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Electronic Collection of Patient-Reported Outcomes to Improve Kidney Care: Benefits, Drawbacks, and Next Steps

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Summary

Kidney services worldwide are increasingly using digital health technologies to deliver care. This includes kidney electronic patient-reported outcome (ePRO) systems: ambulatory digital technologies that enable the capture of PRO data electronically from people with kidney disease remotely and in real time to be shared with their kidney care team. Current kidney ePRO systems commonly aim to support the monitoring and management of symptoms in patients with kidney disease. The majority have thus far only been implemented in research settings and are not yet routinely used in clinical practice, leaving their readiness for real-world implementation largely unknown. Compared with paper-based PRO collection, ePRO systems have certain advantages, which we categorize as efficiency benefits (e.g., lower administrative burden), direct patient care benefits (e.g., automated PRO-based patient education), and health system and research benefits (e.g., collecting ePRO data once for multiple purposes). At the same time, kidney ePRO systems come with drawbacks, such as their potential to exacerbate existing inequities in care and outcomes and to negatively affect staff burden and patients' experience of kidney care. Areas that hold promise for expediting the development and uptake of kidney ePRO systems at the local, organizational, and national level include harnessing national kidney registries as enabling infrastructures; using novel data-driven technologies (e.g., computerized adaptive test systems, configurable dashboards); applying implementation science and action research approaches to enhance translation of ePRO research findings into clinical practice; and engaging stakeholders, including patients and carers, health care professionals, policymakers, payers, ePRO experts, technology providers, and organizations that monitor and improve the quality of kidney services.
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INTRODUCTION

Digital technology is rapidly permeating our daily lives, with around 5 billion people worldwide using smartphones and the internet.[1,2] This impacts not only how people work, shop, and socialize but also how they interact with the health care system. Digitization of health and care services had already started in the 1970s[3] and was expedited during the coronavirus disease 2019 pandemic, when providers and patients were forced to rapidly shift from in-person to remote care. Although this shift has somewhat decelerated, health care systems worldwide are digitally transforming. This includes kidney health and care services,[4,5] where we have seen a steady rise in the availability and uptake of technologies, such as virtual consultation platforms,[6] patient portals,[7] health apps,[8] and remote monitoring systems.[9]

This article focuses on one type of digital health technology, electronic patient-reported outcome (ePRO) systems, which are increasingly prominent in kidney care[10,11] as well as in other clinical settings.[12,13] In line with previous reviews,[14,15] we define kidney ePRO systems as ambulatory, noninvasive digital technologies that enable people with kidney disease to report and record PRO data electronically remotely and in real time and to transmit these data to the kidney care team for assessment and to inform clinical decision-making. Such systems are deployed using web-based or smartphone applications, often as part of

patient portal solutions that also offer additional functionalities (e.g., patient access to health records).

Although ePRO systems have certain advantages over paper-based collection, such as lower administrative burden and better data quality, they also come with potential downsides that may hamper the ability of these systems to reach their full potential for improving health care and outcomes, such as an increased risk of generating kidney health inequities. In the following sections, we discuss the current state of kidney ePRO systems, give an overview of their benefits and drawbacks compared with paper-based PRO collection, and suggest how to expedite the development and uptake of these systems for enhancing kidney services, health equity, and kidney patients' experiences and outcomes.

CURRENT STATE OF KIDNEY ePRO SYSTEMS

Compared with some other clinical areas, particularly cancer, ePRO systems for kidney disease are still in their relative infancy. A review conducted in 2019 identified 41 unique systems for monitoring cancer treatment side effects.[13] A recent study found 15 kidney ePRO systems, mostly launched after 2016.[10] The majority were developed in the United Kingdom, United States, or Canada; had dialysis patients as their target population; and primarily aimed to support symptom monitoring and management. The latter aligns with the 2022 Kidney Disease: Improving Global Outcomes recommendations, which state that kidney health care professionals should capitalize on routinely collected PROs to acknowledge, prioritize, and manage symptoms that matter to patients even if treatment options are limited.[16] Furthermore, most kidney ePRO systems provide patients and professionals with (close to) real-time access to ePRO results using a patient or clinician portal or an electronic health record system, but none of the systems extend this access to health care professionals beyond the kidney care team. Many systems present current ePRO scores as well as a change over time, with the clinical response often consisting of regular face-to-face or virtual follow-up visits; only some systems have a mechanism for generating PRO-based clinical alerts.[10] Most kidney ePRO systems have only been implemented in research settings and have not yet reached a phase of routine and sustained use in clinical practice. This leaves the systems' readiness for real-world implementation largely unknown, and the following section elaborates on this. The subsequent section then describes the rise of national kidney registries as enabling infrastructures for ePRO systems.

