The Role of Patient-Reported Experience and Outcome Measures in Kidney Health Equity-Oriented Quality Improvement

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Summary

Risk, prevalence, management, and outcomes in chronic kidney disease (CKD) are influenced by social and broader determinants of health. Consequently, there are wide-ranging kidney health inequities. As patients are key stakeholders, their perspectives on the care they receive and on health status are central in guiding health system improvement, particularly to reduce the impact of disadvantage. Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) are important self-report tools in quality improvement, acting to guide initatives aimed at enhancing access to timely and relevant support. However, the extent to which PREMs and PROMs address the reduction of kidney health inequities is unclear. The aim of this review is to summarize how PREMs and PROMs are designed and implemented, highlighting key dimensions that are integral to health equity-oriented quality improvement in kidney care. There are several problems yet to be overcome so that such tools do not unintentionally reproduce kidney health gaps. Inclusive generation of the scope of tools, transparent reporting on attributes of patients who engage, and embedding PREMs and PROMs within a framework of value-based quality improvement is fundamental to their impact as part of equitable health system transformation.

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INTRODUCTION

Chronic kidney disease (CKD) is a major public health challenge, with an estimated prevalence of 13.4% worldwide.[1] Evidence suggests that risk, occurrence, progression, access to kidney replacement therapy (KRT), and outcomes vary across people in society. This is true for both within- and between-country variations in CKD burden.[2] Differences in health risk, experience, and outcomes reflect forms of health inequities, a term used to indicate that disparity is unfair and reasonably avoidable.[3] The acronym PROGRESS-Plus was put forward by the Cochrane Equity Methods Group to delineate the range of social and wider determinants of health disadvantage including: place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education, social economic status, and social capital plus personal attributes associated with discrimination (e.g., disability), features of relationships (e.g., exclusion from school), and time-dependent relationships (e.g., respite care).[4] Dimensions of PROGRESS-Plus are consistently associated with exposure to health risks, and issues with access to health services and timely care.[5] This includes in the context of CKD.

EVIDENCE OF KIDNEY HEALTH INEQUITIES

There is stark evidence of inequities in burden of CKD. For example, data from the UK highlight the social gradient in CKD, with people living in deprivation more likely to be diagnosed, progress faster to kidney failure requiring KRT, and experiencing worse outcomes.[6] In low- and middle-income countries, poor access to diagnosis and KRT are leading factors in adverse outcomes, with greater burden of disease and mortality in the most economically disadvantaged.[7] Data from the United States further exemplify that CKD risk is higher among minority ethnic communities,[8] a pattern that is also observed in other multiethnic and multicultural settings.[9] Access to therapies for minoritized communities is unequal even in systems where health care is publicly funded or subsidized in other ways.[6,10,11] Adults and children from minority ethnic backgrounds wait longer for a kidney transplant despite this form of KRT offering better opportunity for life engagement. Where patients do receive intervention in the form of kidney transplantation, a recent review has shown that significant survival advantage is delayed in minority ethnic people compared with their White heritage counterparts.[12] Such

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differences are likely in part to reflect systemic racism, including biased systems of organ allocation.[13,14] Sex differences in vulnerability to CKD also persist whereby women are more likely to be diagnosed with CKD, but globally kidney failure and KRT are more common in men.[15] This finding has been attributed to a combination of physiological differences and structural issues in society.

MEASUREMENT OF PATIENT EXPERIENCE AND OUTCOMES MATTERS TO REDUCE DISADVANTAGE

Against a backdrop of social and wider determinants of health and their complex interplay, it is essential that mechanisms to assess health disadvantage are developed and used effectively to evaluate the impact of equity-oriented initiatives. Patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) have a role to play in both measuring and evaluating kidney health and well-being. PREMs and PROMs provide a window into patient experience and outcomes (in terms of how patients feel and function), offering a fuller picture of health status, functional capacity, quality of life, and health care priorities. They go beyond what can be gleaned from clinical indicators alone.[16] As patients are key stakeholders in health, their experience, needs, preferences, and priorities should be central to health improvement. Many countries use PREMs and PROMs to inform improvement in health service design and delivery.[17-19] This is to align provision of care with how patients experience their health. For such efforts to have equitable benefit, it is important that their scope is relevant and that take-up is prioritized across diverse patient communities. The extent to which PREMs and PROMs are effective in reducing health inequities is, however, unclear. The aim of this review is to summarize PREM and PROM design and implementation factors, highlighting opportunities for their use to reduce kidney health inequities.

