

Patient-reported Experience Measures to Evaluate and Improve the Quality of Care in Nephrology.

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Abstract:

Patient experience is considered a pillar of high-quality care, integral to patient-centred care, but despite significant policy focus on patient reported experience measures (PREMs) little is published regarding their development, use or impact in clinical practice.

In nephrology, PREMs are increasingly used in research to capture and quantify patients' perceptions of their experiences with healthcare services. It has been shown that negative patient experience impacts patients' physical and psychological health, and a small but significant proportion of patients across a selection of settings report their experiences of healthcare as poor or suboptimal. Evidence of whether PREMs improve quality of care or support person-centred care in the clinical setting remains largely theoretical.

Extensive effort has been invested to develop various PREMs for kidney services. Whilst little evidence linking PREM collection to meaningful change in delivery of care currently exists, work is underway. Early indications are that with the right facilitators, implementing PREMs into routine practice can help providers recognise where change is needed and galvanise transformation. The journey towards understanding the connection between PREM data and modifiable provider characteristics to target and enable change has started, but further evidence is needed.

This article outlines the history of PREMs in nephrology and details their current use alongside implementation challenges. The use and benefits of PREMs are discussed before considering the evidence base for their impact in renal healthcare. Possible next steps for PREMs are suggested and best practices highlighted.

Keywords

1. Patient reported experience measures (PREMs)
2. Patient reported outcomes (PROs)

3. Quality Improvement

4. Patient-centred care

Abbreviations

AHPEQS	Australian Hospital Patient Experience Question Set
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CPES	Cancer Patient Experience Survey
CQC	Care Quality Commission
HRQL	Health Related Quality of Life
ICH-CAHPS	In-centre haemodialysis CAHPS
KQIP	Kidney Quality Improvement Partnership
NHS	National Health Service
NPREM	Needling PREM
PROMs	Patient Reported Outcome Measures
PREMs	Patient Reported Experience Measures
PROs	Patient-Reported Outcomes
QI	Quality Improvement
TP-CKD	Transforming Participation in Chronic Kidney Disease

Introduction

Patient Reported Outcomes (PROs) are widely used in healthcare to support quality improvement initiatives. Patient Reported Experience Measures (PREMs), a type of PRO, are specific tools used to collate patients' experiences of the healthcare they receive¹, enabling the evaluation of the quality of services from the patient's perspective. Alongside patient safety and clinical effectiveness, patient experience is viewed as one of the three pillars of high-quality care^{2,3}, an integral part of patient-centred care⁴. In contrast to Patient Reported Outcome Measures (PROMs), PREMs are considered a more holistic measure of the patient's experience of care and service delivery^{5,6}.

There is evidence that patient experience varies between healthcare types and whilst a large proportion of patients report good experiences, a small but significant proportion report their experiences to be poor or suboptimal⁷. Approximately 5% of adult inpatients in the UK rated their experience of care as 0, 1 or 2 (out of 10) in 2022 (with 0 being a very poor experience) and, within the GP setting, the proportion reporting a poor overall experience has more than doubled since 2018, perhaps due in part to service delivery changes introduced since the COVID-19 pandemic. It has been shown that negative patient experience has an impact on patients' physical and psychological health, with potential to affect their clinical outcomes⁸. Monitoring changes in experience ratings can indicate newly arising issues, with the potential to facilitate system or service delivery changes.

PREMs cover multiple domains of care, often including accessibility, quality of communication between healthcare providers, shared decision making, continuity of care and patient safety among other things⁹. A study across 41 countries¹⁰ found that the domains most important to patients were prompt attention, dignity and communication, though it is important that each condition- or treatment-specific PREM is coproduced with patients and healthcare professionals to ensure that the relevant domains of care are included.

PREMs are separate from measures such as process indicators, cost measures, clinical outcomes or clinician reported outcome measures¹¹. The purpose of PREMs is ultimately to help create more person-focussed healthcare systems (care that aligns with patient preferences, values and priorities) rather than the preferences of the care “system” or individual clinicians. Wider use across the NHS in England (UK) “wherever practical” was prioritised in the government’s white paper and subsequent NICE guidelines^{12,13}. These measures are increasingly influential from a policy perspective reflecting a pivotal shift towards value-based healthcare.

Whereas PROMs are largely subject to extensive validation as outcome measures, surveys presented as PREMs are often more akin to audit tools, assessing patients’ perceptions of service delivery against some predefined standards¹⁴. Such PREMs, sometimes self-defining as surveys, lack evaluation of an underlying unitary measurement construct but do serve the purpose of evaluating service against a standard that may map onto recognisable indicators, although that relationship is often not explained or reported.

