures showed differential improvement compared with hospitals in non-implementing states [14]. The findings do not establish that policy alone determines experience, but they illustrate the field's increasing attention to organizational and regulatory conditions surrounding patient-professional encounters.

The evolution visible across these studies is therefore multidimensional: from global ratings toward specific domains; from isolated encounters toward care journeys; from patient-level perceptions toward organizational and policy context; and from instrument availability toward stronger concern with psychometric adequacy, accessibility, and conceptual fit.

The distinctions are summarized below because a temporal matrix makes the changing analytical unit more visible than a chronological narrative alone (**Table 1**).

Table 1. Changing analytical emphasis in contemporary patient experience research

Research emphasis	Dominant question made visible	Characteristic unit of analysis	Measurement tendency	Interpretive boundary	Direction of field development
Service evaluation	Was care rated favorably?	Encounter or service	Global rating or satisfaction item	Favorable rating does not identify which experience process produced it	Movement toward domain-specific interpretation
Instrument-focused measurement	Can experience be measured reproducibly?	PREM or scale	Structured questionnaire	Instrument availability does not establish complete psychometric validity	Greater attention to validation and construct fit
Care-process experience	Which aspects of care shape what patients report?	Communication, coordination, access, transitions	Multidomain PREMs and service surveys	Association does not establish causal mechanism	Expansion toward relational and pathway-level interpretation
Organizational context	How do service structures coincide with experience?	Practice, hospital,	Aggregated and organization-	Organizational variation cannot be reduced to individual perception alone	Explicit multilevel analysis

		coordination system	linked experience measures		
Policy and system context	Can broader healthcare arrangements alter experience-relevant processes?	Regulation, institutional practice, system environment	Patient- experience outcomes linked to policy or system change	Policy association is not proof of a singular causal pathway	Increasing system- level contextualization
Contemporary contextual measurement	Is the measure meaningful for this population, modality, and purpose?	Population- setting-measure combination	Disease-, modality-, accessibility-, or equity-sensitive measures	Cross-context transfer requires validation rather than assumption	Movement toward contextual and participatory measurement

Note: The temporal categories are an interpretive synthesis proposed by this review. They do not imply that one period ended when another began; multiple approaches coexist in contemporary research.

Definitions of patient experience

Patient experience is commonly treated as the patient's report of what occurred during healthcare and how relevant aspects of care were encountered or perceived. This formulation is useful but incomplete because contemporary literature increasingly situates experience within ongoing relationships, interpretation, agency, and accumulated care journeys.

A broader conceptual development is the recognition of patients' experiential knowledge. Work extending chronic-care partnership models argues that people living with chronic disease bring knowledge generated through daily management, repeated encounters, adaptation, and interaction with healthcare services [15]. Under this view, experience is not merely an evaluative response collected after care. It may also constitute knowledge that affects communication, decision-making, continuity, and partnership.

Patient experience should nevertheless remain analytically separable from adjacent constructs.

Satisfaction usually contains an evaluative judgment relative to expectations. Participation describes involvement in a process such as decision-making. Trust concerns confidence in people or institutions. Perceived quality is a broader evaluative construct. Clinical outcomes concern changes in health status. These phenomena may correlate, but correlation does not make them interchangeable.

The definition used in this review therefore treats patient experience as a context-dependent account of what patients encounter, perceive, interpret, and consider consequential across healthcare interactions and journeys. This proposed synthesis intentionally leaves room for relational, organizational, digital, social, and structural conditions without claiming that every condition is itself a patient-experience construct.

A multilevel constraint map is useful here because different conditions can affect either the experience itself, the way it is reported, or the meaning assigned to the resulting measure (**Table 2**).