EMBEDDING KIDNEY HEALTH EQUITY IN THE DEVELOPMENT AND IMPLEMENTATION OF PREMS AND PROMS

PREMs and PROMs are increasingly used as part of everyday practice to assess patient perceptions while receiving care and their experience of health status.[16] To maximize their benefit for CKD patient communities, it is important that PREM and PROM development is inclusive. The scale development process consists of three main phases: item development, scale development, and scale evaluation.[20] To form a comprehensive understanding of the dimensions of experience and health that matter to patients, representation of the diversity of people affected by CKD is important at each of these junctures.

Inclusive Scale Development

Best practice guidelines for scale development suggest that both deductive and inductive methods should be used to generate scale items.[20] This means that the development of PREMs and PROMs should be informed by available evidence (deductive) as well as exploration of qualitative information such as opinions and experiences of those impacted (inductive). A systematic review of current practices revealed that over one-third of studies exclusively use deductive methods in scale development.[21] This is problematic for two reasons. It is well recognized that clinical research has systemically underrepresented people in society, especially with regard to exclusion based on ethnicity, disability, sex, and capacity to consent.[22-24] Related to this, evidence suggests that patient experiences of kidney care differ according to demographic factors such as age, sex, ethnicity, and deprivation.[6] Failure to adequately represent people with different life experiences and identities within the scale development process therefore compromises inclusivity and introduces bias in relevance.

A systematic review of PREMs/PROMs identified three PREMs specific to the dialysis population[25]: the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS),[26] the Consumer Quality Index for In-Center Hemodialysis,[27] and the Consumer Quality Index for Peritoneal Dialysis and Home Hemodialysis.[27] Since the publication of this review, the Kidney PREM (commissioned by the UK Kidney Association and Kidney Care UK) has also been validated for use within the broader CKD patient population.[28]

The Kidney PREM used deductive methods with input from a multidisciplinary expert group to generate scale items. The other three PREMs used focus groups in combination with deductive methods to generate items. Although it is reassuring that patient perspectives were incorporated within the latter measures, the extent to which the scale items capture diversity of experience is difficult to establish. For example, reporting of attributes aligned with PROGRESS-Plus dimensions such as education, deprivation, and ethnic identity for patients contributing to item generation was poor. Only the ICH CAHPS detailed patient sex. This is a significant limitation of the tools and demonstrates the need for more transparency in patient characteristics to ensure that inclusivity and relevance can be considered. Assessment of patient experience and health system performance should be informed by the priorities of intended beneficiaries of change. There are opportunities, therefore, as the field of PREM and PROM design expands to further embed health equity at the vital stage of exploring what matters and for whom.

Implementation of Tools to Reduce Disparities

The Kidney PREM and ICH CAHPS are national-level surveys that are used to assess patient experience of kidney care across the UK and United States, respectively. The ICH CAHPS is administered biannually to patients receiving in-center hemodialysis at Medicare dialysis facilities.[26] Although patient survey ratings for each dialysis facility are readily reported on the Medicare website (www.medicare.gov/care-compare/), information on who completes this measure is not publicly available. Nevertheless, nonresponse data from the 2012 ICH CAHPS indicate that some patient groups may be underrepresented in the survey findings.[29] For example, nonresponders were more likely to be male, of non-White heritage, and younger with lower levels of educational attainment. Data from the 2009-2010 Medicare Consumer Assessment of Healthcare Providers and Systems (used prior to the development of a hemodialysis-specific measure) revealed that patients with end-stage kidney failure who identified with Black heritage backgrounds or who had lower levels of education were more likely to report poor experiences of care.[30] Given that there are differences in patient experience and outcomes related to social determinants of health, representation in PREM and PROM completion is important for equitable quality improvement.