The Patient Experience Improvement Framework¹⁵ linked patient experience with Care Quality Commission (CQC) ratings. The CQC are the independent regulator of health and adult social care in England (UK) and their use of linked data supports trusts in achieving ‘good’ ratings. This framework references a scan of the evidence around patient experience conducted by the Health Foundation (2013)¹⁶, in which various methods to assess experience, including PREMs, were reviewed to support NHS trusts in the UK when collecting this information. A similar initiative has been undertaken in the USA, with an emphasis on care delivery evaluated and rewarded by good patient experience (Consumer Assessment of Healthcare Providers and Systems, CAHPS, of which more below)¹⁷. The authors understand that several other countries have supported similar programmes, but these programmes remain unreported to a wider audience. The measures, as indicators of quality, expose organisations to external scrutiny and limiting publication of the data protects organisations from criticism beyond the local and policy context. Other countries (Spain, New Zealand, Australia) have

requested information about the use of the Kidney PREM in the UK, with several translations underway at the time of writing¹⁸.

Patient experience measures are viewed as important not least because they give gravitas to the patient voice. Herein lies the gap between recognition of the importance of the patient voice but failure to use this voice in co-production and meaningful patient engagement in service development. Often PREMs and audits are driven by clinical imperative and clinical outcomes, whilst patients' interests often have a different focus. The potential benefit of PREMs is not in the collection of the data itself but any subsequent impact on improving outcomes for patients¹⁹.

This paper will focus on the development and use of PREMs, specifically on their use in evaluating and improving the quality of care for patients with chronic kidney disease.

History of development of PREMs

Good patient experience and involvement is thought to result in better clinical outcomes across healthcare populations^{20,21}, though the evidence base is lacking.

For 20 years or more, healthcare services have been collecting patient experience data, with some national surveys in England being regularly administered as far back as the late 1990's. Patient-centred care underpinned early PREM development led by the Picker Institute²². Respect, dignity, information sharing, joint decision making and collaborative working between healthcare teams, families and patients formed the basis of surveys developed specifically for use in in-patient surveys and tested across five geographies: United Kingdom, Germany, Sweden, Switzerland and the USA²³. Both face and content validity were found to be high (ibid).

The USA was an early adopter of national patient experience data collection, with the development of the range of Consumer Assessment of Healthcare Providers and Systems (CAHPS)²⁴ surveys in 1995.

The first survey collected information on participants' experiences of health plans (1997), with the CAHPS hospital survey (HCAHPS) following in 2002. Subsequent CAHPS surveys²⁵ have been developed, covering specific types of providers (e.g., hospices, surgical care), conditions (e.g., cancer, mental health), programs (e.g., dental plans) and facilities (e.g., emergency department, in-centre haemodialysis), with survey scores often used to determine incentive payments to centres. CAHPS reports are intended to be used to facilitate patient choice around accessing healthcare, though they have been characterised as creating top-down pressure to improve quality of care²⁶. The CAHPS programme represents one of very few cases where patient experience measures are used beyond research.

In the UK, progress was first made within the field of oncology with the Cancer Patient Experience Survey (CPES)¹⁴ in England. The CPES was introduced in 2011 by the Department of Health²⁷ and has been used to look at inequalities, and more broadly to explore how providers can improve the experience of patients at a national, regional and local level²⁸. It has since been expanded by introducing similar surveys in Wales²⁹, Scotland³⁰ and Northern Ireland³¹.

Although shown to cover five sub-constructs of cancer care³² (shared decisions, care coordination, diagnostic care, timely tests, aftercare), the CPES reports question-level results by tumour site or treatment location rather than an overall measure of patient experience. In contrast, CAHPS measures were developed using a formal validation process, repeated for each subsequent survey which, following analysis, results in a composite score³³.

It is commonly reported that PREMs are widely used in the United States, but peer reviewed published reports are less common. The ICH-CAHPS (in-centre haemodialysis CAHPS) has been widely used in the United States³⁴, developed as part of a quality incentive programme to underpin value-based payments and help haemodialysis patients make better choice around healthcare providers^{34,35,36}. It

was implemented to integrate patient experience into providers' compensation calculations for quality of care³⁷.