Table 2. Levels that constrain the meaning and interpretation of patient experience

Analytical level	What can enter the patient's reported experience	How interpretation can be distorted	What must remain analytically separate	Implication for measurement
Encounter	Listening, explanations, respect, involvement, responsiveness	A single memorable interaction may dominate a broader journey	Specific interaction versus overall service judgment	Define the encounter window explicitly
Relational	Trust, continuity, recognition, ability to question or disclose	Relationship history can alter interpretation of identical care processes	Relational process versus satisfaction with outcome	Include relational domains only when relevant to the construct
Care journey	Transitions, coordination, repetition, information continuity	Retrospective measures may obscure where a problem occurred	One encounter versus accumulated pathway experience	Match recall period and unit of analysis to the journey

Organizational	Access systems, staffing, coordination structures, environment	Organizational constraints may be attributed to individual clinicians	Patient report versus organizational mechanism	Avoid interpreting experience scores as direct measures of staff performance
Social and cultural	Language, norms, family involvement, expectations, social resources	Standardized wording may not carry equivalent meaning across groups	Cultural context versus assumed psychological traits	Test accessibility and cross-context interpretability
Digital	Modality, platform usability, privacy, connectivity, communication affordances	Technical convenience can be confused with relational quality	Technology function versus interpersonal experience	Validate modality-specific domains where needed
Structural and equity-related	Discrimination, power asymmetry, resource constraints, exclusion	Conventional PREMs may omit experiences of inequity or under-sample affected groups	Structural exposure versus individual preference	Design recruitment and items capable of detecting inequitable experience

Note: This multilevel organization is proposed by the present review as an interpretive framework. Levels can interact, but they should not be collapsed into a single causal hierarchy.

Conceptual domains and theoretical foundations

The contemporary literature suggests that patient experience is best understood as a multidomain construct embedded in a multilevel care environment. Communication remains foundational, but its importance is not simply informational. Explanations may shape understanding, while listening communicates recognition and can affect whether patients feel able to disclose concerns or participate in decisions. Relational continuity can influence how individual encounters are interpreted, especially when care extends across time.

Coordination introduces a pathway-level domain. Patients encounter not only clinicians but also transitions, referrals, records, scheduling systems, diagnostic sequences, and discontinuities between organizations. Consequently, an experience measure centered entirely on bedside or consultation behavior may perform well psychometrically while missing burdens generated elsewhere in the care pathway.

Organizational conditions constitute another level. Staffing patterns, access arrangements, appointment systems, physical environments, continuity structures, and coordination practices can shape what becomes possible within the clinical encounter. These conditions should not be psychologized as individual patient preferences when they represent characteristics of service organization.

Theoretical development must also accommodate patient knowledge and agency. The partnership-oriented literature challenges models in which experience is collected only after care as feedback to professionals. Patients may instead contribute experiential knowledge during decision-making, service redesign, and quality

improvement. The conceptual shift is from the patient solely as respondent toward the patient as interpreter and potential knowledge partner.

This does not imply that all patient reports represent objective evaluations of technical quality. Patient experience and technical quality intersect but remain distinct. Patients can reliably report whether communication occurred, whether they felt heard, whether transitions were confusing, or whether care was accessible, while being less able to assess some technical dimensions of diagnosis or treatment. A rigorous theory of patient experience must therefore specify which aspects are directly reportable, which are interpretive, and which require other forms of measurement.

Distinction from satisfaction and related constructs

The distinction between experience and satisfaction is particularly important because the terms remain intertwined in both historical and contemporary research. Satisfaction usually represents an evaluative judgment. It can depend on expectations, preferences, perceived outcomes, prior experiences, and the standard against which care is judged. Experience measures can instead ask whether particular events or processes occurred and how they were encountered.

Research on shared decision-making illustrates why this separation matters. In a large outpatient study, determinants of participation in shared decision-making and satisfaction with that participation did not behave identically, although trust was associated with both [16]. A patient can therefore report involvement as a process while evaluating that involvement differently. Treating

participation and satisfaction as interchangeable would erase this distinction.

Patient experience must also be separated from clinical outcomes. A prospective inpatient cohort found associations between selected experience factors and 30-day readmission, but the study did not establish patient experience as a direct causal mechanism and some anticipated associations were not significant [17]. Such evidence supports studying experience alongside outcomes while cautioning against substituting one for the other.