Most Kidney ePRO Systems Are Still Being Evaluated

The majority of kidney ePRO systems are still in the formative evaluation stage,[10] with studies assessing systems' acceptability, feasibility, or clinical utility.[17-21] For some ePRO systems, their comparative effectiveness is being evaluated.[22-24] For example, the Symptom Monitoring With Feedback Trial (SWIFT) is currently testing the hypothesis in people on hemodialysis that electronic collection of patient-reported symptom data with ePRO feedback to patients and their kidney care team is cost-effective and improves health-related quality of life, overall survival, symptom burden, and health care utilization.[24]

AmbuFlex is one of the few kidney ePRO systems currently being used in a routine care context. AmbuFlex is a generic ePRO system from Denmark that supports more flexible outpatient care for people with long-term conditions, such as chronic kidney disease, who require frequent follow-up visits and where patient-reported aspects of health and disease play a central role in disease management.[25] AmbuFlex is integrated into the electronic health record, where it combines PRO data with clinical parameters (e.g., ambulatory blood pressure measurements) to generate advice on the need for a clinic consultation. In people with rheumatoid arthritis, the system improved self-management, quality of care, and health care utilization.[26] The PROKID pragmatic randomized controlled trial aims to provide similar evidence for people with chronic kidney disease not requiring dialysis.[22] Findings from the process evaluation were published recently, showing that the intervention had been implemented as intended, with high patient and clinician adherence to collecting and using ePROs.[27] Reports of the trial results are expected later in 2024.

National Registries as Emerging Enabling Infrastructures for Kidney ePRO Systems

There is an emerging trend in kidney disease as well as in other areas of medicine and health where clinically focused registry data sets are extended with patient-reported information.[11,28] This responds to the call for leveraging existing digital registry infrastructures to facilitate longitudinal and sustainable ePRO collection and to use these data to enable more patient-centered service planning, policymaking, and research.[11] Kidney registries in Sweden, the Netherlands, Australia, the United States, and the United Kingdom have been trailblazers in this respect.[29-33] In addition, the US National Kidney Foundation (NKF) Patient Network was launched by the NKF in 2021, which links patient-reported data on demographics, medical history, lifestyle, quality of life, and stress for adults across all stages of chronic kidney disease with their electronic health record data.[33]

For kidney registries that are planning to incorporate ePROs into their data set and infrastructure in the future, there are helpful guidance documents available for implementing PROs in clinical practice in general[34]

as well as for incorporating them into registries specifically.[35,36] These provide checklists of areas to consider, such as determining the primary purpose of PRO collection; selecting the target patient group; identifying and selecting existing PRO measures; deciding how, when, and how often to administer PRO measures without overburdening respondents; and designing strategies for analyzing and reporting PRO results for a variety of stakeholders.

BENEFITS OF KIDNEY ePRO SYSTEMS

Figure 1 shows three broad categories of benefits of ePRO systems compared with paper-based systems: efficiency benefits, direct patient care benefits, and health system and research benefits. The following sections elaborate further on each of these. Combined, they have the potential to reduce costs, facilitate delivery of more efficient and tailored health care services, and improve patient outcomes.