Collecting patient experience information traditionally focussed on using the data to guide quality improvement within services. This premise was underlined in the Darzi report³⁸ which linked the use of patient experience (and satisfaction) data, safety, and clinical measures with quality. PREMs are distinct from satisfaction surveys although the two are often conflated. Rather than seek an opinion about their experience, PREM surveys will "seek to record what occurred to a patient, from their perspective, rather than their overall evaluation"^{4,39}. Larson et al⁴⁰ consider that "patient satisfaction is an outcome measure of a patient's experiences of care, along with health outcomes and confidence in the health system, reflecting whether or not the care provided has met the patient's needs and expectations". Satisfaction surveys are neither sensitive or useful in terms of quality improvement⁴¹ and the patient expectation around quality of care, and thus the discrepancy between this and reality cannot be accounted for⁴². Although satisfaction surveys often capture the global impression of a service, experience measures are focussed more on specific aspects of the care delivered, and so provide a more informed and nuanced assessment of the care received from the patient's perspective.

Current use of PREMs

The development and use of patient experience measures has changed in the past decade growing in scale and scope, though this is not always well documented in academic literature⁴. Others have highlighted that the experience of the patient is now globally recognised as an independent dimension of health-care quality⁴³, but research has established that collection of data is not always followed by meaningful use and there is less evidence of any direct use beyond quality improvement.

The CAHPS surveys are an example of a national (USA) based initiative to collect patient reported experience data. Similar programmes in the UK include the PROMs, PREMs and Effectiveness

programme⁴⁴, and the GP Patient Survey⁴⁵. Further afield, the Australian Hospital Patient Experience Question Set (AHPEQS)⁴⁶, as well as other digital based initiatives such as those used in Italy⁴⁷.

In kidney care, PREMs are increasingly used in research to quantify how patients “feel and function” and their experiences of care⁴⁸ with a variety of tools in use across nephrology settings (Table 1). Although the CAHPS surveys include an experience of care measure for end stage kidney disease patients, this is limited to those receiving haemodialysis in centre, excluding those receiving alternative kidney replacement therapies or attending clinic for disease monitoring.

Table 1: A list of PREMS focusing on commonly available Kidney specific PREMs.

Kidney Specific PREMs	Description	Domains of experience included
Kidney PREM ⁴⁹	Kidney PREM developed in the UK to support a national Quality Improvement programme. 39-item validated measure.	Access, Support, Communication, Patient Information, Fluid Intake/Diet, Medication, Needling, Tests, Sharing Decisions, Privacy & Dignity, Scheduling & Planning, How Team Treats You, Transport, Environment, Overall Experience
Short form Kidney PREM ⁵⁰	Adapted from the Kidney PREM. Study underway to gather further data for validation (mid 2024, UK). 15-item measure.	Same as Kidney PREM
Paediatric Kidney PREM (PPREM) ⁴⁹	Pilot version developed from the Kidney PREM. Current study (2024 to 2025) to validate the measure in the UK funded by the NIHR (NIHR206218). 41-item measure.	Access, Support, Communication, Patient Information, Fluid Intake/Diet, Medication, Medication, Tests, Sharing Decisions, Privacy & Dignity, Scheduling & Planning, How Team Treats You, Transport, Environment, Overall Experience
Needling PREM (NPREM) ⁵¹	Development and validation of a Needling PREM (UK). Paper submitted. Study funded by the NIHR (PB-PG_0418-20047). 21-item measure.	Communicating with Team, My Fistula/Graft and Needling, Steps in Needling, Working Together, My Personal Experience, Overall Needling Experience
Kidney PREM Spanish and Catalan translation ¹⁸	Adapted from the Kidney PREM. Study completed early 2024, peer reviewed paper submitted April 2024. Validation underway (Spain). 39-item measure.	Same as Kidney PREM
In-Center Hemodialysis CAHPS (ICH CAHPS) ⁵²	Validated survey used widely in the USA supporting consumer assessment of	Communication/Caring (doctors), Quality of dialysis centre, Patient Information, Global Ratings

	providers of in centre haemodialysis. 58 core items plus 20 supplemental.	
Home haemodialysis PREM ⁵³	Validated survey focused on delivery of dialysis at home (USA). 26-item measure.	Communication/Education, Concern/helpfulness of team, proficiency of team, patient-centred care, care coordination, amenities/environment.
Consumer Quality Index for in-centre haemodialysis (HD) and peritoneal dialysis (PD) ⁵⁴	Two older, validated scales (UK), 42 items (centre HD) and 31 items (PD). Developed in 2012, superseded by the Kidney PREM.	Care/Communication, cooperation, organisation, tests, information, environment.
The ESUR-HD scale The Scale for Evaluation of Haemodialysis in Patient's with Service provided at a Chronic Kidney Disease Unit. ⁵⁵	Validated 44-item survey developed in Spain.	Facilities/organisation, Care from nurses/nursing assistants, Attention to psychological/administrative issues, Contact/social work personnel, Medical attention/care, Nutritional attention/care, Medications, admission process, Care from head nurses
Experience of patients on peritoneal dialysis during the COVID-19 Pandemic - unvalidated survey ⁵⁶	Unvalidated COVID-19-specific survey, developed in the UK, 16 items.	Shielding, accessing dialysis/general medical care, thoughts about the pandemic/the future
Patients' assessment of satisfaction with haemodialysis/peritoneal dialysis and the impact of the therapy on their lives ⁵⁷	Unvalidated survey developed in the USA. 17 items.	Overall health, stress level, family life, social life, independence, finances, mood, religion/spirituality, sex life, energy level, recreation/hobbies, exercise ability, living arrangements, appetite, body image.

