MANCHESTER 1824
The University of Manchester

Supported by
The Health Foundation

Putting patients at the centre: including the patient perspective in UK kidney care and research.

A roadmap for collecting electronic patient-reported outcome measures (ePROMs)

Sabine N van der Veer, Derek Kyte, Helen Chadwick, Paul Cockwell, Angelo Ercia, Rachel Gair, Rob Finnigan, Simon DS Fraser, Sarah Knowles, and Shivani Sharma.

May 2023

Supported by

The Health Foundation

This roadmap is part of the Health Foundation's Insight Research Programme. The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK.

Cite as: Van der Veer SN, Kyte D, Chadwick H, Cockwell P, Ercia A, Gair R, Finnigan R, Fraser SD, Knowles S, and Sharma S Putting patients at the centre: including patients' perspective into UK kidney care and research. A roadmap for collecting electronic patient-reported outcome measures (ePROMs) [Internet]. 2023. Available from: **https://doi.org/10.48420/21916518**

Foreword by partner organisations

High quality healthcare should always start, continue, and end with the needs of the patient. Ensuring that a patient is fully supported to identify what matters to them in symptom burden and treatment choice is the cornerstone of this principle, enabling the delivery of truly personalised care through increasing healthcare literacy, patient and carer activation, and shared decision making.

Patient-reported outcomes provide patients with the ability to directly report on their symptom burden and the quality of life issues that are important to them, removing bias and allowing a comprehensive and objective assessment based on the needs of the individual. Historically, patient-reported outcome data has been collected through validated paper questionnaires (patient-reported outcome measures (PROMs)) completed by the patient. However, this approach is cumbersome for patients and healthcare professionals and may simply not be practical for routine clinical care.

Therefore, the future is through electronic PROMs (ePROMs) with direct reporting through a portal, such as a smartphone app, using measurement tools that have adaptive algorithms that minimise patient burden and with appropriate support for the digitally excluded.

There is an increasing realisation that ePROMs could transform patient care by facilitating direct communication of the lived experience of their condition from patients to their health professionals, who can use this information to inform care. For patients, it is empowering to know that they are being listened to and that their reported experience is contributing to improved care.

Examples include:

- People with advanced kidney disease may report their symptoms before a consultation with a healthcare professional, at an agreed frequency in between consultations, or whenever there is a change in symptoms;
- Symptoms following medication change, or requiring evaluation for an early infection can be quickly reported by people who live with a kidney transplant;
- Symptom burden can take centre stage at the dialysis multi-professional team quality assurance meeting, with laboratory results supporting rather than driving decision making.

In late 2020, Dr Sabine van der Veer and Dr Derek Kyte, UK-based world-leading researchers in ePROMs for people with kidney disease, convened a national summit with an outstanding stakeholder faculty of patients and professionals whose collective views have been instrumental in the development of this roadmap report.

This document cogently and clearly sets out the practical steps required for the further development and adoption of ePROMs that can benefit all people with kidney disease. At the centre of the report are core principles that include evidence, integration, implementation, and equality. The report also provides a rationale for these principles and, crucially, some delivery principles on how to take them forward.

As representatives of stakeholder organisations involved in this work, we thank Sabine, Derek and all contributing faculty for their outstanding work. On behalf of our organisations, we hereby commit to working together to implement the recommendations of this report.

Stakeholder Representatives:

Miranda Scanlon
Lay Advisory Group Lead
for Kidney Research UK

Paul Bristow
Chief Executive for
Kidney Care UK

Andrea Brown
Chief Executive for the
National Kidney Federation

Paul Cockwell
President of the
UK Kidney Association

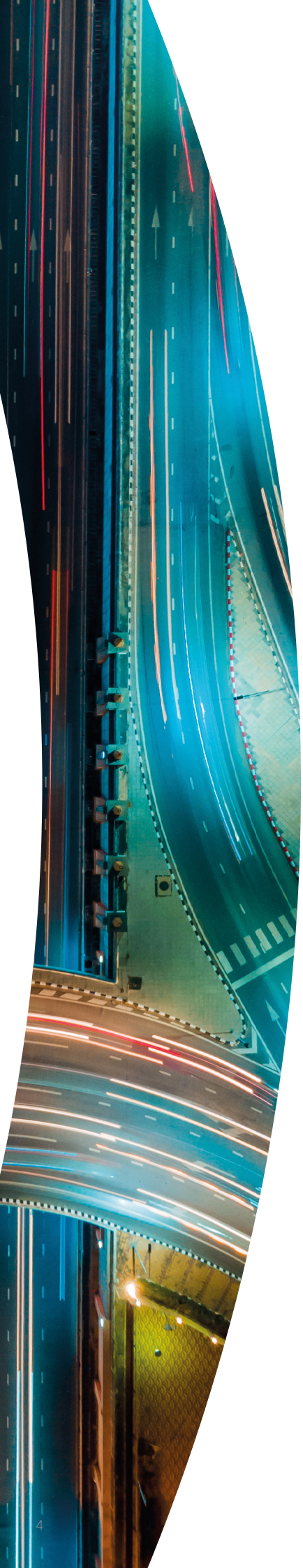


Table of contents

Foreword by partner organisations 3

Glossary 5

About this report 6

Summary of recommendations 7

Key facts about chronic kidney disease 12

About electronic patient-reported outcome measures for kidney care 14

- What are patient-reported outcome measures? 15
- What are electronic patient-reported outcome measures? 15
- What are the benefits of electronic patient-reported outcome measures? 16
  - Improving health services and patient outcomes 16
  - Helping kidney centres to follow national policy recommendations 18
  - Adding value to service improvements and research 21
- Collecting electronic patient-reported outcome measures as part of kidney care is feasible and acceptable 22
- Example ePROM intiatives 24

National collection of electronic patient-reported outcomes for UK kidney care: long-term vision and recommendations 26

- Long-term vision 27
- Recommendations for achieving the long-term vision 28
  - How we developed the recommendations 29
  - How the recommendations are organised 29
  - Overview of recommendations 30

References 39

Appendices 40

- Appendix 1: Personal stories of people using ePROMs 41
- Appendix 2: Suggestions for roadmap report from public consultation 44
- Appendix 3: Patient and healthcare professional requirements and preferences for the design of ePROM systems 47

Glossary

The terms in this glossary are underlined in the text where they first appear.

Term	Meaning
Business case	Plan to demonstrate that a project is the right choice in terms of strategy and value for money.
Chronic kidney disease	Long-term condition where the kidneys do not work as well as they should.
Contemporary item bank	Large collection of questions to select from when putting together a questionnaire.
Computerised adaptive test (CAT)	Flexible online questionnaire where a person's response to one question determines which question is shown next.
Digital inclusion	Situation where people are supported by policies and programmes to access and use digital technology (such as smartphones and the internet), regardless of their ethnicity, culture, age, income, or ability.
Electronic patient-reported outcome measures (ePROMs)	Online questionnaires that ask people how they feel about their health, their illness, and the treatments they receive. The results help people and their health professionals to make shared decisions about their care.
Haemodialysis	A type of treatment for people whose kidneys have failed. It is a way of replacing some of the functions of the kidney by using a machine to filter and clean the blood
Immunosuppressants	Drugs that lower the body's ability to reject a transplanted organ, such as a kidney.
Information governance	The effective use and management of an organisation's information. It describes the key rules and regulations that an organisation needs to follow when it creates, shares, and uses information.
Kidney centre	Centres that are often based within a hospital and where people receive specialist care for their kidney health.
Kidney community	The kidney community is a collection of groups of people who are: • Living with kidney disease • Carers of people who have kidney disease • Professionals who deliver, monitor, pay for, research, or improve kidney care.
Multimorbidity	The presence of two or more long-term health conditions
Patient outcomes	The results from care and treatments that patients receive.
Peer mentoring	Relationship where a peer mentor shares their knowledge, experiences, and skills with a mentee to help the mentee progress toward their goals
Primary care	Services that provide the first point of contact in the healthcare system, acting as the 'front door' of the NHS. Primary care includes general practice, community pharmacies, and dental and eye health services.
Qualitative research	Research that involves collecting and analysing non-numerical data (e.g., text, video, or audio) to understand concepts, opinions, or experiences.

Term	Meaning
Quantitative research	Research that involves collecting and analysing numerical data.
Randomised controlled trial	Study to test a treatment or intervention where people are placed into groups based on chance (i.e., randomly)
Secondary care	Services related to: • Planned or elective care, which usually takes place in a hospital. • Urgent and emergency care, including 999 and 111 services, ambulance services, hospital emergency departments, and out-of-hours GP services. Kidney centres form part of secondary care.
Side effects	Unwanted negative effects related to a drug or treatment.
Symptom burden	The impact of the type, number, frequency, and severity of symptoms on a person's physical and emotional wellbeing.
Underserved groups	Groups of people who do not have adequate access to healthcare, or do not benefit from healthcare as much as others.
Validated questionnaire	Questionnaires that have been tested to see if they measure what they were designed to measure.
Value-based commissioning	Planning and purchasing healthcare services that deliver and improve outcomes important to patients and the community.
Value proposition	Explanation of how something (a new product, a company, ePROMs) will be beneficial to those who use it.

About this report

This report presents recommendations for collecting electronic patient-reported outcome measures (ePROMs) for chronic kidney disease in the UK. This will help to put patients at the centre of kidney care and research in the UK, and contribute to better and fairer kidney outcomes.

This report covers all adults receiving care from a kidney centre in England, Wales, Scotland or Northern Ireland, regardless of their kidney disease stage or the treatment they receive.

The report does not cover:

- children and young people under the age of 18;
- adults receiving kidney treatment in primary care only; or
- questionnaires that measure people's experience of the health service, referred to as 'patient-reported experience measures' (PREMs), such as the Kidney PREM.

Summary of recommendations

On pages 8-10, we present the most important recommendations for what should be done in the short, mid and longer term to achieve a vision of collecting ePROMs for chronic kidney disease in the UK; page 11 shows a visual summary.

This vision aims to make kidney care and research more patient-centred, with better and fairer outcomes for people with kidney disease.

We have divided the recommendations between different groups of stakeholders. Together, these groups are the shared 'owners' of the vision. However, achieving the vision will be challenging, so all stakeholders will need to work together, especially because many recommendations depend on each other. Only if we consider them in combination, we can make the change that is needed for successful kidney ePROM collection in the UK.

Short term

(in the next 3 years)

All stakeholders

- Set up a national kidney ePROM working group to inform and oversee activities to achieve national collection of ePROMs.
- Set out a clear vision on what is needed for ePROM collection to lead to more responsive and more personalised kidney services.