Efficiency Benefits

Efficiency benefits arise where a well-designed electronic platform enables people to complete a PRO questionnaire more quickly than would be the case for a paper-based version.[12] Electronic collection of PRO data directly from patients also removes the need for staff to copy data into electronic format, minimizing data entry errors and lowering costs and processing time.[37] Related benefits involve the potential of ePRO systems to achieve higher response rates and better data quality

compared with paper-based systems. For example, incorporating computerized adaptive testing (CAT) systems can decrease completion time and overall questionnaire burden by tailoring the questions to the respondent's individual circumstances.[38] In turn, this limits the number of items that people are asked to complete while optimizing the relevance of items.[39] Other ways in which ePRO systems can enhance response rates and data quality include configuring a data collection schedule that better aligns with people's daily routines,[40] automating the sending of reminders via phone text or email or both, and mandating completion of items before people can submit their questionnaire.[12,20]

Direct Patient Care Benefits

Direct patient care benefits of ePRO systems come from the ability to share data simultaneously with patients and health care professionals at the point of entry, the greater flexibility these systems offer for presenting and feeding back PRO results, and the opportunities provided by automating patient education and self-management support. First, electronic data capture facilitates uploading of PRO reports in real time, allowing prompt review by the kidney care team, as results are available immediately.[40] Second, dashboards offering a choice of alternate graphical views allow tailoring of reports in line with the information needs of individual patients and professionals, thereby enhancing the usefulness of the PRO data for more users.[41] This potential of ePRO systems to display the same real-time longitudinal data to both patients and kidney care team in a way that optimizes
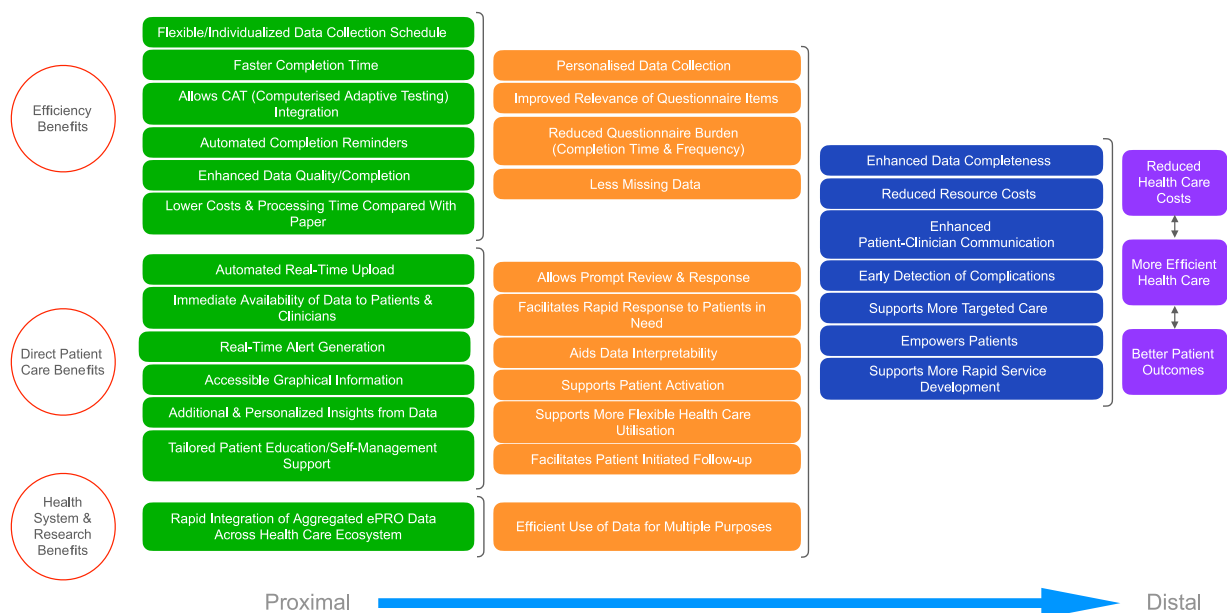

Figure 1. Efficiency, direct patient care, and health system and research benefits of ePRO systems compared with paper-based collection, going from proximal to more distal benefits. Abbreviation: ePRO, electronic patient-reported outcome.

interpretability for both user groups is key in supporting enhanced patient-clinician communication and shared decision-making.[12,40] This is further enhanced if ePRO data are aggregated to provide additional insights to inform discussions in clinic and development of treatment plans (e.g., by presenting reference values for an individual patient based on summaries of ePRO data from other patients with similar characteristics).[40]