Examples of other PREMS

Consumer Assessment of Healthcare Providers and Systems (CAHPS) ⁵⁸	Nationally available surveys to support consumer evaluation of health care providers in the USA. Various surveys available.	N/A
The Health Foundation ¹⁶	A general list of PREMS (p23)	N/A
Cancer Patient Experience Survey (CPES) ⁵⁹	Cancer survey developed by Picker on behalf of the NHS	Overall experience Support from your GP practice, Diagnostic tests, Finding out that you had cancer, Support from a main contact person, Deciding on the best treatment, Care planning, Support from hospital staff, Hospital care, Your treatment, Immediate and long-term side effects, Support while at home Care from your GP practice, Living with and beyond cancer
Cancer PREM-item bank ⁶⁰	New development (2024) to provide a dynamic system to support evaluation in cancer services in the Netherlands	Organization of healthcare, Competence of healthcare professionals, Communication, Information & services, Patient empowerment, Continuity & informal care, Environment and Technology.

Kidney centres in the UK use the Kidney PREM to capture patient experience on an annual basis. This cyclical data collection lends itself to giving staff time to consider and act on findings, whilst providing a powerful and longitudinal dataset in the longer term. Launched in 2016, the Kidney PREM was validated in 2018⁵⁰ and is facilitated by Kidney Care UK and the UK Kidney Association. The measure was co-produced by a group of patients, clinicians and academics as part of the Transforming Participation in Chronic Kidney Disease (TP-CKD) programme⁶¹, following feedback from individuals with kidney disease that measuring patient experience should be a priority.

Kidney PREM aims to put the patient voice at the heart of understanding the experience of the care they receive. Routine data collection enables variation in experience to be identified, which has the potential to enable change and improvement beyond just understanding how patients feel about their experience of care. The data are made available to all UK kidney centres and patients via the Kidney PREM portal hosted by the UK Renal Registry and annual reports are publicly available⁴⁹. This method of dissemination, and record of consistently high completion rates (generally >10,000 per year), means there is an opportunity to use the data to make changes at a local level to subsequently improve quality of care, whilst also using the data to make comparisons with a high level of precision. Alongside this is the opportunity to tailor healthcare and improve outcomes for patients, moving further towards delivering person-centred care, whilst also making staff aware where things are being done well, not just highlighting areas requiring improvement. Celebrating things being done well is sometimes perceived by staff as less valued than highlighting where there is room for improvement⁶².

Ongoing work by UK kidney charities such as the UK Kidney Association and Kidney Care UK, supported by the Kidney Quality Improvement Partnership (KQIP⁶³) has continued to underline the importance and need to prioritise patient experience as part of good care. However, outside of the specific examples that are identified, the published peer reviewed literature indicates that progress has been slow in implementing such measures. Some argue that healthcare staff remain less familiar with PREM instruments⁴², although the yearly UK Kidney PREM survey has changed that perception. However, the

emphasis remains on the developments of PROMs more generally, and even where these have been evaluated for use in the kidney disease population⁶⁴ (such as the Beck Depression Inventory II (BDI-II) for depression screening)⁶⁴, there have been few in-roads into widespread clinical use. For example, the challenges presented by routinely screening for depression in primary care during the early 2010s in the UK, resulted in the guidance being dropped⁶⁵. Similarly, and in relation to PREMs, is the problem of identifying need where insufficient service provision exists.

Challenges when implementing PREMs

Successful implementation of PREMs in clinical practice requires an understanding of the patient population, the purpose of collecting the data and a mechanism for some form of action or change in the clinical process. Barriers to their use, aside from time and resource, include a lack of infrastructure to support routine collection and analysis, poor understanding around the value of PREMs (establishing the need), perceived lack of relevance to clinical staff, and no definitive action in response to data collection from the perspective of the patient⁴². Patients have expressed concern about not knowing how or if their data are being used. In qualitative work conducted by Anderson¹⁹ a patient commented that 'If they haven't got a point for collecting them that isn't going to be actioned or put into a specific piece of research, then they shouldn't be there'. The same research group also flag the lack of integration of PREMs into existing digital systems, an issue not helped by the complexity and diversity in the many digital systems holding patient information across the NHS. In the main, clinical staff often have little training in use of PREMs and may not have collected this data as part of routine care¹⁹. Staff are also subject to uncertainty about how to respond to identified need, lack of relevant referral pathways, and perhaps a need for communication skills training⁶².