The same principle applies to quality, engagement, adherence, empowerment, trust, and person-centredness. These constructs may overlap with domains of patient experience, but each has its own theoretical content. A patient may trust a clinician but report poor organizational coordination; may be satisfied because expectations were low despite encountering avoidable service problems; may participate extensively in decisions but remain dissatisfied with the available options; or may report technically efficient digital access while experiencing weak relational connection.

For contemporary patient experience research, construct discrimination is therefore not a semantic exercise. It determines what can legitimately be inferred from a measure, which domains need separate assessment, and whether comparisons across populations, settings, technologies, and periods are meaningful. The next stage of the review turns from these conceptual distinctions to the measurement architectures used to operationalize them.

Measurement approaches

Patient experience is measured through several methodological families that differ in what they make visible. Structured PREMs permit standardized comparison across respondents and, when appropriately developed, can identify discrete domains of care. Their apparent precision, however, depends on whether the construct, recall period, response options, and target population correspond to the question being asked.

Recent intensive-care evidence illustrates the problem. A systematic review identified instruments labelled either as experience or satisfaction measures and found that measurement properties were incompletely evaluated across the available scales [18]. The distinction is consequential: an instrument may demonstrate internal consistency without establishing adequate content validity, responsiveness, cross-context interpretability, or conceptual separation from satisfaction.

Measurement should therefore be evaluated along at least three dimensions: construct fit, referring to whether the instrument actually represents the intended aspect of experience; measurement maturity, referring to the properties that have been tested; and context fit, referring to whether the instrument remains interpretable for the population, care setting, language, modality, and purpose in which it is applied.

The resulting measurement problem is summarized below. The table is intended to distinguish different kinds of evidential adequacy rather than rank instruments (**Table 3**).

Table 3. Construct-discrimination requirements across contemporary patient experience measurement approaches

Measurement case	Primary experiential information captured	Main strength	Principal ambiguity	Validation requirement	Appropriate interpretive use
Global service rating	Overall evaluation of a visit or service	Low respondent burden and straightforward benchmarking	May blend expectations, outcomes and satisfaction with specific care processes	Evidence that the global rating represents the intended evaluative construct	Broad service monitoring, not detailed causal diagnosis
Multidomain PREM	Reports across defined care-process or relational domains	Separates different aspects of experience	Domains may still reflect locally developed assumptions	Content validity, structural validity, reliability and contextual interpretability	Domain-specific quality assessment
Disease-specific PREM	Experience within a defined condition or pathway	Greater relevance to disease-specific needs	Reduced transferability outside the target pathway	Patient relevance plus external validation in intended populations	Condition-specific improvement and monitoring

Qualitative journey inquiry	Meaning, sequence, disruption, coordination and context	Reveals mechanisms and experiences not anticipated by fixed items	Does not estimate population frequency	Transparent sampling, analysis and contextual interpretation	Discovery, explanation and instrument development
Virtual-care PREM	Experience shaped by digital modality and remote interaction	Captures modality-specific domains	Technical usability may be confused with relational experience	Validation across technologies, populations and modes of care	Digital-care evaluation
Near-real-time feedback	Experience collected close to the care event	Reduces recall delay and can accelerate improvement cycles	Responsiveness of organizations may vary independently of measurement quality	Workflow feasibility, response validity and implementation evaluation	Local improvement and monitoring
Equity-oriented experience measure	Experience of responsiveness, discrimination, power or structural disadvantage	Makes otherwise omitted experience dimensions measurable	Group comparisons may be distorted by differential interpretation or participation	Accessibility, measurement equivalence and contextual validity	Equity-sensitive assessment and improvement

Note: The distinctions are proposed by this review as an interpretive measurement architecture. They do not constitute a ranking of methods.

Patient-reported experience measures

Recent PREM development increasingly incorporates patients earlier in instrument design. In inflammatory bowel disease, patient-led consensus and think-aloud methods were used to identify relevant experience content and test whether proposed items were understandable and meaningful [19]. Such approaches strengthen content validity by reducing the likelihood that professional assumptions determine the entire instrument.