Finally, ePRO systems open up the possibility of tailoring patient education and self-management advice based on people's PRO results.[20] In turn, this may promote self-efficacy, enhance self-management, and improve patient outcomes.[40] Self-efficacy and self-management may be further increased where an ePRO system is used to support patient-initiated follow-up, such as in the aforementioned PROKID trial.[22,27]

Health System and Research Benefits

A third category of benefits of ePRO systems is the ability to rapidly integrate aggregated ePRO data across different parts of the health care ecosystem to be used for multiple purposes. Accelerated sharing of information in this way promotes efficient use of once-collected PRO data to meet a variety of stakeholder needs;[42] for example, by supporting more timely audits and service improvement initiatives at the provider level or benchmarking and commissioning at the national level. In this way, and with appropriate ethical and governance frameworks in place, ePRO data routinely collected for direct patient care become available for secondary use in service evaluations, resource planning, and health research. Ultimately, this reduces the overall burden for patients and costs associated with PRO data collection for purposes beyond direct care.

DRAWBACKS OF KIDNEY ePRO SYSTEMS

Whereas the previous section outlined some potential advantages of kidney ePRO systems, this section presents some drawbacks that may hamper their ability to reach their full potential for improving kidney care and outcomes. In their systematic review, Meirte et al[12] identified three main types of disadvantages of ePROs compared with paper-based collection: increased concerns and requirements regarding data governance and privacy, greater initial effort and investment for development and implementation, and risk of digitally excluding certain patient groups. We discuss the latter in more detail in the following section, with subsequent sections outlining the negative impact on staff burden and patients' experience of kidney care.

Impact on Kidney Health Equity

Several studies have provided clear evidence of persistent kidney health inequities.[43,44] Older people with lower socioeconomic status or from ethnic minority backgrounds are more likely to be diagnosed with chronic kidney disease, have a higher disease burden, and have poorer access to kidney replacement therapies. At the same time, it is also these groups who are at a higher risk of being digitally excluded because they do not have a smartphone or internet connection or because they lack the confidence, skills, motivation, or support to use digital technology.[45] This means that they are less likely to engage with and benefit from kidney ePRO systems, thereby exacerbating the existing kidney health inequities.[5]

Empirical studies have confirmed that not all people with kidney disease can or want to complete PRO measures electronically. For example, a feasibility study in a mixed sample of people with kidney and hematological diseases found that 48% of those invited to complete a PRO questionnaire preferred to do this on paper; they were significantly older than those who agreed to complete the questionnaire electronically.[46] This warrants a concerted effort to ensure equitable engagement with ePRO systems, which was confirmed by stakeholders, who mentioned "making sure ePROs do not add to inequalities in kidney health" as one of the top four issues to address with regard to achieving national ePRO collection in the United Kingdom.[47] The concerted effort could include things such as offering dedicated support for those with lower digital literacy or providing devices with internet connection to access the system in clinic.[33] Extra attention is also needed to address the (often unconscious) bias from health care professionals, who may selectively encourage patients to use ePRO systems and other digital health technologies based on their assumptions of patients' digital skills and interest; this then drives inequitable uptake and use.[48] However, promising findings from other clinical areas suggest that equitable implementation of ePRO systems is feasible,[49] which in turn can improve care and outcomes for those who need it most.[41,50]

Impact on Staff Burden

Another potential drawback of kidney ePRO systems is their risk of increasing burden on staff, which was one of the other four key issues that stakeholders prioritized for achieving UK-wide ePRO collection.[47] A study on burnout among nephrologists in the United States reported frustrations with the time spent on the electronic health record system as the main driver for burnout.[51] These frustrations may worsen when introducing an ePRO system, especially if it is poorly integrated with existing clinical information systems and workflows.[52] For

example, in a Canadian ePRO study in home dialysis settings, nephrologists frequently asked for PRO questionnaires to be printed out for patients to complete before their clinic visit and then manually entered into the electronic health record by nurses afterward. Establishing this paper-based workaround was largely driven by lack of access to computers for viewing ePRO results during the consultation.[53] Furthermore, health care professionals may be concerned about ePRO systems disrupting already tight workflows and further reducing time with patients,[54,55] potentially leading to a lack of acknowledgment or discussion of ePRO results during consultations.[53,56]

One option to minimize the burden on nephrologists and nurses is using ePROs to enable increased involvement of allied health professionals, such as social workers and psychologists. Apart from spreading the burden of reviewing and discussing ePRO results more equally across the kidney care team and thereby increasing patients' access to care,[57] some members may be better equipped than others to manage particular patient-reported issues (e.g., psychosocial symptoms and conditions).