Response bias continues to be a challenge in the use of PREMs, leading to significant ceiling effects. Treatment for patients with end stage kidney disease is an existential issue, and providing negative feedback to the people who provide access to that care brings with it a range of social issues that are

challenging to address⁶⁶. Much of the design of the Kidney PREM in the UK has been premised on enabling patients to remain anonymous, giving people permission to say how they feel without fear of impact on their care. This also makes completion of these types of survey at the point of care (for example while on dialysis) much more challenging. Similarly, the fear of poor scores for centres, especially when not considered within the context of the served community where factors such as deprivation, co-morbidity, and frailty among others may not be accounted for, may also influence engagement. Much of the emphasis in design has been to reduce as far as possible routine use of the highest response score across the scale.

It is noticeable that variations across patient characteristics reported in the Kidney PREM are limited; for example, small but consistent variations are apparent across age ranges and ethnicity groups. Over the period encompassing the COVID-19 pandemic, significant changes in patient responses by treatment modality were apparent⁶⁷ within some themes of care. However, the most significant indication of variation in patient responses is in relation to variation across treatment centres (described in the next section). These observations give confidence that the Kidney PREM is sensitive to difference, and change over time, despite the challenges presented by inevitable response biases.

A further difficulty with PREMs can be the delay between surveying patients and reporting results, particularly when collecting data at a national level. The time between collection and reporting can be a barrier to successful implementation of any potential quality improvement initiatives, leaving centres feeling pressure to make quick changes before the next cycle of PREM collection.

When implementing PREMs, mode of collection should be considered. The Health Foundation¹⁶ reviewed modes of PREM administration as part of their report on Measuring Patient Experience and concluded that potential limitations of online data collection include narrowing the types of people able to participate (often younger and in better health), uncertainty of provenance of responses, and the tendency towards more negative feedback. To mitigate against some of these issues, support to

complete Kidney PREM is given where needed, either from staff or volunteers at centres, or from friends and family. In the UK Kidney PREM 2023⁶⁸ cycle, there was an increase in the number of participants receiving help to complete the survey, reflecting the change to online only data collection. Whether this increase in support brings with it any unintended consequences around response bias, is yet to be fully explored. Although some studies report differences in experience between those completing an online survey versus a postal version, when both options were available prior to 2023, any differences between the two were negligible for Kidney PREM.

Of more concern is the potential overburdening of patients with regards to questionnaire completion, particularly those who may be frail, have multi-morbidity or have communication difficulties (such as language barriers), and the frequency with which patients are asked to complete questionnaires. The Health Foundation report that, in general, surveys are moving towards being used as regular feedback as part of ongoing quality improvement. Incorporating PREMs into routine data collection could reduce this burden, so long as suitable infrastructure is in place to support completion where needed.

Use and benefits of PREMs

There is evidence that patient experience is associated with clinical effectiveness and patient safety, and patient reported experience measures can have an important role in informing clinical work⁶⁹. However, there is less published on the meaningful use of PREM data and how they can be used to examine impact, which remains true within kidney care. Less is known about how kidney PREMs are correlated with clinical outcomes and adherences and even where evidence exists, less still is known about the effective mechanism underpinning any associations. Very little is published about the process of using PREM data to effect change in clinical areas or outcomes⁴.

As is evident with the Kidney PREM, benchmarking and comparisons across kidney centres is possible using longitudinal experience data but should be caveated with information about patient population,

deprivation, and perhaps contextual issues such as local workforce gaps or issues. The use of ICH-CAHPS in the US has been scrutinised in terms of the direct link between patient experience and quality of care, and some suggest an adjustment for underlying differences in patients’ cultural and social preferences, or by region, may be required³⁷ to improve trustworthiness in the data.

An adjusted version of the UK’s Kidney PREM has been piloted for use by children and young people (CYP) aged 12 to 16 years and by parents/carers of CYP of all ages. Work is ongoing to produce a validated measure for use by CYP of all ages. Both the adult Kidney PREM and the Paediatric Kidney PREM allow for reporting by each separate domain within the measure, enabling centres to see which aspects of care could be improved. Both Kidney PREMs contain items across 13 themes of care, as well as an item measuring patients’ Overall Experience of their care (Table 2).