The Kidney PREM is administered annually across the UK. Completed by over 12,000 patients with CKD, data are used to help kidney care teams understand how patients feel about their care at a local level, highlighting what is going well and areas for improvement. The Kidney PREM also offers an opportunity for national monitoring of the impact of system-level changes aimed at patient care enhancement.[31] The Kidney PREM is led by Kidney Care UK and the UK Kidney Association, and information on the results at a national and site level is available from the UK Kidney Association website and the annual reports. There is evidence of overrepresentation among those who engage, with patients aged 75 and older contributing 25% of responses while making up 15% of the patient population, with fewer younger (<55) patients completing.[32] In addition, patients from White heritage backgrounds are overrepresented. For example, those of Asian ethnicity comprise 14.1% of CKD patients, but only 9.3% of respondents to the Kidney PREM are Asian despite the tool being available in relevant languages, such as Urdu and Gujarati. This may signal something about applicability, implementation methodology, or both. Proportions of gender representation are broadly similar to national trends. Importantly, the 2022 Kidney PREM introduced “nonbinary” and “other” for inclusive gender self-identification. This reduced the number of participants selecting “prefer not to say,” again indicating that inclusive data collection is important to quality improvement to understand differentials based on social and wider health determinants. As with the ICH CAHPS, the underrepresentation of minority ethnic and younger patients means that issues specific to these patient groups are likely to be overlooked.

Research therefore suggests that the way in which kidney PREMs and PROMs are developed and implemented does not fully account for the complexity of factors that influence patient experience of the care they receive and the way in which health is experienced. This questions the extent to which such tools can support equity-oriented quality improvement, acting to reduce the systemic disadvantage that is a reality for many CKD patients in settings where PREM and PROM use is commonplace. Exclusion from PREMs and PROMs is not unique to the context of CKD. For example, research has previously identified that routinely collected PROMs in other patient groups, such as cardiac patients, are biased toward younger age and healthier patients,[33] with lower completion rates also shown in women.[34] Rolnitsky et al[35] undertook a systematic review of quality improvement studies, identifying that although a third of studies focused on quality improvement in vulnerable communities, relatively few targeted improvements in care for women, minority ethnic people, and rural residents. Specific patient groups remain disadvantaged in care improvement endeavors, resulting in skepticism about the use of experience and outcome measures to reduce rather than unintentionally widen health gaps.

OPPORTUNITIES FOR PREMS AND PROMS IN STRENGTHENING HEALTH SYSTEMS

When designed and implemented inclusively, PREMs and PROMs offer opportunities to support equity in health system improvement. This is because they are underpinned by commitment to patient-centered care in which individual or aggregate data can help understand disparities and shape a partnership approach to mitigating disadvantage;[36] for example, by acting as a lever to talk about issues that might be difficult to approach for cultural, gendered, or other social reasons or by highlighting place-based disparity to advocate for health investment. Health systems around the world are operating in increasingly resource-pressured environments, where policymakers, commissioners, and health leaders strive to improve efficiency and reduce costs while improving value in care provision.[37] Achieving this without compromising access, quality, equity, and safety is a challenge. For quality improvement to be informed by patient voice, addressing systemic exclusion of underrepresented groups in both the development and implementation of experience and outcome tools is important.

For scale development, established frameworks for cross-cultural or indigenous co-creation offer methodologists guiding principles to promote relevance and meaning,[38,39] where broad principles can be adapted for wider inclusion aims. A recent study on the development of PREMs and PROMs for indigenous communities highlighted the importance of 13 key "protocols" that should inform the process.[39] This emphasized the importance of dynamics such as ensuring that lived experience is embedded in research planning from end to end to "do with" rather than "do to"; building open, transparent, reciprocal, and trust-based relationships with members of the community intended to benefit from the tool; using engagement, consultation, and co-creation to support relevance, appropriateness, validity, and reliability of scale content and design; embedding storytelling as an approach to sharing knowledge; ensuring that implementation is sensitive and responsive to the needs, preferences, and ways of connecting that are meaningful considering cultural or wider inclusion factors; and agreeing to accountability for the analysis, communication, and quality improvement actions that arise from PREM and PROM collection. This recognizes that systemic injustices and exclusion may reduce confidence in the collection and meaningful use of patient-level data. Similarly, the principles of good practice for the translation and cross-cultural adaptation process for PROMs focus on two overarching aspects of adapting scales for use specifically in cross-cultural settings, emphasizing aspects of preparation and adaptation that advance cultural meaning and relevance.[40] Such approaches can helpfully guide inclusive efforts to ensure that kidney PREMs and PROMs are informed by what matters to a broader range of patient communities—importantly, often those known to experience greater burden of inequity across the care continuum.[41]