Impact on Patient Safety and Experience

A final example of a drawback of ePRO systems in kidney disease is their potential negative effect on the safety and patient experience of kidney care. First, this negative effect may occur when ePRO systems lead to a reduction in (in-person) clinic visits (e.g., in the study by Grove et al[22]). Although this reduction has clear benefits, some people with kidney disease—particularly those from groups at risk of health inequities—may prefer to speak to their nephrologist in person rather than on a phone or video call.[58] Similarly, health care professionals worry about overlooking important symptoms in people with kidney disease in the absence of face-to-face visits.[27,53]

Second, people with kidney disease and their health care professionals may have different expectations related to ePRO systems.[55] For example, patients may want such systems to ensure a rapid response by the kidney team and to offer the option to directly discuss ePRO results with the care team, whereas professionals fear this may disrupt care for other patients and compromise the patient-professional relationship. By contrast, patients and health care professionals may both assume the other will start a conversation about ePRO results.[53,59] Unless we manage these diverging expectations, ePRO systems may lead to disappointment, confusion, and potentially hazardous situations where important patient-reported issues remain undiscussed.

Finally, kidney care teams may lack guidance and support for providing an adequate and timely response to ePRO results;[54,59-61] for example, because they are not aware of available treatment options, do not feel comfortable managing psychosocial symptoms, or consider it outside their remit to treat some patient-reported issues. This may further explain why ePRO reports are not always discussed in clinic. Therefore, although ePRO systems have the potential to facilitate more holistic kidney care, additional training and support for multidisciplinary approaches and symptom management are needed to ensure ePRO systems have a positive rather than a negative effect on the safety and patient experience of kidney care.

EXPEDITING DEVELOPMENT AND UPTAKE OF KIDNEY ePRO SYSTEMS

In this final section, we discuss some areas that hold promise for progressing the development and uptake of kidney ePRO systems by harnessing their benefits and minimizing their drawbacks.

The Potential of New Technologies

As previously discussed, CAT systems offer opportunities for sophisticated delivery of ePRO questionnaires that are more efficient, relevant, and accurate. Examples in kidney disease are the ongoing work in the United Kingdom to establish a multidimensional CAT system for measuring kidney symptom burden[62] and the Patient-Reported Outcomes Measurement Information System (PROMIS) program in the United States. PROMIS is supported by the US National Institutes of Health and offers a CAT system with access to a wide range of standardized and tested PRO questionnaires (e.g., on pain, physical functioning) for use in long-term conditions, including chronic kidney disease. For example, the PROMIS instrument for fatigue showed good measurement properties and low questionnaire burden when tested in people receiving kidney replacement therapy.[63] To aid the implementation and wider adoption of PROMIS CAT instruments in clinical pathways, they can be accessed through PROMIS's proprietary web-based platform or third-party applications or via commonly used electronic health record systems (e.g., Epic).[64]

Similarly to CAT systems, other data-driven technologies, such as dashboards and computerized decision support systems with embedded artificial intelligence-based algorithms,[65,66] could relieve part of the ePRO-related burden for kidney patients and staff by aiding quicker and easier interpretation of ePRO results. Such technologies also facilitate combined analysis and visualization of ePRO data alongside routinely collected electronic health record data. In addition to further enhancing interpretation, this may encourage and support coproduction of kidney care[67] and enrich prediction of important outcomes, such as kidney disease progression.[68] Although the added predictive value of PROs has

not been widely studied in kidney disease, the evidence from other clinical areas is promising.[69]