Table 2: Themes in the 2024 Kidney PREM, with the response scale.

Section	Theme	Questions	Response scale
1	Access to the Kidney Team	Q1-Q3	1 (Never) – 7 (Always)
2	Support	Q4-Q6	
3	Communication	Q7-Q11, P02 [§]	
4	Patient Information	Q12-Q13	
5	Fluid Intake and Diet	Q14-Q15	
P1 [§]	Medication	P03-P04	
6 [¥]	Needling	Q16 [#]	
7	Tests	Q17-Q19	
8	Sharing Decisions	Q20-Q22	
9	Privacy and Dignity	Q23-Q24	
10	Scheduling and Planning	Q25-Q26, Q27 [#]	
11	How the Kidney Team Treats You	Q28-Q30	
12	Transport	Q31-Q33 [#]	
13	The Environment	Q34-Q38, P05 [§]	
14	Your Overall Experience	Q39 [*]	1 (Worst it can be) – 7 (Best it can be)

[#]Filtered questions (depending on treatment modality), ^{*}Overall experience – not included in scale score, [§]Paediatrics only,

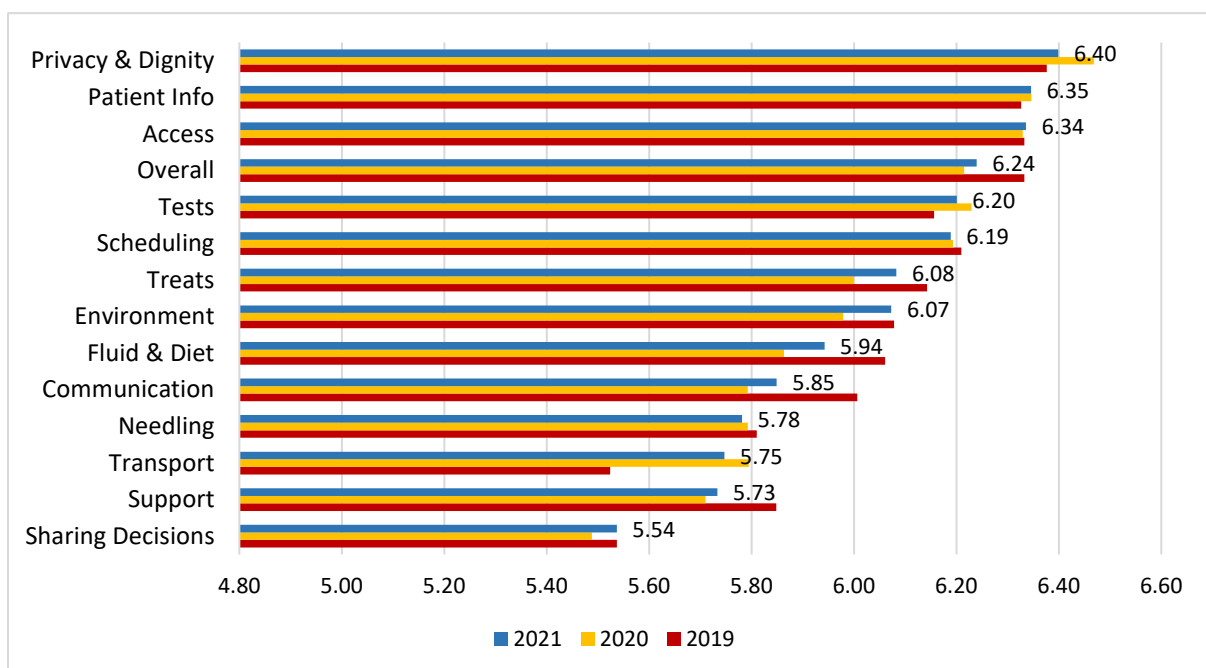
[¥]Adults only

Due to the nature and speed of spread of COVID-19⁷⁰, rapid and fundamental changes to the way that healthcare services were delivered was evident across the NHS and in other healthcare systems. Implementation of social distancing, strict use of PPE, isolation wards and postponement of non-

urgent procedures and for kidney patients, the suspension of transplants were some of the key changes ⁷¹. A rapid review⁷² investigating kidney services post pandemic describes several main impacts including the introduction of telemedicine to maintain healthcare delivery while reducing the need for face-to-face contact, poorer psychological wellbeing among patients, and variation in patient experience based on treatment modality.