Organisations and groups that represent people with kidney disease and their carers

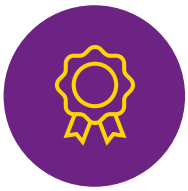
- Develop and signpost to resources and support networks to help people with kidney disease and their carers with accessing technology, and using and acting on ePROMs.

Kidney centres and organisations that represent kidney health professionals working in primary and secondary care

- Set up local multidisciplinary working groups and identify local champions (patients and professionals) to promote kidney ePROMs and support people to use them.

Organisations and people who monitor and commission kidney services

- Develop quality indicators for assessing kidney centres' ePROM collection efforts.



Organisations that help to deliver and improve the quality of kidney services

- Include ePROM collection into service improvement projects whenever possible.

Companies and organisations that supply IT systems or collect data for kidney services

- Make it possible for people with kidney disease to complete, review and share their ePROMs with others.

Researchers and funders of kidney research

- Assess how introducing ePROMs may impact health equality, and ask what patient need if they are to use ePROMs. This should especially include people who currently struggle to access good quality kidney care and those living with other long-term conditions.

Mid term

(in 4 to 6 years)

All stakeholders

- Organise a national campaign to communicate the value that ePROMs could offer. The content of the campaign should be based on research evidence and tailored to different stakeholders.

Organisations and groups that represent people with kidney disease and their carers

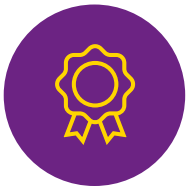
- Encourage a movement led by patients to communicate how ePROMs can put patients at the centre of kidney care and research, and how this can lead to better outcomes.

Kidney centres and organisations that represent kidney health professionals working in primary and secondary care

- Give staff enough time and resources to learn how to use ePROMs and make it part of their usual ways of working.

Organisations and people who monitor and commission kidney services

- Include ePROM collection within service specifications and/ or commissioning products as appropriate

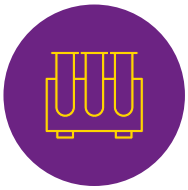


Organisations that help to deliver and improve the quality of kidney services

- Develop a regional strategy for promoting and introducing ePROMs in line with regional priorities, capabilities, and projects.
- Train implementation coordinators that understand the national kidney ePROM framework as well as the regional and local challenges and opportunities when introducing ePROMs.

Companies and organisations that supply IT systems or collect data for kidney services

- Design ePROM systems that:
  - follow the national kidney ePROM framework
  - follow recommendations informed by research, and
  - use existing systems so people do not have to log into a separate system for their ePROMs.



Researchers and funders of kidney research

- Strengthen the evidence on if ePROMs make a difference to the quality and costs of kidney care, health equality, and outcomes. To achieve this, do randomised controlled trials in the UK across all stages of kidney disease and all treatments.

Long term

(in 7 to 10 years)

All stakeholders

- Develop a national kidney ePROM framework that sets out:
  - the main purposes of ePROMs
  - the minimum ePROMs that need collecting, how often they need collecting, and who to collect them from.
  - IT standards for collecting, sharing and storing ePROM data
  - actions to manage the impact of ePROMs on kidney health equality
  - resources to support kidney centres with introducing ePROMs in their local area.

Organisations and groups that represent people with kidney disease and their carers

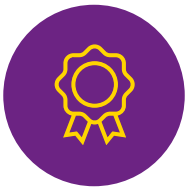
- Make sure the resources for using and benefitting from ePROMs keep meeting the needs of a broad and diverse group of people with kidney disease.

Kidney centres and organisations that represent kidney health professionals working in primary and secondary care

- Monitor kidney team members' ePROM use, and give them feedback on this as part of their continuous professional development.

Organisations and people who monitor and commission kidney services

- Put patients at the centre of resource planning and service delivery by using ePROMs for value-based commissioning.



Organisations that help to deliver and improve the quality of kidney services

- Put patients at the centre of service improvement by using ePROMs for assessing what patient needs are not being met.

Companies and organisations that supply IT systems or collect data for kidney services

- Store ePROM data centrally and link it to data on patients' experiences and clinical outcomes.

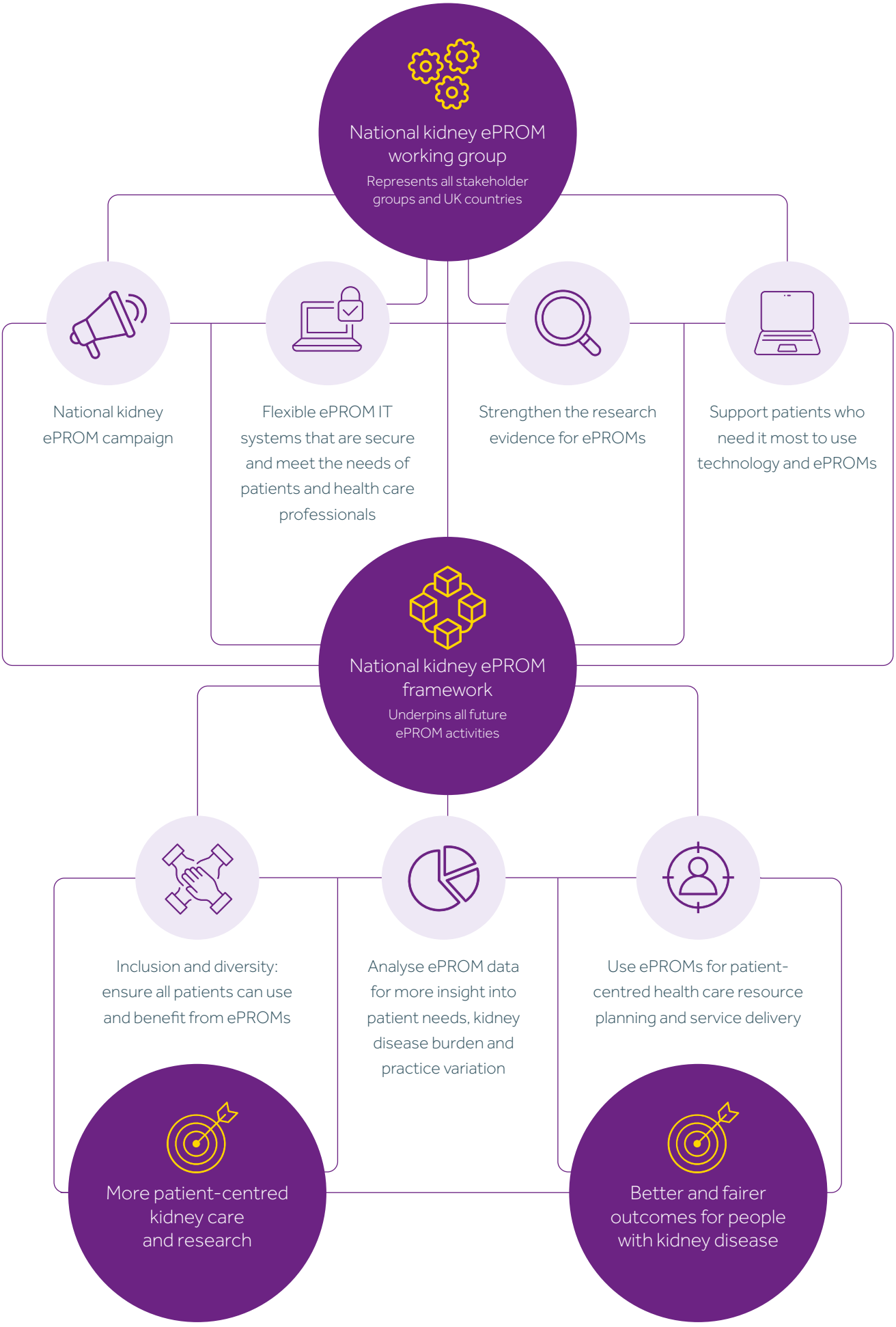
Researchers and funders of kidney research

- Analyse centrally stored and linked ePROM data to get more insight into:
  - the burden and impact of living with kidney disease;
  - patient needs that are not being met; and
  - unexplained differences across kidney centres and groups of patients.

Short term

Time

Long term



Key facts about chronic kidney disease

Chronic kidney disease in the UK[1]

Around 3 million people in the UK are living with chronic (long-term) kidney disease.

More than 68,000 of these people are receiving treatment for kidney failure.

Every year, between 40,000 and 45,000 people die early because of chronic kidney disease.

Quality of life and kidney symptoms[2–4]

Overall, people with chronic kidney disease, and especially those who receive dialysis, have a much poorer quality of life than people in general.

For people with chronic kidney disease, lack of energy and poor mobility (trouble getting around) are most likely to have a negative effect on their ability to do their usual activities.

Many people with chronic kidney disease experience several symptoms at the same time. This is true regardless of the stage of their kidney disease or the treatment they are receiving. The most bothersome symptoms that people report are:

- extreme tiredness and lack of energy;
- anxiety and depression;
- sexual problems;
- itching; and
- bone and joint pain.

Treating kidney symptoms[5,6]

Some people are not receiving treatment for their kidney symptoms, even though treatments are available. Often, this is because their symptoms have not been recognised. For example, among all people receiving haemodialysis, 1 in 5 who are (almost) always bothered by itching have not mentioned this to their healthcare professional, so they are not getting treatment for it.

It is difficult for kidney centres to monitor and treat symptoms in between patients' clinic appointments. This can worsen patient outcomes and lead to having to start kidney replacement therapy unplanned.

For some kidney symptoms, such as extreme tiredness and lack of energy, we need more data and research to find out what treatments work best.

Brian's story

Brian McEvoy, 86 years old, was diagnosed with kidney disease in 2015 and is now being treated with ambulatory peritoneal dialysis. Shortly before he started dialysis treatment, he took part in RePROM study to test the feasibility of ePROM system for patients with advanced kidney disease at Queen Elizabeth Hospital Birmingham, UK (see Example of an ePROM project on page 24).

The following quotes illustrate Brian's experiences of taking part in the RePROM study and his thoughts about ePROMs.

> *The hospital has an internet site called 'MyHealth' and I'm able to use that to find out the results of my blood tests [...] and the questionnaires were carried out on that, I could get to them quite easily. They listed a dozen or so symptoms of kidney disease [...] and they were all very relevant.*

> *One of the nicest things was that if I said I was having a lot of problems with sleeplessness or whatever, within a day or two I'd get a phone call from the hospital picking up on that, having a discussion about it and finding a solution to it [...] It was also just very reassuring that someone was watching over the problems.*

> *It depends really how capable you are at filling in forms on computer, you know, ticking boxes and uploading something. Not everybody can do that.*

> *There's a chance it might have made me look for things and think about things that weren't actually wrong with me. It said: 'are you suffering from itchiness', and I started to think 'oh, perhaps I am itchy.*

About electronic patient-reported outcome measures for kidney care

What are patient-reported outcome measures?