Finally, and related to one of the aforementioned drawbacks of ePRO systems, introducing these new technologies warrants careful consideration of the abilities and needs of people at risk of experiencing kidney health inequities. For example, apart from being mindful of people's (health) literacy levels and cultural backgrounds,[70] kidney services should systematically assess respondents' digital skills and preferences and offer modes of PRO administration accordingly, including low-tech options (e.g., the PROKID trial used a mix of electronic and paper-based collection, with 84% of patients opting for the former[27]). Additional efforts could include, for example, inviting representatives of underserved patient groups to participate in codesigning kidney ePRO systems and the materials to support their implementation,[20,71] employing approaches centered around the experiences of disadvantaged and disinterested groups if appropriate.[72]

Building on Implementation Science and Related Approaches

As outlined in the preceding section on the current state of kidney ePRO systems, there is a gap between research and the day-to-day delivery of kidney care. Even though many kidney patients and health care professionals may see empirical evidence of the effectiveness of ePRO systems as crucial for successful implementation,[73] research studies provide little information on a system's uptake and sustainability in real-world settings. This highlights an urgent need to better understand how to translate research findings into practice and what factors may influence the real-world implementation of ePRO systems, especially as poor implementation is likely to hamper a system's ability to positively affect outcomes.[74]

Implementation science is "the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practice into routine practice and, hence, to improve the quality and effectiveness of health services."[75] An implementation science approach is therefore well suited for enhancing the readiness of kidney ePRO systems, optimizing the organizational and societal context for their uptake, and identifying and addressing unintended consequences. Stover et al[76] illustrated this by presenting four case studies of PRO system implementation in different clinical areas that used an implementation science approach. Across the case studies, they found that implementation barriers were similar (e.g., lack of integration into the electronic health record, unclear objectives of the ePRO system), whereas enabling factors differed depending on the implementation context and therefore required localized implementation strategies. Table 1 lists four categories of models, theories, and frameworks commonly

used in implementation science[77] and illustrates how these have been applied to ePRO system implementation in kidney disease and other clinical areas:

- Process models aim to describe or guide (or both) the process of translating research-based knowledge into practice. They typically specify steps, phases, or stages in how research gets into practice, from initial discovery to production and implementation of knowledge.
- Implementation theories aim to understand or explain (or both) different aspects of implementation and to enable identification of issues that are most likely to be critical in particular circumstances.
- Determinant frameworks help to understand or explain (or both) implementation success by describing types, domains, or levels of determinants that are hypothesized or known to influence implementation outcomes. They vary in the extent to which they consider relationships between determinants and, unlike theories, do not explicitly consider causal mechanisms.
- Evaluation frameworks aim to systematize the evaluation of implementation efforts by specifying aspects that can be assessed to determine implementation success.

Closely aligned and often used in combination with an implementation science approach are hybrid effectiveness implementation studies and action research studies. The former study type aims to speed up translation from research into practice, deliver more useful information for stakeholders, and increase the likely success of implementation strategies by blending components of effectiveness and implementation studies (e.g., by observing and gathering information on implementation while evaluating effectiveness of an intervention).[78] The latter study type, action research studies, has similar aims as the former but focuses more on iterative cycles of scoping, planning, acting, and evaluating action.[79] It emphasizes cocreation of practical knowledge in collaboration with participants and focuses on participatory action and solutions for real problems that people experience. Hybrid effectiveness implementation and action research studies for ePRO systems are emerging in other clinical areas,[80,81] with examples in kidney disease hopefully following soon.

Wider Stakeholder Engagement

The previous section on drawbacks described how patients and health care professionals may have different views and expectations regarding kidney ePRO systems and how this may impact staff burden and patients' experience of care. Understanding and overcoming potentially conflicting needs between stakeholders are therefore crucial for successful implementation of ePRO systems. To date, studies in kidney disease have primarily explored perspectives of individual patients and health

Table 1. Categories and Examples of Implementation Science Models, Frameworks, and Theories and Their Application in Electronic Patient-Reported Outcome System Implementation in Kidney Disease and Other Clinical Areas