In 2020, the Kidney PREM received almost 10,000 responses, achieving over 12,000 in 2021 while the pandemic was ongoing. During this period, changes in scores were apparent across some themes (Figure 1)⁷³, with some decreasing compared to pre-pandemic levels (e.g., Fluid & Diet, Communication, Support) and others showing an increase (e.g., Transport). This highlights how PREMs can be sensitive to change, particularly when considering specific sub-constructs within them. Findings such as these can be used to identify specific aspects of care which could be improved, or those requiring attention, enabling the implementation of focussed quality improvement programmes.

Figure 1: Mean scores for the 13 Kidney PREM themes and Overall Experience in 2019, 2020 and 2021



A natural question to address with a large dataset is the extent to which variation in reported experience can be attributed to measurable provider (or treatment centre) characteristics, as the first

step to identifying potentially modifiable features and enacting change. Analysis of Kidney PREM⁷⁴ results from haemodialysis patients showed that of the 45% of explained variance in scale score, 40% was explained by variance between centres and the remainder related to patient-level factors. Whilst counterintuitive, this likely reflects that the focus of the Kidney PREM is the treating unit, not the patient as with PROMs. Variations between centres are extensive, with many characteristics (such as staff/patient ratios) that could contribute to the observed variation in reported experience. Currently there are no reported studies that provide an indication of which differences between centres are important explanatory factors for the observed variation. Further work is required to explain these findings, particularly in relation to their potential impact on kidney care.

Using PREMs for impact – what is the evidence?

Evidence of a direct link between use of PREMs and change in care delivery or improved quality of service for patients is sparse, and broadly, it is unclear how PREMs are being used to guide effective action to improve patient experience or influence other system outcomes or change. Evidence of whether their use works to improve quality of care or to support person-centred care remains largely theoretical⁷⁵.

Aside from the CPES and Kidney PREM, patient experience data are not routinely used as a standard of care or well-integrated into healthcare systems across the UK, and this applies internationally with few exceptions (notably CAHPS in the USA). Some use of PREMs at a local level, such as that of the Kent and Medway Partnership Trust⁷⁶ (UK) has shown that there is appetite for patient experience data that can be used to monitor changes over time.

In kidney care, a study is underway to determine how Kidney PREM data are used in improving quality of care and galvanising broader change at the local level of service delivery and across regional networks of the UK. Using an electronic survey and centre interviews, both staff and patients will be

asked about their understanding of Kidney PREM data and how it has been used locally to bring about change. One example of local change, self-identified via a participating centre, describes an improvement in the experience of transport provision for haemodialysis patients via a dialogue with transport providers about patient needs⁷⁷. Collecting survey, as well as qualitative data on the potential impact of the Kidney PREM is even more pertinent given that quantitative results are often not reported in research or grey literature relating to improving PREM scores⁴.

In addition to this, results from the Kidney PREM have been integrated into quality improvement (QI) initiatives. The Kidney Quality Improvement Partnership (KQIP), part of the UK Kidney Association, uses results to inform national QI projects alongside supporting regions on how to use Kidney PREM results to drive QI at a local level, further details are available in the 2023 report⁴⁹.

The Kidney PREM annual survey results indicate that more detailed information about some aspects of patient experience was needed. To address this, a PREM evaluating patients' experience of cannulation, the Needling PREM (NPREM) has been developed and is undergoing peer review⁷⁸. The NPREM was developed in response to needling being one of the more poorly scored themes of the Kidney PREM each year. In addition, as described above, an extension of the Kidney PREM for use in paediatric care is also underway. The Paediatric Kidney PREM will collect data from patients aged 12-17 years, or parents and carers of children and young people of all ages with chronic kidney disease. Outside of the UK, work has been undertaken in the USA to develop a validated experience measure for those receiving home haemodialysis, the Patient-Reported Experience Measure for Home Dialysis⁵³. Each of these PREMs have been (or plan to be) created with significant patient involvement, recognising the importance of the patient voice in the development of surveys measuring patient experience.

Beyond this, there is insufficient knowledge about how best to use PREMs for maximum advantage in improving quality and service delivery. A recent realist synthesis of PROMs and PREMs in nephrology

undertaken by Schick-Mararoff ⁷⁹, examines how and why PROs are used in the clinical setting. They report that the evidence-base for the use of PROs at the individual and aggregate levels remains inadequate and the use of PROs to support-person centred kidney care has not been evaluated. In a later study, they found patient reported outcomes collected electronically, remain tailored to clinician rather than patient needs and use by clinicians was variable⁷⁹. To be properly implemented, the value of PREMs must be demonstrated to both healthcare staff and patients, and evident in subsequent action. The wider implementation of PREMs requires a culture shift in terms of the value placed in these kind of measures, and demonstrable impact and benefit to data collection¹⁹.