In England, a study on inclusive patient-reported experience of depression among ethnically diverse dialysis patients ensured that patients informed priority setting, scale adaptation, and methods of implementation.[42] The study included multiple modes of PREM implementation, such as self-completion, in a language of origin or aided through community connectors to build trust in how the data would be used and why the data were important along with offering a mechanism of support for those who would not be able to self-complete (e.g., because of literacy or other disadvantage). This research evidenced that engagement with PREMs and PROMs can be advanced by applying an inclusive lens from end to end. The approach described has recently been emphasized in a rapid evidence synthesis of PREM collection in ethnically diverse populations, highlighting that informing patients about PREMs, creating relevant and accessible instruments, and offering a meaningful mechanism to engage are essential strategies for inclusion.[38] Understanding patient experience and outcome differentials is of course an essential step in narrowing disadvantage. Although the frameworks and approaches to inclusion described mainly address dimensions of cultural relevance and inclusion, the underpinning principles of building trust and using co-creation as an anchor to inclusion are transferable to address a broader range of disadvantage (e.g., disability inclusion).

However, evidence is lacking on the extent to which PREMs and PROMs in general would support quality improvement even if their collection were to be inclusive.[43] This is arguably because they would benefit from operating within a wider philosophy of quality improvement. Taking inspiration from other sectors, health services have looked to achieve efficiency and patient experience and outcome objectives by adopting philosophies such as "Lean health care," within which PREMs and PROMs are integral to mapping the patient journey and assessing the impact of changes in care delivery.[44,45] Lean techniques, as an illustrative example, have their origins in the manufacturing industry but, when applied to health care, strive to improve service quality and experience for patients. Lean is best described as a philosophy of continuous improvement that follows a universal set of principles designed to identify and make value flow at every step of the patient journey.[44] Table 1 sets out the key assumptions of Lean in relation to health care.

Application of the principles of such philosophies has been evidenced to improve patient experience, satisfaction, and outcomes across a range of health settings[45,46] from reducing waiting times for care and time between tests and results being available to increasing take-up and experience of KRT (e.g., peritoneal dialysis). These are all points in the care continuum in which experience and outcomes may vary because of the social determinants of health. Embedding quality improvement in an overarching framework therefore structures thinking and interventions from the agents of change in a way that is experience, value, and equity-centric.[44] PREMs and PROMs become tools for understanding and measuring improvement in a more meaningful whole systems improvement approach.

Table 1. Assumptions of Using Lean in Health Systems: An Underpinning Philosophy to Patient Experience, Quality, and Outcome Improvement*

Lean in Health Systems
Defining value and waste from the perspective of the patient
Creating value by either reducing non-value adding activities or increasing value adding activities at no extra cost
Appreciating there is defined and measurable benefits to the organisation
Freeing up resources that can help to continue to improve processes
Understanding the 'heart' of Lean is the concept of customer or patient value
Ensuring the main focus remains on quality and safety rather than on cost

*Adapted from Radnor and Osborne.[44]