Cancer-care PREM development has likewise combined patient-derived domains with formal psychometric testing. A multidomain cancer PREM underwent factor analysis and assessments of reliability and validity, illustrating the transition from qualitative domain identification toward structured measurement evaluation [20].

Audiology provides a particularly clear example of staged development. The My Hearing PREM was created specifically to capture experiences relevant to people receiving hearing-related care [21]. Subsequent refinement and validation then tested shortened forms using Rasch and conventional psychometric approaches [22]. The sequence demonstrates that instrument creation and instrument validation are separate evidential stages. Contemporary PREM research should consequently avoid binary descriptions of measures as simply “validated” or “not validated.” Content development, dimensional structure, internal consistency, test-retest performance, construct validity, measurement error, responsiveness, accessibility, and external transferability

are distinct questions. An instrument may be strong in one respect and uncertain in another.

Qualitative and mixed-method approaches

Qualitative methods remain essential because standardized questionnaires necessarily constrain what patients can report. Journey-oriented inquiry can identify how experiences develop through transitions between professionals and organizations rather than at one encounter.

A critical-incident study of people with cancer demonstrated this value by showing how patients could become de facto messengers between hospitals when information continuity failed [23]. A conventional encounter-level PREM might register dissatisfaction with communication without revealing the pathway mechanism producing it.

Qualitative evidence is especially useful for identifying unexpected domains, understanding why similar processes are interpreted differently, examining relational and organizational context, and generating content for future PREMs. Its limitation is different from that of standardized measurement: qualitative depth cannot legitimately be converted into prevalence estimates without appropriate quantitative evidence.

Mixed-method strategies can therefore be particularly productive when the methods are assigned complementary jobs rather than treated as interchangeable confirmation. Structured measures can estimate distributions of defined experiences, while

qualitative inquiry can examine meaning, mechanism, exceptions, and context.

Digital and real-time experience measurement

Digital care has created both new measurement opportunities and new construct problems. Contemporary virtual-care research indicates that traditional relational domains do not disappear when the encounter becomes digital. Listening, clear explanation, courtesy, and respect remain important components of reported virtual-care experience [24].

At the same time, digital encounters contain modality-specific features that conventional clinic PREMs may not adequately represent. A dedicated measure of video-care encounters was developed and validated within the US Veterans Affairs system, demonstrating that virtual experience can be operationalized directly rather than inferred from generic satisfaction measures [25].

Real-time and near-real-time feedback introduces another methodological shift. Instead of waiting for periodic survey cycles, experience data can be relayed rapidly to healthcare professionals or organizations. A systematic review found potential value in this approach but also substantial heterogeneity in implementation and effectiveness [26]. Faster measurement does not automatically produce more responsive organizations.

Digital patient-experience measurement therefore requires separation of at least three questions: whether the technology works, whether patients can access and use it, and whether the healthcare interaction delivered through it is experienced as responsive and relationally adequate. Collapsing those dimensions into one digital-

satisfaction score can conceal the mechanism that actually requires improvement.

Population and setting coverage

The meaning and measurement of patient experience change markedly across healthcare contexts. In rural South African referral hospitals, outpatient experience varied across service and environmental domains, with important deficits differing between institutions [27]. Such evidence cautions against assuming that priorities derived from highly resourced urban systems transfer unchanged to other organizational environments.

People experiencing homelessness demonstrate an even broader contextual challenge. A scoping review identified accessibility, timeliness, dignity, kindness, and person-centredness as recurring concerns while also showing limited use of standardized survey measures in this population [28]. A measurement system that depends on stable contact details, literacy, digital access, or conventional follow-up can systematically underrepresent precisely those patients whose care experiences may reveal serious accessibility failures.

Direct reporting by children and people with intellectual disability raises related issues. Adaptation of an inpatient PREM showed that patients who are frequently represented through proxy reports can, with appropriate design, contribute their own experience data [29]. Accessibility is therefore not merely an implementation consideration; it determines whose experience enters the evidence base.

These context-dependent states are organized below as implementation decisions rather than as a hierarchy of populations (**Table 4**).