How PREMs can be used to support patient-centred care remains unclear (this applies also to PROs more generally), but fundamentally they should initiate discussion and potentially better communication between patients and healthcare workers. The realist synthesis published by Schick-Makaroff⁷⁹ suggests that aggregate data can be used to inform treatment decision making.

It is possible that the potential impact of PREMs has been muted due to lack of an educational framework and training around their use¹⁹. Already in its seventh year, the Kidney PREM provides a unique opportunity to gather longitudinal data to better understand how to improve patient experience. Prioritising or mandating PREMs within national guidance is likely to highlight areas where improvement is needed and reveal variation. By re-prioritising in this way, it has been suggested that improvement may follow⁸⁰, underpinned by bottom-up pressure from patients about their kidney care experience. Developing guidance around the use of PREMs may contribute to better awareness and education around their use, and development of such guidance is planned for NPREM.

What's next for PREMs?

The potential for patient reported experience measures to support better patient-centred care, improve the discussion of PREM results between patients and healthcare workers, and improve the

quality-of-service provision is appealing but not yet realised. For PREMs to be useful, we have to understand more about how they can be used in practice to support meaningful change in service delivery. This process will start with understanding the modifiable factors that are related to patient experience that currently remain unidentified.

Moving forward, greater clarity and distinction should be made between tools that are designed to audit or survey patient experience, and measures that are designed (to an appropriate standard) to measure a well-defined underlying unitary property. Researchers and clinical groups should follow best practice and provide a clear statement (peer reviewed or otherwise) making clear the process of development and evaluation of any published measure. Where a PREM claims to provide a unitary outcome measure, the development of the measure should be robustly validated on a sufficiently large and heterogenous sample^{81,82}, with input on content from both healthcare providers, patients and carers.

More work needs to be done to understand the challenges around action relating to the collection of PREMs, sustaining data collection and supporting completion, particularly among elderly or frail patients, while mitigating against response bias and maintaining trust in the data. Working with clinical data registries to integrate data collection would be helpful in providing a convenient platform to support robust routine data collection at a large scale. More work needs to be done to understand how best to develop PREMs that reflect the patient voice (rather than just that of the clinical team), and how PREMs can be used in practice effectively. Part of the solution is in providing convincing evidence of effectiveness; that PREMs can make a difference to patient care despite the challenges of implementation. Another predicament is how to utilise PREM data to support engagement in discussion with a wider range of interested parties to enable and enact meaningful change in services. As part of this consultation, patients themselves should be involved in interpretation and contextualising the data, alongside other stakeholders.

Conclusion

Advances have been made in the development of measures of patient experience within the realm of kidney care over the past decade. However, with a few notable exceptions the implementation of PREM tools has been slow, patchy, lacking a systematic approach and fraught with barriers. Tools are often developed to meet a specific purpose, not necessarily as a robust, more global measure of patient experience. Few have been used to assess quality of care, and published data demonstrating impact or action to improve patient care is sparse. In 2014, Coulter³⁹ observed that there is limited evidence of the impact of collecting PREM data on patient safety and quality of care. This remains the case in kidney disease⁷⁵. There is no clear evidence around the use of PREMs and improvements in service-level outcomes.

Failure to fully realise the value of PREMs in kidney care is, in large part, due to the focus on development of measures and data collection, with less done to expand our understanding of what the data says about care. Minimal published data exists linking PREM outcomes to identified modifiable characteristics that can be addressed to enact change in the way the care is delivered. Critically, it is apparent that variation between treating services appear to be the most important factor in describing variation, but that observation as yet only indicates where to look for modifiable factors, rather than what those factors are.

Quantification of patient experience is only part of the equation. Strong leadership and championing of change are some of the mechanisms required for quality improvement, alongside resources and greater patient and public involvement. For some decades now, policy makers have identified patient experience as one of the three pillars of high-quality care, and an essential component of patient-centred care. Much work has been done to develop a range of PREMs in Kidney services, and to collect data. However, whilst the journey towards understanding the link between PREM data and modifiable characteristics that can be targeted to enable meaningful change in the delivery of care has been

started, more evidence is needed. Some of the concepts and ideas necessary to enable change, for example, understanding the process of implementing a programme of change, are understood⁸³. That body of work will be important in taking a programme of change forward once more is understood about the relationship between patient experience and the delivery of care. Renewed interest in a range of settings within renal services across the world and in other settings is growing, with a focus on understanding not simply what and how to measure PROs, but also how to engage the wider community in change to support better outcomes for patients, for services, and for the community who support patients in their daily lives.

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