A patient-reported outcome measure (PROM) is a validated questionnaire that asks an individual how they feel about their health, their illness, or the treatment they are receiving[7]. A PROM can ask people what they think and feel about their:

- symptoms;
- side effects of treatment, such as immunosuppressants after a kidney transplant;
- quality of life; and
- mental wellbeing.

For many people, these aspects of living with kidney disease are at least as important as the aspects that are measured more objectively; for example, by laboratory tests or blood pressure tests[8].

An example of a PROM about symptoms is shown in Figure 1.

PROMs do not include questions that ask people about their experience of the health service. For this, we use patient-reported experience measures (PREMs), such as the Kidney PREM – a yearly national survey of kidney patients[9]. We do not look at PREMs in this report.

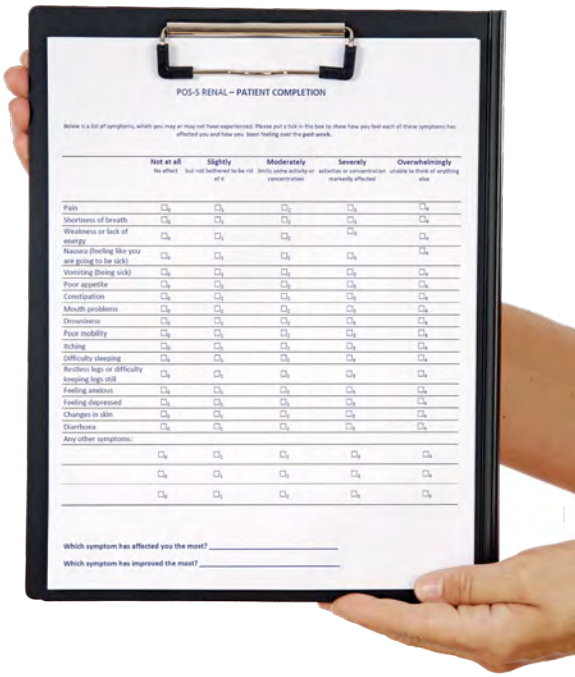
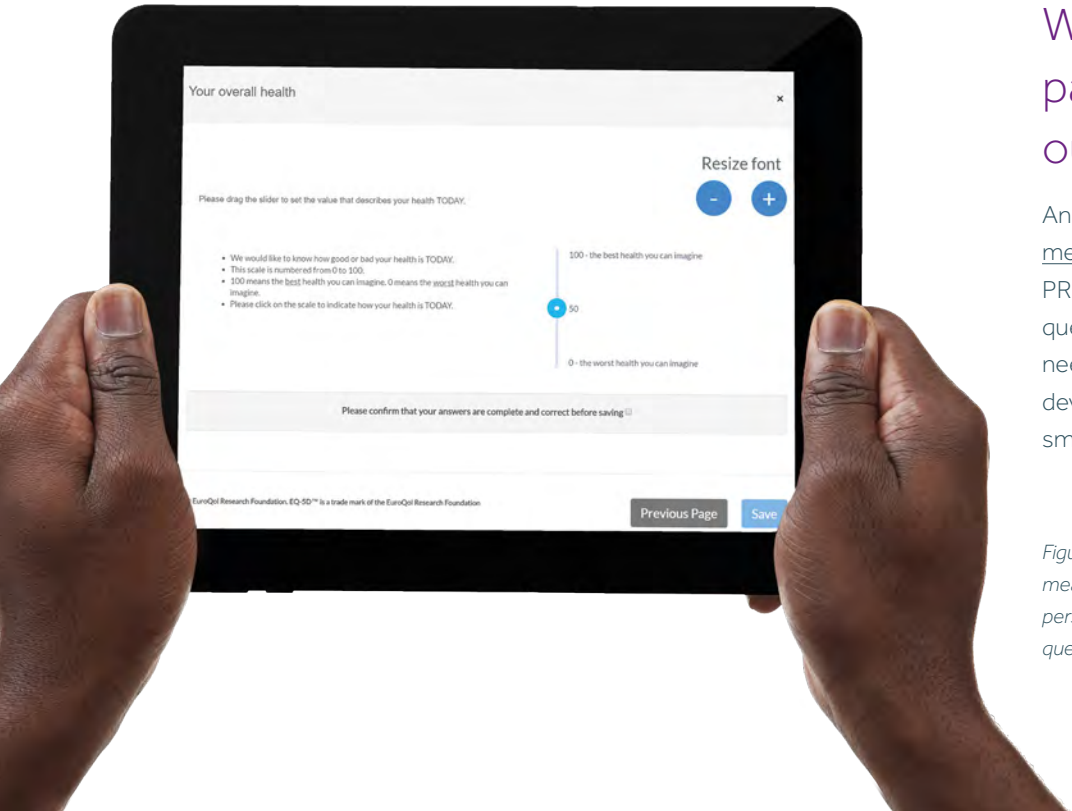


Figure 1: A patient-reported outcome measure (PROM) that asks people with kidney disease if (and how badly) they are bothered by certain symptoms



What are electronic patient-reported outcome measures?

An electronic patient-reported outcome measure (ePROM) is a digital version of a PROM. A common example is an online questionnaire (see Figure 2). People need to complete ePROMs on a digital device, such as a computer, tablet, or smartphone.

Figure 2: An electronic patient-reported outcome measure (ePROM) that collects people's perspectives on their health as part of an online questionnaire on quality of life

What are the benefits of electronic patient-reported outcome measures?

Improving health services and patient outcomes

Using **ePROMs could support** patients and kidney teams to make **shared decisions** about their care and treatment, **improving care** that people with kidney disease receive. In turn, this could lead to **better outcomes for people with kidney disease**. Figure 3 explains this.

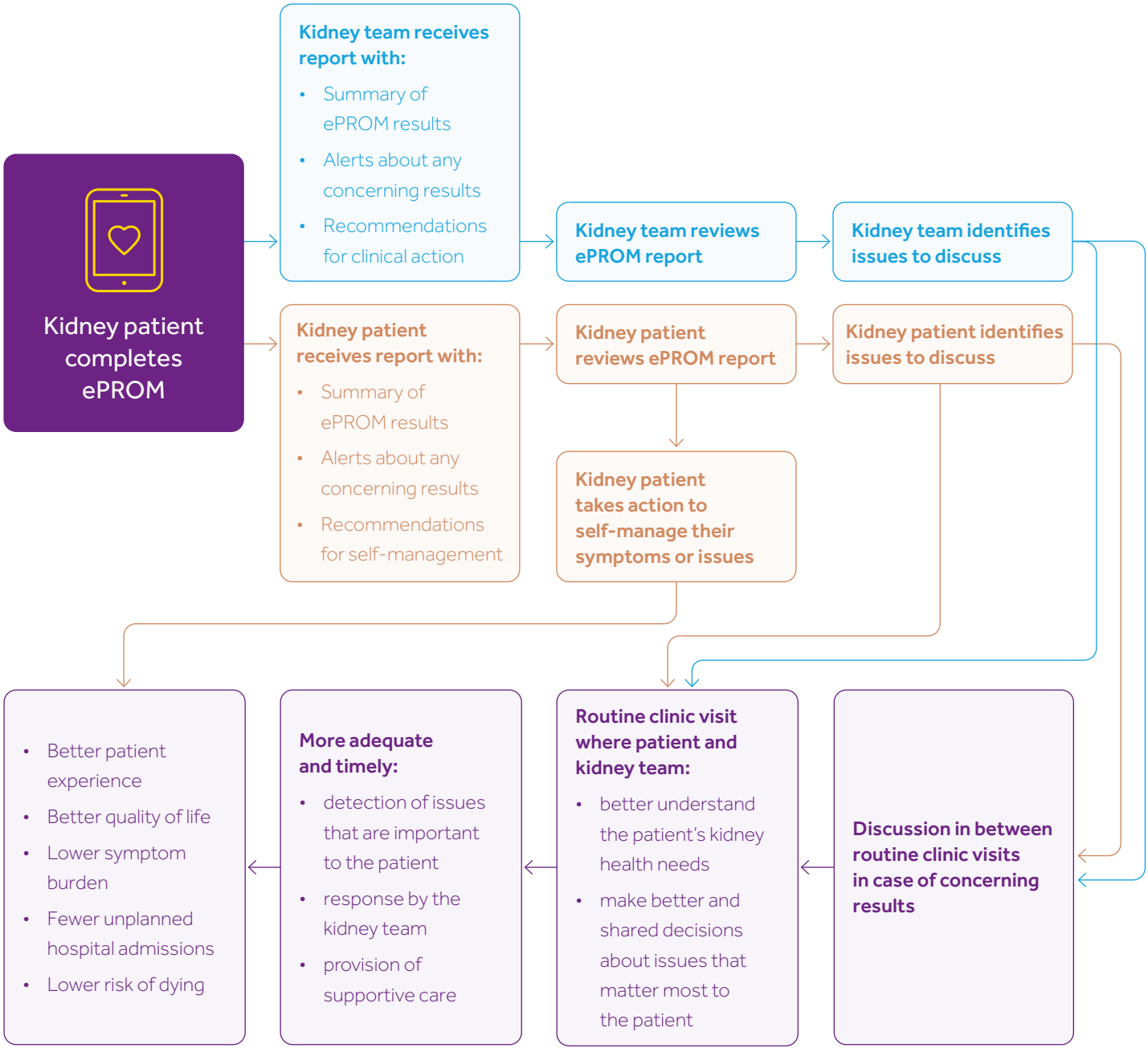


Figure 3: How ePROMs can support shared decision making and improve care and outcomes for people with kidney disease[10].

There is strong evidence of these benefits when using ePROMs with people with cancer[11,12]. Asking people with cancer to complete an ePROM as part of their routine care helps to make services more consistent. It also makes it easier to have conversations with people about the outcomes that are important to them during their clinic consultations. The benefits are even greater if reporting the ePROM results back to the patient and their healthcare team.

These benefits help to better detect and control symptoms and other issues. They also help to offer people better supportive care. This leads to:

- a better experience as a patient;
- a better quality of life;
- a lower symptom burden; and
- less chance of dying or having an unplanned stay hospital.