Category of Models, Frameworks, and Theories	Example Models, Frameworks, and Theories	Illustration of Application in ePRO Systems
Process models Describe and guide the process of translating research into practice	KTA model[83]	The KTA model guided a process evaluation of educational support for kidney health care professionals for the routine use of ePROs in their practice.[53]
Implementation theories Explain different aspects of an implementation and help prioritize critical issues	NPT[84] COM-B model[85]	NPT was combined with participatory codesign methods to guide workshops with kidney health care stakeholders to design a kidney ePRO system and generate recommendations for implementation support.[32,71] NPT informed a qualitative study to understand and explain the causal mechanisms that underpin successful implementation of ePROs within palliative care.[86] The COM-B model combined with the NASSS framework was used to organize the findings from a qualitative evidence synthesis aiming to understand barriers and enablers influencing the planning, development, implementation, and use of ePROs in routine care of older adults.[87]
Determinant frameworks Describe determinants that may influence implementation outcomes	CFIR[82] TDF[88] i-PARIHS framework[89] NASSS framework[90]	A mixed methods study used CFIR to gain insight into the implementation of kidney ePRO systems.[10] A prospective application of implementation science theories combined CFIR with TDF to inform the use of ePROs in an integrated chronic pain network and to identify barriers to and enablers for their implementation.[91] A pilot study used the i-PARIHS framework to identify implementation barriers and enablers to inform facilitation support strategies for using electronic and paper-based PROs in a medical oncology outpatient department.[92] NASSS guided a requirements analysis for a scalable ePRO system integrated into the electronic health record for remote monitoring of asthma symptoms in primary care.[93]
Evaluation frameworks Systematize implementation evaluations by specifying how to assess implementation success	RE-AIM framework[94]	The RE-AIM framework guided evaluation of the implementation of a disease-agnostic ePRO system for older adults.[95]

Abbreviations: CFIR, Consolidated Framework for Implementation Research; COM-B, capability, opportunity, motivation, and behavior; ePRO, electronic patient-reported outcome; i-PARIHS, Integrated Promoting Action on Research Implementation in Health Services; KTA, Knowledge-to-Action; NASSS, non-adoption, abandonment, scale-up, spread, and sustainability; NPT, Normalization Process Theory; PROs, patient-reported outcomes; RE-AIM, Reach, Effectiveness, Adoption, Implementation, and Maintenance; TDF, Theoretical Domains Framework.

care professionals and their role in local ePRO system implementation.[54,71] However, when planning larger-scale implementations, it becomes more pertinent to additionally consider the perspectives of a wider group of stakeholders. For example, in the Consolidated Framework for Implementation Research,[82] mentioned in Table 1, "innovation recipients" (in this case, patients and professionals as ePRO system end users) make up only one of nine stakeholder types, with others being, for instance, high-level leaders and implementation facilitators.

An example in kidney disease where a wider multistakeholder group was involved in shaping the design and implementation of a national ePRO system is the previously mentioned NKF Patient Network in the United States.[33] Through an extensive stakeholder mapping exercise, kidney patients, health provider systems, community kidney services, sponsor companies (e.g., pharma), academics, contract research organizations, the NKF, and technology providers were identified as relevant groups. It was acknowledged that different groups

may have different levels of interest and influence, and stakeholder engagement was planned accordingly, with more extensive strategies for patients, providers, and sponsor companies.

Another example of wider stakeholder engagement is the development of a roadmap with recommendations for achieving national collection of ePROs in the United Kingdom in the next 10 years.[47] Partly overlapping with the NKF Patient Network, the roadmap listed as stakeholders kidney patients and carers; kidney health care professionals working in primary and secondary care; organizations commissioning, monitoring, or improving the quality of kidney services; companies supplying information technology systems, collecting data for kidney services, or both; funders of kidney research (government, charities, pharmaceutical companies); and ePRO researchers and experts. Stakeholders' input in the roadmap's recommendations was captured through individual interviews with 18 representatives, a full-day online event with group discussions attended by 58

Table 2. Goals and Strategies for Expediting Kidney Electronic Patient-Reported Outcome Systems at the National, Organizational, and Individual Level