Table 4. Context-sensitive decisions required when extending patient experience measurement across populations and settings

Patient or care context	Measurement vulnerability	Adaptation priority	Interpretation risk if adaptation is absent	Decision requirement
Resource-constrained or rural services	Standard benchmarks may ignore local access and infrastructure constraints	Preserve locally consequential service domains	Low scores may be attributed to individual providers when system constraints dominate	Interpret experience alongside organizational context
People experiencing homelessness	Conventional recruitment and follow-up may exclude unstable or marginalized participants	Flexible access, trust-building and low-burden participation	The most structurally excluded experiences may be missing from the dataset	Evaluate participation bias before generalizing

Children and young people	Adult wording and response formats may be inappropriate	Developmentally accessible language and response methods	Proxy report may replace the child's own perspective unnecessarily	Maximize direct reporting where feasible
People with intellectual disability	Cognitive and communication requirements may prevent participation	Co-designed accessible instruments and supported administration	Apparent absence of negative experience may reflect exclusion from measurement	Treat accessibility as part of validity
Culturally and linguistically diverse communities	Translation alone may not ensure conceptual equivalence	Community involvement, language adaptation and culturally appropriate recruitment	Cross-group differences may reflect measurement inequivalence	Test meaning and participation across groups
Digitally mediated care	Connectivity, device access and digital literacy influence who can participate	Multimodal measurement and modality-specific domains	Convenience for connected users may obscure exclusion of others	Separate digital access from experience of care

Note: The decision register is a synthesis proposed by this review and should be adapted to the specific healthcare system and population rather than applied as a universal checklist.

Geographic and equity representation

Equity increasingly appears not only as a topic within patient experience research but as a challenge to the measurement process itself. A rapid evidence synthesis examining ethnically diverse communities identified multiple strategies for improving patient-experience measurement, including language adaptation, culturally informed engagement, community support, and alternative recruitment approaches, while finding limited comparative evidence about which strategies work best [30].

A systematic review of diversity-sensitive care similarly showed that patients' evaluations of appropriate care involve communication, responsiveness, tailoring, and recognition of individual circumstances [31]. These dimensions cannot be reduced to ethnicity or demographic membership, because patients within the same nominal group may have different needs, preferences, language abilities, resources, and prior experiences.

Equity-oriented measurement has therefore begun to address structural and interpersonal conditions more directly. Brief patient-experience measures developed through a health-equity lens have attempted to capture experiences related to discrimination, power, and inequitable treatment rather than treating disadvantage only as a background variable [32].

Digital transformation makes these issues more complex. Qualitative research with South Asian patients in English primary care after COVID-19 described concerns

involving remote access, choice, and perceived quality or safety [33]. Digital availability may thus improve convenience for some patients while creating new barriers or reducing preferred modes of interaction for others.

An equity-sensitive patient-experience field must therefore examine both distribution of experience and distribution of measurement opportunity. The absence of reported inequity cannot be interpreted confidently when affected populations are less likely to receive, access, understand, trust, or complete the measurement instrument.

Emerging research directions

Several contemporary developments point toward a different future for patient experience research. First is movement from adapting instruments *for* underrepresented groups toward co-producing instruments *with* them. A PREM developed with people with intellectual disability illustrates this direction by embedding accessibility and lived experience within the development process rather than applying modifications only after a conventional instrument has been created [34].

Second is movement from asking only whether patients were satisfied toward asking what was consequential to them. A scoping review of "What matters to you?" approaches found applications in care planning, service design, and understanding patient priorities, although implementation varied across settings [35].

Third is the extension of patient experience into healthcare improvement itself. Qualitative work involving patient and family partners in improvement collaboratives indicates that meaningful participation requires deliberate structures for partnership rather than symbolic presence [36].

Taken together, these developments suggest that the next stage of patient-experience research may depend less on

collecting additional decontextualized ratings and more on connecting measurement validity, experiential relevance, accessibility, organizational responsiveness, and consequential patient partnership.

The relationships are represented in **Figure 1** as a proposed research architecture rather than an empirically validated causal model.