Many people think **ePROMs could have similar benefits for people with chronic kidney disease**[13,14]. For example, people with kidney disease and healthcare professionals say that using ePROMs could:

- improve communication and relationships between patients and professionals;
- provide insight into what is most important for each person with kidney disease;
- help with detecting symptoms; and
- support people to monitor and manage their own symptoms[14].

Healthcare professionals also see ePROMs as important in digitising health services so they can monitor people remotely between appointments and provide personalised follow-up plans.

Researchers in Canada have recently looked at using ePROMs in haemodialysis services[15]. They found that ePROMs can only lead to better care if patients and kidney teams understand:

- what the ePROM is for;
- why it is worth using; and
- how to use it to communicate and make shared decisions.

Researchers are currently collecting evidence on whether using ePROMs can lead to better outcomes for people with kidney disease. As part of this work, people with kidney disease are taking part in randomised controlled trials in Denmark[16] and Australia and New Zealand[17]. So far, no ePROM trials have been done in the UK.

Although using an ePROM could improve kidney care and outcomes, **some groups of people are less likely to benefit from ePROMs than others**. In particular, people who are less able – or less willing – to complete an ePROM online are less likely to benefit[18–21]. These may include:

- older people;
- people from an ethnic minority background;
- people with a lower level of education;
- people with limited physical or cognitive abilities; and
- people who live in a socially or economically deprived area.

To make sure nobody is left behind and avoid adding to inequalities in kidney health, we need to make sure kidney ePROMs meet the needs of these diverse groups of people. Our recommendations emphasise the importance of this (see recommendations in theme 3, page 34).

Helping kidney centres to follow national policy recommendations

Making ePROMs part of health services can help kidney centres follow the recommendations made in national policies. For example, policies that recommend engaging patients in their care, enabling shared decision making, and educating patients. For more examples, see Table 1.

Table 1: How ePROMs in kidney services can help with policy recommendations in England

National policy	Recommendation	ePROMs can support this by...
Getting It Right First Time	• Ensure that patient experience and shared decision-making are central to the planning and delivery of kidney services.	• Providing information that supports transitions between kidney stages and treatments. • Supporting shared decision-making (see Figure 3), especially as part of advanced kidney care.
NICE and NHS England guidance on shared decision making	• Before a discussion, offer people access to resources in their preferred format (for example, a booklet, flyer, or app) to help them prepare for discussing options and making shared decisions. • Agree an 'agenda' at the start of each discussion to prioritise together what is important to discuss.	• Helping patients with identifying the issues they want to discuss with their kidney team as part of their clinic consultation (see Figure 3).
NHS England long-term plan	• Engage patients in decisions about their health and wellbeing. • Make better use of data and digital technology. • Enable people to contribute data to their own health records.	• Helping patients manage their health and play an active role during consultations (see Figure 3). • Making ePROM results available in clinical and personal health records, so patients and kidney teams can use them to make better, shared decisions about treatment. • Using ePROM collection (on tablets or a smartphone app, for example) as a pilot where kidney centres embed digital patient-facing technology into the service.
National Institute for Clinical Excellence (NICE) guidance for assessment and management of chronic kidney disease	• Offer patient education programmes providing knowledge about kidney symptoms. • Give adults access to their medical data through information systems to encourage and help them to self-manage their chronic kidney disease.	• Helping patients to understand if (and how) the symptoms they experience are related to their kidney disease. • Making ePROM results available in personal health record systems (such as Patients Know Best), together with laboratory results, medication prescriptions and other clinical information to support people to manage their kidney health.
Medicines & Healthcare products Regulatory Agency (MHRA) dialysis guidance	• Base patients' fluid management on consistent assessment of weight gain between dialysis sessions, pre- and post-dialysis blood pressures and patient-reported symptoms.	• Supporting patients to monitor their symptoms at home in between dialysis sessions.
NHS England Outpatient Recovery and Transformation Programme	• Adopt a personalised approach to outpatient follow-up where patients' care is tailored to their individual clinical needs, circumstances, and preferences.	• Giving people the opportunity to report their symptoms and other relevant information at home. • Using the reported information to support them and the kidney team to decide when to arrange a follow-up appointment.

Mary's story

The Kidney Dietetics Service team at Hull University Teaching Hospitals NHS Trust are working to use ePROs for nutritional screening. Mary-Wilson Brown, clinical lead renal dietician at the trust, has been overseeing the collection of ePROMs for kidney patients to assess their diet and nutrition via Patients Know Best, the national portal for people with kidney disease.

Mary explained that all kidney patients receive the nutritional screening ePROM, followed by additional assessments tailored to individual patients based on their symptoms, stage of kidney disease, and treatment modality. After that, the team arranges a dietary review appointment depending on the patient-reported nutrition risk score.

The following quotes illustrate Mary's experiences of administering ePROMs and working with ePROM data:

> *We have a bowel health questionnaire that we send to patients and they fill it out and send it back to us and there's dietary intake assessments that we can ask the patients to complete. So there's a quick 24 hour recall one, but then there's a more in-depth 5-day food diary."*

> *We may not be expecting to see a patient for a few months, but if the patient themselves finds that are a bit concerned about like their oral intake, they can then fill out that form when they choose and then we'll act on it sooner rather than waiting."*

> *When they signed up to Patients Know Best the patients had to agree to how their data is going be used [...] We're always very clear that the reason why we're asking for that information to help advise them and make sure they're diets nutritionally adequate. I think they're always aware why we're requesting the information from them."*

> *If we know that we are seeing a patient in-clinic, we can send them a request to complete a diet history before the appointment. So instead of taking the diet history, we can actually spend that time giving the appropriate dietary advice."*

> *It's part of our normal practice now. It's an easy way for the patients to be able to provide that information at a time that's convenient for them instead of having to wait until they have a diet appointment."*

Adding value to service improvements and research

ePROMs data collected as part of routine clinical care will be even more valuable if we can use it for secondary purposes[7,22]. In this context, a secondary purpose is when the data is used for something other than informing the provision of direct care. For example, including ePROMs in the national audit of kidney services could help researchers and kidney care professionals to identify:

- what needs of kidney patients are not being met;
- unexplained differences between kidney centres or groups of patients in how well these needs are being met.

This information can be used to:

- **improve care quality** through local, regional and national projects; and
- help commissioners and healthcare providers **put patients at the centre of resource planning**.

Information collected through ePROMs as part of routine care can also help researchers to gain more insight into the burden and impact of living with kidney disease. Routinely collecting ePROMs also makes it easier to use them in randomised controlled trials to evaluate the effect of new treatments. PROMs are increasingly being included as outcomes for kidney[23] and to help regulators decide whether to approve new kidney treatments. This supports the use of ePROM data for **kidney research**.

Collecting electronic patient-reported outcome measures as part of kidney care is feasible and acceptable

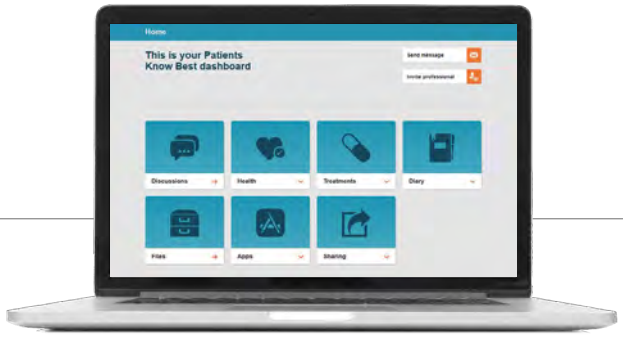
Many **people with kidney disease and healthcare professionals think it is feasible and acceptable to use ePROMs as part of kidney care**. They would rather use them electronically than on paper because:

- it is cheaper;
- the information collected is more accurate and complete; and
- automated reminders and alerts can help people manage their health and make decisions about treatment[24].

Kidney services in the UK are more digitised than other parts of the NHS. All kidney centres have an electronic patient record system that is linked to the UK Renal Registry. Several systems that are already in use would enable people with kidney disease to enter ePROM information into their own medical record and view it alongside other information, such as prescriptions and laboratory results (see Box 1). **This puts UK kidney services in a strong position to consider collecting ePROMs nationally.**

Research in kidney disease and other illnesses shows that **using ePROMs does not lead to people visiting the clinic more often (either planned or unplanned) or needing longer appointments;** some studies even found that people seemed to need fewer visits[25–28]. This contradicts the concerns that are often raised about ePROMs leading to more use of healthcare services.

Many research projects have confirmed that collecting kidney ePROMs is feasible and acceptable. These include research in the UK[25,29], the Netherlands[30], Denmark[16], Sweden[31], and Australia and New Zealand[32]. We have included two of these in this report as examples of kidney ePROM initiatives (on pages 24 and 25). We have also included five personal stories: two in the main text and three in Appendix 1. The stories show how kidney patients and healthcare professionals have gone about completing and using ePROMs. Despite our best efforts, we were not able to connect with patients from ethnic minority groups who had used ePROMs. This shows that we need to do more to find out how ePROMs may affect equality in kidney health (see recommendations in theme 4, pages 35-36).



Patients Know Best

- Patients Know Best (PKB) is Europe's biggest platform for personal health records. It allows patients and healthcare professionals to access health information in real time.
- In the UK, people can access PKB on the NHS app, so they do not need a separate username and password.
- In 2020, the UK Kidney Association signed a contract with PKB to replace Renal PatientView as the system for people with kidney disease.
- Through PKB, people with kidney disease can view information about them that is entered or held by primary, secondary, mental, and social care providers.
- People with kidney disease can also enter and upload data themselves, such as ePROMs, blood pressure measurements taken at home, and Fitbit data.
- PKB combines information entered by a person and their healthcare providers into a single, unified copy of that person's health data. This allows people to access all their health data through one online portal. This can help them to manage their own health and wellbeing.
- Healthcare professionals can access the same unified copy, even if their hospital has not registered for PKB. This helps them make better clinical decisions, manage care more effectively, and help people continue to live independently.
- **For more information, see the PKB website: patientsknowbest.com/renal**

MyChart

- MyChart is another platform for personal health records. It is part of an electronic patient record system provided by Epic Systems, a global software company.
- Several hospitals in the UK – including all kidney centres in Northern Ireland – use Epic.
- In MyChart, a person can access all the health information about them that has been entered by healthcare organisations that use Epic. They can extend this access to people in their family and healthcare providers from other organisations that use Epic.
- People can use the symptom checker in MyChart to enter their symptoms, ask questions about them, and get recommendations for care.
- People and their care teams can communicate over the MyChart messaging service. People can also book and manage appointments.
- MyChart's Care Companion helps people follow the care plan they agreed with their doctor. It sends medication reminders, offers educational information and suggests tasks to help people monitor their health.
- **For more information, see the MyChart website: www.mychart.com**

Note: Other similar local, regional and national solutions may also be available or under development

Box 1: Examples of systems where patients can report ePROMs and view their results alongside other information on their kidney health

Example ePROM intiative 1:

RePROM
Renal Electronic Patient Reported Outcome Measures

When? 2019–2020

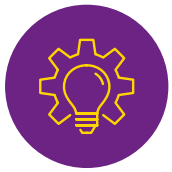
Why? To look at how feasible it is to use ePROMs to manage kidney symptoms better.