Level	Goals	Stategies for Achieving Goals
National and regional National/regional health services, national registries, professional bodies, patient organizations, etc.	• Well-resourced, equitable, and sustainable kidney ePRO systems that support routine and systematic ePRO data collection in line with patients' and professionals' needs • A context and culture that acknowledge the added value of PROs to complement clinical data for delivering safe, effective, and person-centered care • Harmonized, flexible, and secure ePRO collection platforms that offer access to validated PRO measures; enable linkage to other data sources; and support ePRO data analysis, visualization, and interpretation	• Establish multistakeholder groups to shape national and regional strategies for kidney ePRO implementation in line with stakeholders' diverse needs. • Encourage and provide guidance for inclusive, diverse, and meaningful patient and public involvement in designing, evaluating, and implementing kidney ePRO systems. • Harness existing ePRO platforms and other digital data infrastructures whenever possible. If needed, develop new ones in line with best practice guidance. • Develop ethics and governance frameworks to enable ePRO data to be used for direct patient care as well as other, secondary purposes. • Fund and conduct high-quality, theory-informed research to generate empirical evidence of the benefits of ePROs, including hybrid effectiveness implementation and action research studies. • Continue development and evaluation of valid and efficient ePRO measures to assess aspects of kidney health and disease that are relevant to patients and health care professionals.
Organizational Kidney care centers, dialysis units, etc.	• Sustainable and equitable implementation of kidney ePRO systems tailored to the local context with minimal impact on staff and patient burden • Optimal engagement with kidney ePRO systems from patients and health care professionals by addressing perceived and actual implementation barriers	• Define and communicate the main objectives of the kidney ePRO system and what it is trying to achieve, with messages tailored to local stakeholders' needs and expectations. • Integrate the kidney ePRO system into the electronic health record to facilitate alert systems and easy-to-interpret visualizations to minimize the impact on staff burden. • Provide people with kidney disease with easy-to-interpret visualizations of their own ePRO results linked to tailored education and self-management advice. • Offer training for kidney patients and kidney team members on collecting and interpreting ePRO data. • Identify patient groups who may be underserved by the kidney ePRO system and understand their needs. • Include kidney ePRO systems and their impact on care delivery in service evaluations and service improvement initiatives.
Individual People with kidney disease, members of the kidney team, etc.	• Using kidney ePRO systems during and in between clinic consultations to improve patient-professional communication, facilitate shared decision-making, support self-management, and better tailor kidney care to individual patients' needs • Available support for people with kidney disease at risk of experiencing (further) health inequities	• Ensure a systematic approach to discussing kidney ePRO results in clinic and manage expectations regarding review of results in between consultations. • Support an effective response to ePRO results involving members across the multidisciplinary kidney care team as required by offering clear pathways and adequate resources for, for example, symptom management. • Raise awareness of (un)conscious bias among members of the kidney care team around patients' interest and ability to engage with kidney ePRO systems. • Address needs of people from underserved patient groups; this includes, for example, providing devices in waiting rooms or dialysis units for accessing kidney ePRO system and low/no-tech alternatives for PRO completion.

Abbreviations: ePRO, electronic patient-reported outcome; PRO, patient-reported outcome.

people, and a public consultation in which nine stakeholder organizations provided over 100 suggestions for refining the draft roadmap.

For sustaining multistakeholder engagement over time, the NKF Patient Network has stakeholder representation in committees across the network's governance structure.[33] In the UK roadmap, the first recommendation states that "all national stakeholder groups should work together to set up a national kidney ePRO working group" to "inform and oversee activities that will help achieve the national collection of ePROs for kidney care and research."[47] This recommendation recognizes the strong influence national kidney stakeholder groups have in many countries, and as they all want better care and outcomes for people with kidney disease, sharing ownership across these influential groups will create the necessary buy-in for implementing kidney ePROs and expedite their larger-scale uptake.

CONCLUSIONS

In this article, we have described how kidney ePRO systems are in their relative infancy, with the majority not yet being used in routine clinical practice. Based on the benefits, drawbacks, and areas of promise discussed in this article, Table 2 summarizes how we can expedite the development of kidney ePRO systems and enhance their readiness and uptake in real-world settings. Once implemented with input from diverse patient groups and a wide range of stakeholders at all levels, kidney ePRO systems enhance the potential of patient-reported outcomes to deliver more efficient and tailored kidney health care services and improve kidney health equity and patient outcomes.

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