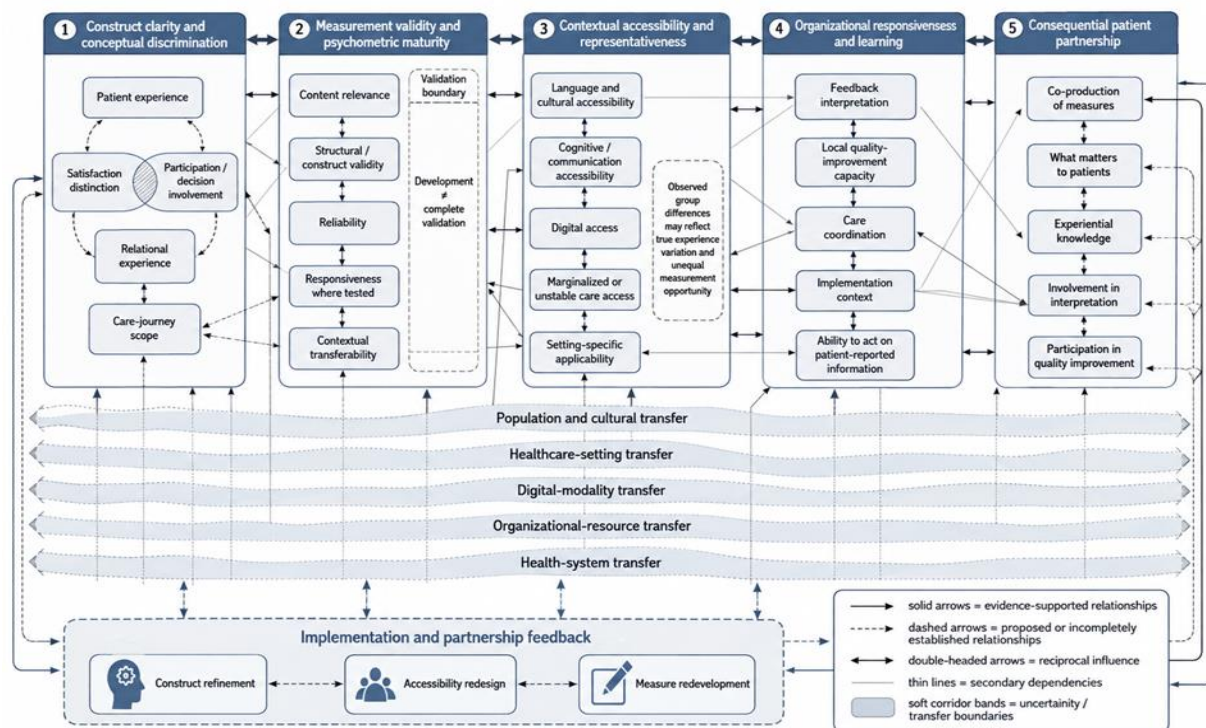


Figure 1. Conditions linking interpretable patient experience evidence to consequential healthcare learning

Evidence gaps

Several gaps recur across the mapped evidence. The first is incomplete psychometric characterization. Contemporary systematic reviews continue to identify instruments for which some properties have been evaluated while others, especially responsiveness, measurement error, cross-context transferability, or theoretical grounding, remain uncertain.

The second gap concerns conceptual specification. Studies may use patient experience, satisfaction, perceived quality, participation, trust, and person-centredness in partially overlapping ways. Without explicit construct definitions, apparently comparable measures can represent different phenomena.

Third, representation remains uneven. Populations requiring adapted communication, culturally responsive

engagement, alternative recruitment, or non-digital participation are at particular risk of exclusion. Geographic concentration in higher-resource systems also limits assumptions of international transferability.

Fourth, implementation evidence remains less mature than measurement development. The field increasingly demonstrates how to collect experience data, but evidence is less consistent about how organizations interpret, prioritize, and act on that information.

Finally, patient partnership frequently remains downstream of measurement. Stronger research should test whether involving patients in defining constructs, designing instruments, interpreting findings, and planning improvement produces more valid, equitable, or actionable experience evidence.