Where? An outpatient kidney clinic in Birmingham.

Who? People with advanced kidney disease (stage 4 or 5) who were not on dialysis.

Approach to collecting ePROMs

- People with advanced kidney disease sent information about their symptoms remotely, using any device that could connect to the internet. There was also space in the questionnaire for them to mention other symptoms or problems they were having.
- People accessed the ePROM system through an existing hospital patient portal called 'myHealth'.
- People completed an ePROM about their symptoms at least once a month. They could complete extra ePROMs whenever they wanted to.



Including ePROMs in clinical workflows

- People could view the ePROM results as graphs and in tables. The patients accessed them in myHealth, and the kidney team accessed them through the electronic patient record system.
- Patients received automated advice about how to manage their symptoms. The advice was tailored to their ePROM scores.
- The ePROM results were included in the electronic patient records and made available to the kidney team in real time.
- If a patient reported a severe symptom, an automated notification was sent to the patient and the kidney team.

What worked well?

- Patients and members of the kidney team rated the structure, clarity, and coverage of the system ePROM as good.
- Patients appreciated the secure login process.
- People felt reassured that their ePROM results, including their free-text comments, were being monitored and responded to promptly or discussed at the clinic with their kidney team.

What did not work so well?

- Technical issues meant some patients did not always receive emails reminding them to complete their ePROM.
- Patients were unclear about which ePROM they should complete and when.
- People were confused about how to view the self-management advice and how to navigate different sections of the ePROM system.
- Some patients had problems submitting their ePROM results.

Perceived value

- Patients reported that the advice around symptoms and self-management helped alleviate anxiety around the symptoms they were experiencing.
- The research data from the RePROM study suggests that people who reported their symptoms using the ePROM did not need to use as many healthcare resources, including visits to the kidney clinic.

More information

Main findings of the RePROM study: **http://bmjopen.bmj.com/cgi/content/full/bmjopen-2018-026080**

Example ePROM intiative 2:

Symptom monitoring with feedback (SWIFT)

When? August 2020–2023

Why? To look at the feasibility of using ePROMs to manage kidney symptoms better.

Where? All haemodialysis units in metropolitan, regional and rural centres in all Australian states.

Who? People receiving haemodialysis at a kidney centre.

Approach to collecting ePROMs

- People completed an ePROM about their symptoms every three months. They also completed an ePROM about their quality of life every six months.
- People completed their ePROMs using an online ePROM system. A unique QR code linked each ePROM to the patient's personal dialysis folder.

Including ePROMs in clinical workflows

- Patients received a copy of their ePROM results if they provided their email address. Patients without their own email address could use a carer's email address.
- The kidney team (the nurse unit manager and the patient's treating nephrologist) received an email every two weeks with a summary of any severe symptoms and links to evidence-based guidelines for managing those symptoms.
- When severe symptoms were flagged in the email, the kidney team contacted the patient to follow it up.
- All the ePROMs were available in English and seven other languages. The aim was to make them more accessible for patients who did not speak English.

What worked well?

- Nurse champions helped to encourage more patients to complete and use the ePROMs.

What did not work so well?

- Technical issues with the ePROM system sometimes made it harder to complete the ePROMs.
- There were not enough resources to incorporate the ePROMs into clinical workflows.

Potential value

- SWIFT was a first step towards using ePROMs as part of kidney health services.
- It emphasised the importance of symptoms and managing symptoms as part of kidney care.
- It led to better communication between patients and the kidney team.

More information

Main findings of the SWIFT feasibility study:
https://pubmed.ncbi.nlm.nih.gov/35085687

National collection of electronic patient-reported outcomes for UK kidney care: long-term vision and recommendations

Long-term vision

Box 2 describes the vision for how we want national collection of ePROMs for kidney disease to look like in 10 years. The aim is to make kidney care and research in the UK more patient-centred, with better and fairer outcomes for people with kidney disease.

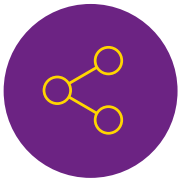
In 10 years' time, everyone who receives care from a kidney centre in the UK can:

use ePROMs to report issues that matter to them, when it matters;

access and use the technology needed to report and review their ePROMs;

routinely discuss their ePROMs results with the kidney team, just as is done now with blood tests;

benefit from completing an ePROM, regardless of their background and skills;



share their ePROM results with trusted members of their support network, for example, their carers, GP, and other care providers; and

give permission to use their ePROM results for secondary purposes, such as research, if they wish to.

This will help to make kidney care and research more patient-centred, and contribute to better and fairer outcomes for people living with kidney disease.

Box 2: Long-term vision for collection of ePROMs in the UK

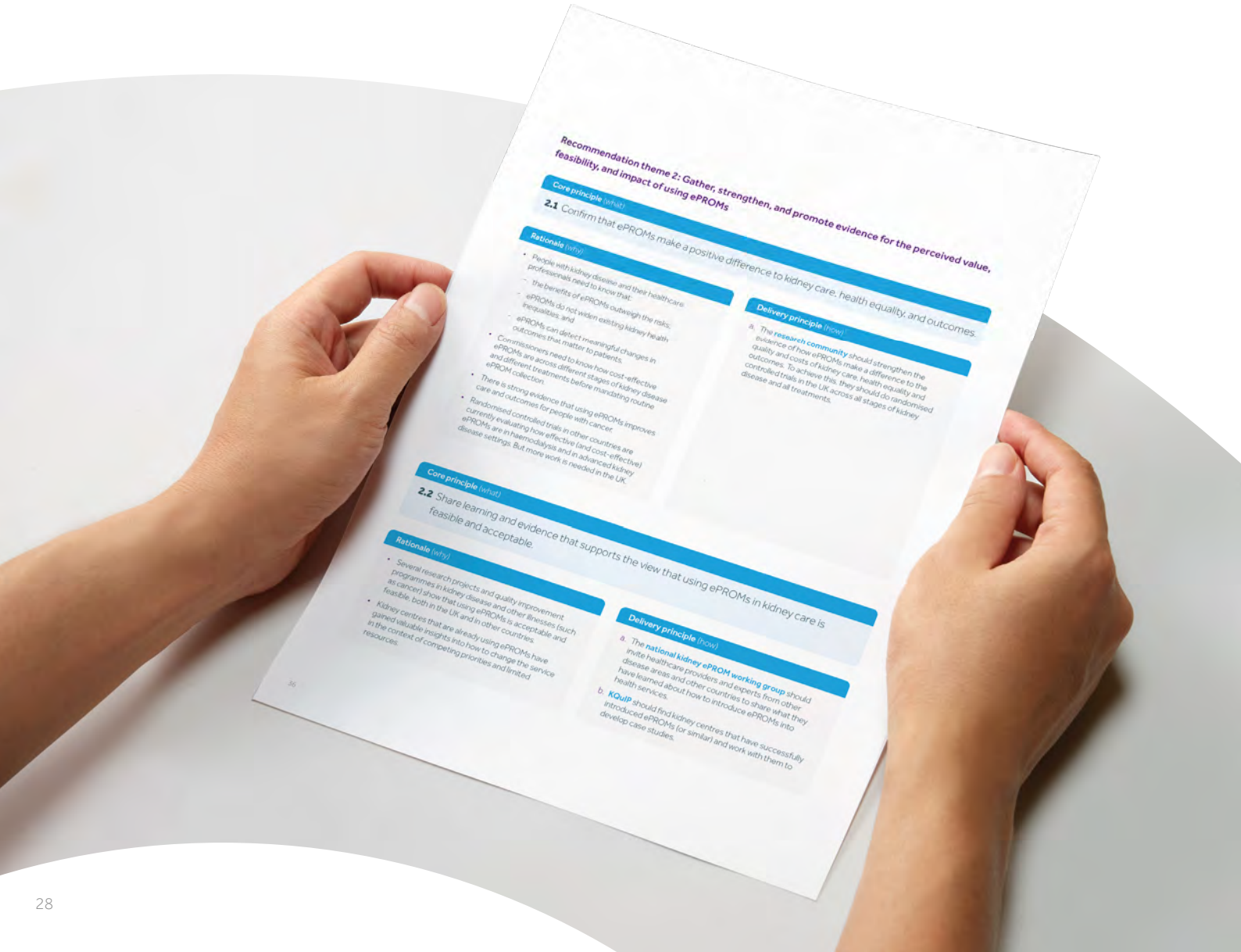
Recommendations for achieving the long-term vision

Achieving the long-term vision will be challenging, so all stakeholders will need to work together.

By 'stakeholders', we mean:

- people with kidney disease and their carers;
- kidney health professionals working in primary and secondary care;
- organisations that monitor, commission or improve the quality of kidney services;
- companies that supply IT systems and collect data for kidney services;
- funders of kidney research (government, charities, pharmaceutical companies); and
- ePROM researchers and experts.

Together, these stakeholder groups are the shared 'owners' of the vision.



How we developed the recommendations

All the stakeholder groups helped to develop the recommendations for achieving the long-term vision. They did this by taking part in the following activities:

- Individual interviews: 18 representatives from the stakeholder groups shared their views on what would be needed to start collecting kidney ePROMs nationally.
- The national ePROM summit: 58 people attended this full-day online event, where they heard from plenary speakers and worked together in breakout groups.
- A public consultation on a draft of this roadmap: nine groups of patients and professionals provided over 100 suggestions (see Appendix 2). We used these suggestions to refine the recommendations and the report.

During the public consultation, people told us that the following things are most important for success:

- Getting buy-in from – and joint leadership between – patients and professionals at all levels of the kidney service.
- Making funding, staff, and supporting materials available for introducing and using ePROMs.
- Limiting the extra burden on staff, especially nurses.
- Making sure ePROMs do not add to inequalities in kidney health.