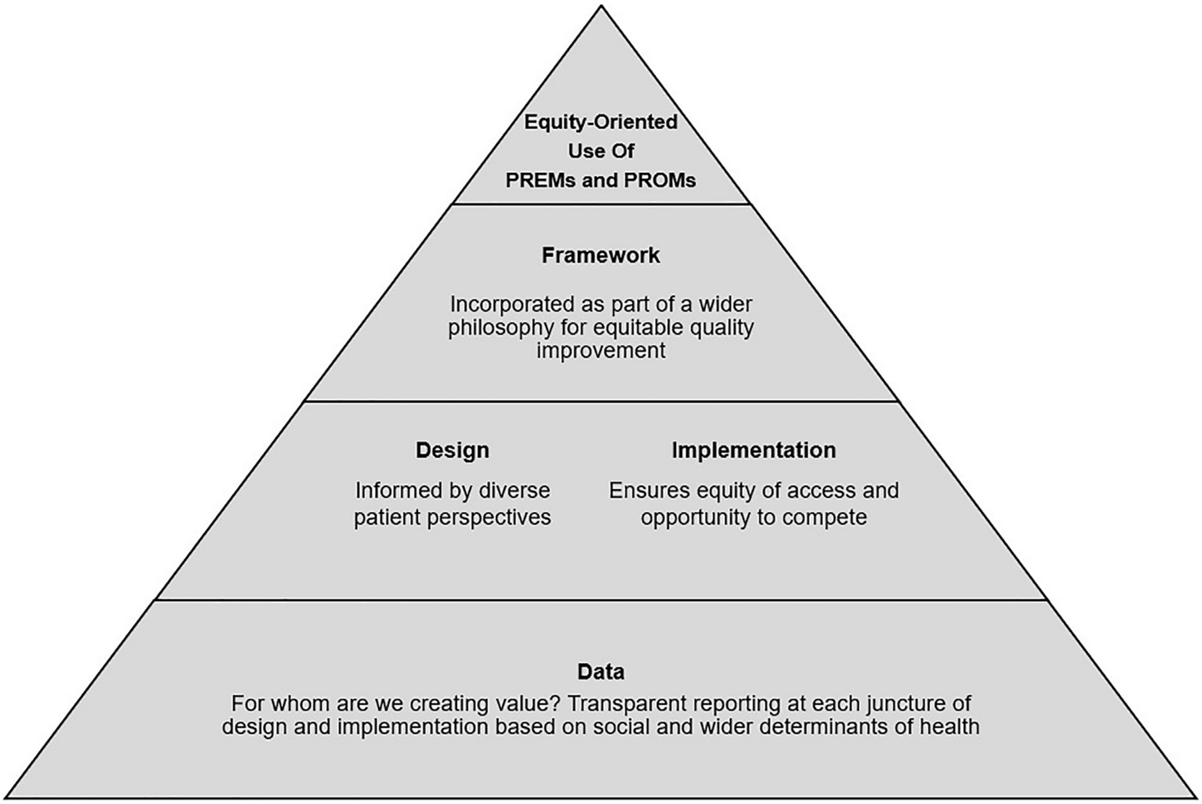

Figure 1. Dimensions of health equity-oriented design and implementation of PREMs and PROMs. Abbreviations: PREMs, patient-reported experience measures; PROMs, patient-reported outcome measures.

A focus on designing and implementing PREMs and PROMs in an inclusive, representative manner with quality improvement itself being grounded in an underpinning philosophy therefore offers the opportunity to advance the most benefit to patients. This avoids the collection of such measures having limited impact. PREMs and PROMs are tools through which to visualize each stage of the patient journey. This helps identify junctures at which experience is suboptimal and necessitates change. Such value-based health care, where patient-centeredness is at the core, can only be realized through inclusive cultures that promote equitable design and engagement with quality improvement. Figure 1 summarizes these key dimensions.

CONCLUSIONS

CKD is not experienced in the same way across or within communities around the world. The burden at each stage of the care continuum, from prevention to management and outcomes, is unequal because of the social and wider determinants of health. PREMs and PROMs can play an important role in reducing disadvantage, but evidence is limited on the extent to which these tools are developed and implemented in inclusive ways. All patients have the right to access and contribute to PREMs and PROMs. Historical exclusion in their development and implementation in kidney care should be addressed, ensuring better reporting of equity-oriented data. The utilization of underpinning frameworks that guide inclusive PREM and PROM creation, implementation, and resulting improvement endeavors may help avoid perpetuating kidney health disadvantage. There are opportunities to transform the use of such tools as part of a coordinated approach to make their use work to narrow kidney health gaps.

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