The contemporary patient-experience field is characterized by diversification rather than convergence around one dominant theory or measure. Research has expanded from global evaluations toward multidomain PREMs, journey-based qualitative inquiry, digital instruments, equity-oriented measurement, accessible co-production, and patient partnership.

This expansion has clarified an important distinction: patient experience is simultaneously something healthcare systems seek to understand and something measurement systems actively construct. The domains included in an instrument, the populations able to respond, the recall period, the healthcare level represented, and the interpretive framework all influence what becomes visible as “patient experience.”

Consequently, measurement quality cannot be judged only by statistical reliability. A highly reliable instrument may still omit important domains, exclude particular populations, or be applied outside the context in which its items carry the same meaning. Conversely, qualitative or co-produced approaches may provide substantial conceptual insight without supplying standardized comparisons.

The review also indicates that no single analytical level is sufficient. Encounter quality can be shaped by relational history; relational experience can be constrained by organizational systems; digital encounters can be influenced by technology and access; and observed inequities can arise through both healthcare interactions and measurement exclusion.

The proposed synthesis therefore treats contemporary patient experience research as a multilevel measurement-and-learning field. Its purpose is not simply to generate increasingly detailed ratings but to produce interpretable evidence about care that can be related, cautiously and transparently, to improvement.

Implications for conceptual development and measurement

Future studies should define the intended patient-experience construct before selecting an instrument. Researchers should specify the unit of experience—encounter, pathway, organization, modality, or longitudinal relationship—and distinguish reported processes from evaluative judgments and clinical outcomes.

Instrument development should treat patient involvement as part of content validity rather than only dissemination. Accessibility and cultural interpretability should likewise

be considered measurement properties rather than optional implementation modifications.

Comparisons across services or populations require evidence that the measure functions meaningfully in those contexts. When equivalence is uncertain, differences in scores should not automatically be interpreted as differences in underlying experience.

Finally, healthcare organizations should align measurement architecture with decision purpose. Benchmarking, local improvement, pathway redesign, equity surveillance, digital-service evaluation, and partnership development may require different combinations of structured PREMs, qualitative inquiry, rapid feedback, and co-produced interpretation.

Strengths and limitations

A principal strength of this review is its deliberate separation of concepts, measurement approaches, populations, settings, and interpretive boundaries. It also integrates psychometric, qualitative, organizational, digital, and equity-oriented evidence rather than treating PREMs as the complete patient-experience field.

The major limitation is methodological. Exact source-specific retrieval, deduplication, screening, exclusion, and final-inclusion counts were unavailable. A complete numerical PRISMA-ScR flow therefore cannot be reconstructed without fabrication. The review consequently avoids reporting unsupported review-selection or evidence-category counts.

The evidence base is also heterogeneous in design and context. Cross-sectional associations cannot establish causality; qualitative findings are context dependent; validation studies may not transfer beyond their original populations; and rapidly evolving digital-care models can change faster than instruments are validated.

Future work should therefore combine prospectively documented scoping-review searches with stronger cross-cultural measurement evaluation, longitudinal testing, comparative implementation research, accessibility analysis, and explicit assessment of whether patient-experience information changes organizational decisions or care processes.

Conclusion

Patient experience research has evolved from predominantly evaluative service measurement toward a broader field concerned with relational processes, care journeys, organizational context, digital interaction,

accessibility, equity, experiential knowledge, and patient partnership. This expansion has increased the relevance of patient experience while also exposing persistent conceptual and measurement ambiguity.

The most defensible direction is not the search for one universal patient-experience measure. Progress instead requires explicit construct definition, measurement matched to purpose and context, separation of experience from adjacent constructs, accessible and participatory development, and transparent recognition of uncertainty when evidence is transferred across populations or healthcare systems.

Patient experience becomes most useful when measurement does more than produce a score: it should make consequential aspects of care visible, preserve whose perspective is being represented, and generate evidence that healthcare organizations can interpret without claiming more than the data support.

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