How the recommendations are organised

The rest of this report presents an overview of the recommendations for how the UK kidney community can start collecting ePROMs over the next 10 years. The recommendations are set out under five themes:

1. Encourage national stakeholder groups to work together to promote, inform and support the introduction of ePROMS.
2. Gather, strengthen, and promote evidence for the perceived value, feasibility and impact of using ePROMs.
3. Be flexible about how to collect, report and store ePROM data, and make use of existing IT systems.
4. Make sure everyone with kidney disease can benefit from ePROMs, regardless of their background or skills.
5. Make sure kidney centres have the support, resources and flexibility they need to introduce ePROMs in their local area.

Each theme contains between two and four recommendations. Each recommendation includes:

- a 'core principle', which explains what the recommendation is;
- a 'rationale', which explains why the recommendation is important and what we know about how best to address it; and
- a 'delivery principle', which suggests how specific stakeholders can take the recommendation forward.

You can find a summary of the recommendations on pages 30–38. This includes a timeline to show which delivery principles could be put into practice in the short, medium and longer term. It also makes clear that most of the recommendations depend on each other. We should consider them in combination so that we achieve the system-level change that is needed for successful national kidney ePROM collection.

Overview of recommendations

Recommendation theme 1: Encourage national stakeholder groups to work together to promote, inform and support the introduction of ePROMS

Core principle (what)

1.1 National groups of patients and professionals should join forces and use their leadership and influence to promote ePROMs.

Rationale (why)

- The kidney community has strong, influential national stakeholder groups, including the UK Kidney Association, Kidney Care UK, the National Kidney Federation and Kidney Research UK. They all want better care and outcomes for people with kidney disease in the UK.
- Sharing involvement and ownership across these groups will build momentum for collecting kidney ePROMs throughout the UK.

a. Collecting ePROMs nationally would support value-based commissioning by encouraging kidney services to put patients at the centre, personalise care, and achieve and improve outcomes that matter to patients.

Delivery principle (how)

a. **All national stakeholder groups** should work together to set up a national kidney ePROM working group. The working group should:
   - inform and oversee activities that will help achieve the national collection of ePROMs for kidney care and research; and
   - include representatives from all the stakeholder groups listed in 'Recommendations for achieving the long-term vision' (page 28) across all four UK nations.

b. The **Clinical Reference Group** for renal services should consider including ePROMS (once available) within service specifications and/or commissioning products as appropriate.

Core principle (what)

1.2 Develop a national ePROM framework to guide regional and local ePROM projects.

Rationale (why)

- Ensuring ePROM data can be used for secondary purposes, such as research and regulation, requires some standardisation of ePROM collection.
- The international Standardised Outcomes in Nephrology (SONG) project is developing sets of core outcomes for research[23]. All SONG outcome sets include PROMs, as do many outcome sets used by regulators.
- Research shows that kidney patients and professionals do not always understand the purpose of ePROMs.
- Service improvements are more likely to be successful if they are aligned to wider system priorities and national policies (see Table 1).
- The 2018 Kidney Health Inequalities report[33] highlights several disadvantaged groups who struggle to access good quality kidney care. Introducing ePROMs may widen these inequalities.

Delivery principle (how)

a. The **national kidney ePROM working group** should develop a national kidney ePROM framework. The framework should include the following information:
   - the main purposes of ePROMs and how these purposes are linked to wider system initiatives and national priorities and policies (see Table 1 and delivery principle 5.3c);
   - the minimum ePROMs that need collecting, how often they need collecting, and who to collect them from. The minimum ePROMs should be selected while considering:
     - widely accepted core outcome sets for research and regulations; and
     - the fact that many people with kidney disease also live with other long-term conditions (see recommendation 2.4);
   - IT standards for collecting, sharing and storing ePROM data (see recommendation 3.1);
   - actions for minimising the negative and maximising the positive impact of ePROMs on kidney health inequalities (see recommendations under theme 4);
   - resources to support kidney centres with introducing ePROMs in their local area (see recommendations 5.2 to 5.4).

Core principle (what)

1.3 Use the existing national and regional structures for providing and improving kidney services to shape and support the roll-out of ePROMs.

Rationale (why)

- From 2023, kidney services will be coordinated by Regional Operational Delivery Networks. Working with regional commissioners, these networks will be best placed to assess what people in their region need if they are to benefit from ePROMs.
- The Kidney Quality Improvement Partnership (KQuIP) is an established structure for improving quality. Drawing on its success, KQuIP could help join up the use of ePROMs across projects.

Delivery principle (how)

a. Using the national ePROM framework, KQuIP should work with **Regional Operational Delivery Networks** and **regional commissioners** for kidney services to develop a regional strategy for promoting and introducing ePROMs in line with regional priorities, capabilities, and projects.

b. **KQuIP** should include ePROMs in their projects whenever possible. This is the first step towards putting ePROMs at the heart of assessing and improving services.

Recommendation theme 2: Gather, strengthen, and promote evidence for the perceived value, feasibility, and impact of using ePROMs

Core principle (what)

2.1 Confirm that ePROMs make a positive difference to kidney care, health equality, and outcomes.

Rationale (why)

- People with kidney disease and their healthcare professionals need to know that:
  - the benefits of ePROMs outweigh the risks;
  - ePROMs do not widen existing kidney health inequalities; and
  - ePROMs can detect meaningful changes in outcomes that matter to patients.
- Commissioners need to know how cost-effective ePROMs are across different stages of kidney disease and different treatments before mandating routine ePROM collection.
- There is strong evidence that using ePROMs improves care and outcomes for people with cancer.
- Randomised controlled trials in other countries are currently evaluating how effective (and cost-effective) ePROMs are in haemodialysis and in advanced kidney disease settings. But more work is needed in the UK.

Delivery principle (how)

a. The **research community** should strengthen the evidence of how ePROMs make a difference to the quality and costs of kidney care, health equality and outcomes. To achieve this, they should do randomised controlled trials in the UK across all stages of kidney disease and all treatments.

Core principle (what)

2.2 Share learning and evidence that supports the view that using ePROMs in kidney care is feasible and acceptable.

Rationale (why)

- Several research projects and quality improvement programmes in kidney disease and other illnesses (such as cancer) show that using ePROMs is acceptable and feasible, both in the UK and in other countries.
- Kidney centres that are already using ePROMs have gained valuable insights into how to change the service in the context of competing priorities and limited resources.

Delivery principle (how)

a. The **national kidney ePROM working group** should invite healthcare providers and experts from other disease areas and other countries to share what they have learned about how to introduce ePROMs into health services.

b. **KQuIP** should find kidney centres that have successfully introduced ePROMs (or similar) and work with them to develop case studies.

Core principle (what)

2.3 Promote available evidence of the value that different stakeholders see in kidney ePROMs.

Rationale (why)

- Evidence needs to convince both hearts and minds. It needs to make a case for impact and cost saving, as well as why ePROMs matter to people.
- Research shows that all stakeholders can see the value of ePROMs for kidney disease and other long-term conditions. Even so, they may have different perspectives on what 'value' means.

Delivery principle (how)

a. The **national kidney ePROM working group** should organise a national campaign to communicate the value that ePROMs could offer. They should base the content on research evidence and tailor it to different stakeholders.

b. **Kidney patient organisations** should consider encouraging a movement led by patients to communicate how ePROMs can put patients at the centre of kidney care and research, and how this can lead to better outcomes.

Core principle (what)

2.4 Establish evidence for the impact of ePROMs across diseases, rather than for kidney disease alone.

Rationale (why)

a. Many people with chronic kidney disease have other long-term conditions too (that is, they live with multimorbidity). They need a person-centred approach rather than a disease-centred approach.

- ePROMs need to ask about a wide range of symptoms and issues that are common across diseases, so they are relevant for people who have kidney disease and other long-term conditions.
- We do not know how relevant kidney ePROMs may be to other diseases.
- Establishing evidence that covers other conditions will help us better understand and manage multimorbidity among people with kidney disease.

Delivery principle (how)

a. The **research community** should systematically review the kidney ePROMs that are available and assess how relevant they are to other conditions, with help from experts in other clinical disciplines. This can inform the ePROMs chosen for a minimum set as part of the national kidney ePROM framework (see delivery principle 1.2a).

b. The UK **Renal Data Collaboration** should collect ePROMs from people with kidney disease who are also living with other long-term conditions. This will pave the way for research into how multimorbidity affects kidney patients' lives and identify opportunities to improve their care and outcomes.

Recommendation theme 3: Be flexible about how to collect, report, and store ePROM data, and make use of existing IT systems

Core principle (what)

3.1 Those who design ePROM systems should standardise data collection for use by different people, kidney centres and IT systems, while making the systems flexible enough to meet the needs of individuals and centres.

Rationale (why)

- Researchers have found out what features of ePROM systems patients and healthcare professionals want and need.
- ePROMs should measure what matters to patients, but this may change over time and differ from one person to the next depending on their characteristics and their kidney health.
- Existing IT systems already comply with requirements for handling health data, which makes it easier to collect ePROM data securely. For example, Patients Know Best is integrated into the NHS app; MyChart is part of the Epic electronic patient record system.
- Several systems in the UK have the functions needed for people to be able to complete and review ePROMs (see Box 1).
- Using contemporary item-bank and computerised adaptive test (CAT) technology for ePROMs makes it possible to:
  - tailor ePROMs to individuals, including for people with less common, more complicated kidney conditions;
  - minimise the number of questions, which reduces the time and effort to complete an ePROM; and
  - add questions to a 'bank' as preferences and health services change.

Delivery principle (how)

a. **Suppliers of IT systems for kidney services** should work with the **national kidney ePROM working group** to design ePROM systems that:
   - align with the national kidney ePROM framework;
   - follow recommendations informed by research (see Appendix 3);
   - where possible, use existing systems so people do not have to log into a separate system when completing or reviewing their ePROMs; and
   - use item-bank and computerised adaptive test (CAT) technology to collect ePROMs.

Core principle (what)

3.2 ePROM data from all kidney patients in the UK should be stored securely and centrally to help with linkage to other data sources and with analysis for secondary purposes.

Rationale (why)

- It is widely agreed that ePROM data would have value beyond enhancing direct patient care.
- The infrastructure of the UK Renal Data Collaboration can be used to securely store and transfer data from kidney patients in the UK.
- For people to trust ePROMs, they need to know who uses their ePROM data and what they use it for.
- It should be easy for people to opt out of their ePROM data being used for secondary purposes.

Delivery principle (how)

a. The **UK Renal Data Collaboration** should use their infrastructure for storing ePROM data centrally and linking it to data on patients' experiences and clinical outcomes. This may involve extending their information governance structures.

b. The **research community** should analyse the linked ePROM data to get more insight into:
   - the burden and impact of living with kidney disease;
   - patient needs that are not being met; and
   - unexplained differences across kidney centres and groups of patients.

c. **Commissioners, KQuIP**, and local service improvement projects should use the insights from delivery principle 3.2b to put patients at the centre of resource planning and service delivery.

Recommendation theme 4: Make sure everyone with kidney disease can benefit from ePROMs, regardless of their background or skills

Core principle (what)

4.1 Assess how ePROMs could affect equalities in kidney health

Rationale (why)

- The 2018 Kidney Health Inequalities report[33] highlights several disadvantaged groups who struggle to access good quality kidney care. For some of these groups, ePROMs may widen these inequalities, but for others they may reduce them.
- People who are underrepresented in audits, service improvement programmes, and research projects often face other barriers too. For example, more deprivation, language barriers, cultural barriers, a poorer understanding of health and health services, and accessibility issues.
- Other projects in kidney disease (such as the Kidney PREM and early ePROM pilots) may allow us to explore which groups are underrepresented. This gives us an idea of who may experience inequalities if ePROMs are introduced.
- Kidney patients with multimorbidity may be more likely to experience health inequalities.

Delivery principle (how)

a. The **research community** should review the literature and do quantitative research to identify which groups of people with kidney disease tend to be underrepresented in projects where participants need to self-report information about their health or treatment.

b. The research community should work with the **national kidney ePROM working group** to assess how introducing ePROMs may impact health equality for all groups who may be underserved (as identified by the research under delivery principle 4.1a or listed in the Kidney Health Inequalities report[33]).

Core principle (what)

4.2 Find out what a broad range of people with kidney disease need to use ePROMs, and address these needs, focusing on underserved groups.

Rationale (why)

- People with kidney disease come from a wide range of backgrounds and have different digital skills and confidence levels.
- Individual people may respond differently to ePROM support depending on how it is delivered and by whom.
- The UK Renal Research Strategy[34] states that we do not know what people with kidney disease prefer and need to benefit from ePROMs, especially those from underserved groups.
- We do not know if the ePROMs that are already available reflect what matters most to a broad range of people with kidney disease.
- If ePROMs and ePROM systems are not developed with the needs of underserved groups in mind, this may hamper their use of ePROMs, damage trust, and make them feel disenfranchised and demotivated.
- Kidney patients with more than one long-term condition (multimorbidity) may be completing ePROMs for each condition.

Delivery principle (how)

a. The **research community** should evaluate whether the available ePROMs align with the priorities of people with kidney disease who:
   - are from different cultural, ethnic, and social backgrounds; and
   - live with other long-term conditions.

b. The **research community** should work with **kidney patient organisations** and **KQuIP** to ask what patients need if they are to use ePROMs. This research should include people from underserved groups and those living with other long-term conditions.

c. **KQuIP** should work with **kidney patient organisations** and the **research community** to design and evaluate a wide range of resources that support a broad and diverse group of people with kidney disease with using ePROMs. To help reduce inequalities in kidney health, this joint work should support people from underserved groups who currently struggle to access good quality kidney care.

Core principle (what)

4.3 Make it possible for others to support patients with using and benefiting from ePROMs.

Rationale (why)

- Research and service improvement programmes show that people with kidney disease need ongoing support to use and benefit from ePROMs.
- Members of the kidney team do not always have enough time, skills, or resources to help people to complete or understand ePROMs, especially when patients have fewer digital skills or poorer understanding of health-related information.
- Many people with kidney disease rely on their partner, family, or friends to access and continue receiving care.
- People from some ethnic backgrounds may view their health as a community or family issue.
- ePROMs can help people with kidney disease to talk to others about their health. This is one of the main benefits.
- Many local projects aim to maximise digital inclusion in healthcare and society.

Delivery principle (how)

a. **Suppliers of IT systems used in kidney services** should work with **kidney health professionals** to make it possible for people with kidney disease to complete, review and share their ePROMs with others (for example, by providing access to their personal health record, printing off their ePROM results, or by sending a summary PDF to their GP).

b. **Kidney patient organisations** should work with **KQuIP** and **kidney health professionals** to develop peer mentoring courses to learn people and their carers how to use ePROMs. This should be supplemented with peer learning on patient forums, in social media groups, and at face-to-face drop-in sessions in the local community.

c. **Kidney patient organisations** should work with **kidney centres** to signpost patients to local resources that may help them to access technology (such as local libraries and community centres) and act on ePROM results (for example, system navigators).

Recommendation theme 5: Make sure kidney centres have the support, resources, and flexibility they need to introduce ePROMs in their local area

Core principle (what)

5.1 To introduce and use ePROMs in local areas, kidney patients and health professionals will need to work together.

Rationale (why)

- Local champions help to improve health services.
- Buy-in within and across kidney centres from clinical and nursing directors is needed to drive ePROM use at all levels.
- The voice of patients has a strong influence on the service improvements that kidney centres prioritise.

Delivery principle (how)

a. **Kidney centres** should work with **local kidney patient groups** to set up a multidisciplinary working group in their area and identify champions (patients and professionals) to promote kidney ePROMs and support people to use them.
   - Consider opportunities to promote kidney ePROMs as part of existing local projects with overlapping aims (for example, promoting patient-centred care or digitising services).

Core principle (what)

5.2 Dedicate enough resources and support for introducing and using ePROMs.

Rationale (why)

- Changing healthcare services takes time, people, and money, but NHS staff are increasingly under strain; ePROMs should not be another burden for them.
- A strong value proposition for any service improvement aligns with national priorities and evidence from research studies (see Table 1 for national policies relevant to kidney ePROMs).
- The business case for ePROMs is probably similar across kidney centres, but it will need to be tailored locally by doing gap analyses and small pilots.

Delivery principle (how)

a. As part of the national kidney ePROM framework, **the national kidney ePROM working group** should work with **commissioners** and **kidney centres** to develop templates for a value proposition and a business case that kidney centres can tailor to their local context. These templates should be based on evidence and informed by policy.

b. **Clinical and nursing directors** of kidney centres should work with **commissioners** to make enough resources and staff time available for ePROMs to be part of centres' usual ways of working.

Core principle (what)

5.3 Kidney centres should take a standardised yet flexible approach to introducing ePROMs locally.

Rationale (why)

- Some kidney centres are ready to start using ePROMs, while others are not. This is partly because centres are at different stages in the process of going digital, with different levels of staff time and resources.
- We need to standardise service delivery across kidney centres so we can compare services and limit unexplained differences between them. However, rigid, top-down recommendations can be unhelpful and hamper local ownership.
- Embedding ePROMs into a kidney centre's usual way of working is complicated, so it needs local and relevant external stakeholders to be coordinated.
- Responding to a person's ePROM results in between visits and using the results to personalise how often they need a follow-up visit is in line with national NHS priorities (see Table 1). But to do this, most kidney centres will need to make a major change to how they deliver their service.

Delivery principle (how)

a. As part of the national kidney ePROM framework, **KQuIP** should work with **kidney centres** to develop a toolkit of solutions for introducing ePROMS. The toolkit should include guidance on adapting the solutions to local contexts while keeping in mind the overall goal of collecting kidney ePROMs nationally.

b. **KQuIP** should work with **kidney centres** to train implementation coordinators that understand the national kidney ePROM framework as well as the local challenges and opportunities for introducing ePROMs.

c. As part of the national kidney ePROM framework, the **national kidney ePROM working group** should set out a clear vision on what is needed for ePROM collection to lead to more responsive and more personalised kidney services.

Core principle (what)

5.4 Members of the kidney team should be trained to interpret and respond to ePROM results.

Rationale (why)

- ePROM results are a newer type of information than clinical information (such as laboratory results).
- Not all health professionals involved in kidney care see managing symptoms and other patient-reported aspects of kidney health as their responsibility.
- Many of these health professionals need training on how to interpret ePROM results, how to discuss them with patients, and how to use them to inform care goals and plans.
- Kidney teams need ongoing training and feedback on using ePROMs if they are to make them part of their normal way of working.

Delivery principle (how)

a. As part of the national kidney ePROM framework, **KQuIP** should work with the **national kidney ePROM working group** and **kidney centres** to develop staff training on ePROMs. It should be flexible and part of existing training schemes and activities.

b. **Clinical and nursing directors** of kidney centres should make ePROM training compulsory for staff, and give them enough time and resources to complete it.

c. **Kidney centres** should monitor kidney team members' uptake of ePROM training and ePROM use, and give them feedback on this as part of their continuous professional development.

References

1. Kidney Care UK. Facts about kidneys. A range of useful facts and statistics about kidneys, kidney disease, and patients in the UK [Internet]. 2022 [cited 2022 Dec 22]. Available from: https://www.kidneycareuk.org/news-and-campaigns/facts-and-stats/
2. Brown SA, Tyrer F, Clarke AL, Lloyd-Davies LH, Niyi-Odumosu FA, Nah RGQ, et al. Kidney symptom questionnaire: Development, content validation and relationship with quality of life. J Ren Care. 2018;44(3):162–73.
3. Fletcher BR, Damery S, Aiyegbusi OL, Anderson N, Calvert M, Cockwell P, et al. Symptom burden and health-related quality of life in chronic kidney disease: A global systematic review and meta-analysis. PLoS Med. 2022;19(4):e1003954.
4. Moore C, Santhakumaran S, Martin GP, Wilkinson TJ, Caskey FJ, Magadi W, et al. Symptom clusters in chronic kidney disease and their association with people's ability to perform usual activities. PLoS One. 2022;17(3):e0264312.
5. Hassan R, Akbari A, Brown PA, Hiremath S, Brimble KS, Molnar AO. Risk Factors for Unplanned Dialysis Initiation: A Systematic Review of the Literature. Can J Kidney Heal Dis. 2019;6:1–14.
6. Rayner HC, Larkina M, Wang M, Graham-Brown M, van der Veer SN, Ecder T, et al. International comparisons of prevalence, awareness and treatment of pruritus in people on hemodialysis. Clin J Am Soc Nephrol. 2017;12(12):2000–7.
7. Kingsley C, Patel S. Patient-reported outcome measures and patient- reported experience measures. BJA Educ. 2017;4:137–44.
8. Himmelfarb J, Vanholder R, Mehrotra R, Tonelli M. The current and future landscape of dialysis. Nat Rev Nephrol. 2020;16(10):573–85.
9. UK Kidney Association. Kidney Patient Reported Experience Measure [Internet]. 2022 [cited 2022 Dec 22]. Available from: https://ukkidney.org/kidney-patient-reported-experience-measure
10. Greenhalgh J, Gooding K, Gibbons E, Dalkin S, Wright J, Valderas J, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. J Patient-Reported Outcomes. 2018;2(1).
11. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, et al. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. J Clin Oncol. 2014;32(14):1480–501.
12. Graupner C, Kimman ML, Mul S, Slok AHM, Claessens D, Kleijnen J, et al. Patient outcomes , patient experiences and process indicators associated with the routine use of patient-reported outcome measures (PROMs) in cancer care : a systematic review. Support Care Cancer. 2021;29:573–93.
13. Flythe JE, Dorough A, Narendra JH, Forfang D, Hartwell L, Abdel-Rahman E. Perspectives on symptom experiences and symptom reporting among individuals on hemodialysis. Nephrol Dial Transplant. 2018;(May):1–11.
14. Anderson NE, Mcmullan C, Calvert M, Dutton M, Cockwell P, Aiyegbusi OL, et al. Using patient-reported outcome measures during the management of patients with end-stage kidney disease requiring treatment with haemodialysis (PROM-HD): a qualitative study. BMJ Open. 2021;11:e052629.
15. Schick-makaroff K, Wozniak LA, Short H, Davison SN, Klarenbach S, Buzinski R, et al. How the Routine Use of Patient-Reported Outcome Measures for Hemodialysis Care Influences Patient-Clinician Communication. A Mixed-Methods Study. Clin J Am Soc Nephrol. 2022;17:1631–1645.
16. Grove BE, Ivarsen P, De Thurah A, Schougaard LM, Kyte D, Hjøllund NH. Remote follow-up using patient-reported outcome measures in patients with chronic kidney disease: The PROKID study-study protocol for a non-inferiority pragmatic randomised controlled trial. BMC Health Serv Res. 2019;19(631):1–12.
17. Greenham L, Bennett PN, Dansie K, Viecelli AK, Jesudason S, Mister R, et al. The Symptom Monitoring with Feedback Trial (SWIFT): protocol for a registry - based cluster randomised controlled trial in haemodialysis. Trials. 2022;23:419.
18. Meirte J, Hellemans N, Anthonissen M, Denteneer L, Maertens K, Moortgat P, et al. Benefits and Disadvantages of Electronic Patient-reported Outcome Measures: Systematic Review. JMIR Perioper Med. 2020;3(1):e15588.
19. Jenkins PJ, Sng S, Brooksbank K, Brooksbank AJ. Socioeconomic deprivation and age are barriers to the online collection of patient reported outcome measures in orthopaedic patients. Ann R Coll Surg Engl. 2016;98:40–4.
20. Ling DI, Finocchiaro A, Schneider B, Lai E, Dines J, Gulotta L. What Factors Are Associated with Patient-reported Outcome Measure Questionnaire Completion for an Electronic Shoulder Arthroplasty Registry? Clin Orthop Relat Res. 2021;479:142–7.
21. Pugh SL, Rodgers JP, Yeager KA, Chen RC, Movsas B, Bonanni R, et al. Characteristics of Participation in Patient-Reported Outcomes and Electronic Data Capture Components of NRG Oncology Clinical Trials. Int J Radiat Oncol Biol Phys. 2020;108(4):950–9.
22. Calvert M, Kyte D, Price G, Valderas JM, Hjollund NH. Maximising the impact of patient reported outcome assessment for patients and society. BMJ. 2019;364:k5267.
23. The SONG Initiative. Standardised Outcomes in Nephrology (SONG). An international initiative that aims to establish core outcomes in chronic kidney disease. [Internet]. 2022 [cited 2022 Dec 22]. Available from: https://songinitiative.org/
24. Eremenco S, Coons SJ, Paty J, Coyne K, Bennett A V., McEntegart D. PRO data collection in clinical trials using mixed modes: Report of the ISPOR PRO mixed modes good research practices task force. Value Heal. 2014;17(5):501–16.
25. Kyte D, Anderson N, Bishop J, Bissell A, Brettell E, Calvert M, et al. Results of a pilot feasibility randomised controlled trial exploring the use of an electronic patient-reported outcome measure in the management of UK patients with advanced chronic kidney disease. BMJ Open. 2022;12:e050610.
26. Laverty L, Gandrup J, Sharp CA, Ercia A, Sanders C, Dowding D, et al. Using patient-generated health data in clinical practice: How timing influences its function in rheumatology outpatient consultations. Patient Educ Couns. 2022;105(3):625–31.
27. Absolom K, Warrington L, Hudson E, Hewison J, Morris C, Holch P, et al. Phase III Randomized Controlled Trial of eRAPID: eHealth Intervention During Chemotherapy. J Clin Oncol. 2021;39(7):734–47.
28. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA, Sabbatini P, et al. Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. J Clin Oncol. 2016;34(6):557–65.
29. van der Veer SN, Ercia A, Caskey FJ, Farrington K, Jury F, Rees M, et al. Developing an intervention to implement electronic patient - reported outcomes in renal services in the UK. Stud Health Technol Inform. 2020;270:936–40.
30. van der Willik EM, Hemmelder MH, Bart HAJ, van Ittersum FJ, Hoogendijk-van den Akker JM, Bos WJW, et al. Routinely measuring symptom burden and health-related quality of life in dialysis patients: first results from the Dutch registry of patient-reported outcome measures. Clin Kidney J. 2020;14(6):1535–44.
31. Pagels AA, Stendahl M, Evans M. Patient-reported outcome measures as a new application in the Swedish Renal Registry: health-related quality of life through RAND-36. Clin Kidney J. 2020;13(3):442–9.
32. Viecelli AK, Duncanson E, Bennett PN, D'Antoine M, Dansie K, Handke W, et al. Perspectives of Patients, Nurses, and Nephrologists About Electronic Symptom Monitoring With Feedback in Hemodialysis Care. Am J Kidney Dis. 2022;80(2):215-226.e1.
33. Caskey F, Dreyer G, Evans K, Methven S, Scott J, Brettle A, et al. Kidney Health Inequalities in the United Kingdom. Reflecting on the past, reducing in the future. [Internet]. Peterborough, UK; 2018. Available from: https://wlv.openrepository.com/bitstream/handle/2436/622571/health_inequalities_report.pdf
34. Karet Frankl FE, Coward RJ, Gallagher H, Hilton R, Loud F, Modi K, et al. UK Renal Research Strategy [Internet]. 2016. Available from: https://www.kidneyresearchuk.org/wp-content/uploads/2019/02/KR9501-UKRRS-Booklet-V8-WEB.pdf
35. Hyland CJ, Guo R, Dhawan R, Kaur MN, Bain PA, Edelen MO, et al. Implementing patient-reported outcomes in routine clinical care for diverse and underrepresented patients in the United States. J Patient-Reported Outcomes. 2022;6:20.
36. Stonbraker S, Porras T, Schnall R. Research and Applications Patient preferences for visualization of longitudinal patient-reported outcomes data. JAMIA. 2020;27(October 2019):212–24.
37. Basch E, Snyder C. Overcoming barriers to integrating patient-reported outcomes in clinical practice and electronic health records. Ann Oncol. 2017;28(10):2332–3.
38. Lordon RJ, Mikles SP, Kneale L, Evans HL, Munson SA, Backonja U, et al. How patient-generated health data and patient-reported outcomes affect patient–clinician relationships: A systematic review. Health Informatics J. 2020;26(4):2689–706.
39. Richards HS, Blazeby JM, Portal A, Harding R, Reed T, Lander T, et al. A real-time electronic symptom monitoring system for patients after discharge following surgery: A pilot study in cancer-related surgery. BMC Cancer. 2020;20:543.
40. Reading MJ, Merrill JA. Converging and diverging needs between patients and providers who are collecting and using patient-generated health data: an integrative review. J Am Med Informatics Assoc. 2018;25(6):759–71.

Appendices

Appendix 1: Personal stories of people using ePROMs

Three stories, starting with Seyda's story, followed by Judith's and Karen's.

Seyda's story

Seyda Oates, 23 years old, was diagnosed with chronic kidney disease in October of 2019 after experiencing sepsis caused by meningitis. She explained that since receiving a kidney transplant three years ago, both her CKD symptoms (such as nausea and persistent fatigue) and her quality of life have drastically improved.

Seyda underwent her kidney transplant at NHS Greater Glasgow and Clyde hospital, where she completed questionnaires about her quality of life before and after having the transplant. The following quotes illustrate Seyda's experiences with filling out those questionnaires:

> *I didn't really know how the transplant was going to affect me [...] It would be better if the questionnaire was focused more on how I'm feeling in that moment, and then post-transplant how I'm feeling in that moment, and then you could compare the difference."*

> *Right after the transplant, I didn't really feel the benefits of anything. Right now, I'm fully recovered and I can see how different my life is. I'm living a life without dialysis, I'm living a life without my medicine and I'm living a life without the stuff I was having to deal with, so I can actually answer the questions because I feel better."*

> *On paper, things can get lost, you might make a mistake, you have to get it done at a certain time, whereas if it's electronic you can it any time you want on your own time, you can do it at home before bed [...] and for collecting results it would be easier as well. The data could be automatically analysed or turned into a graph."*

Judith's story

Lancashire Teaching Hospitals NHS Foundation Trust currently use an ePROM to capture kidney patients' views on a range of issues, including social or psychological problems and symptom control. It is called the Renal Holistic Care Tool. It includes a PROM called the Distress Thermometer. The Distress Thermometer helps to identify, support, and manage patients' distress.

At the moment, patients fill out the Distress Thermometer on paper, which staff then enter into the unit's electronic health record system. In the future, patients will be able to complete the Distress Thermometer on a tablet, with the ePROM results flowing directly into unit's system.

Judith Todd, a sister on the haemodialysis unit, has been instrumental in the collection and processing of ePROM data from the Distress Thermometer. Her responsibilities also include training staff how to use the Thermometer and reviewing its results. The following quotes illustrate some Judith's experiences of collecting ePROM data:

> *They need the opportunity to talk and utilising the assessment tool gives them that chance [...] There's been quite a few situations where [the questionnaires] flagged up things that we had no idea were going on."*

> *I say to patients that they can complete the questionnaire again in three months or they can always ask for it sooner if they've got concerns, because circumstances change. Sometimes they'll say that they don't want any input but maybe in a couple of weeks' time once they've mulled it over they will say 'I would actually like some support.' We keep it as an ongoing conversation."*

> *The electronic health record that we have is a very old system and it's not very user-friendly. Ideally, any member of staff who completes the assessment tool will fill the data into the system themselves but because it's such an old system, most staff aren't familiar with using it. So it does mean it's down to a couple of members of staff."*

> *I do try to look at the data from different areas of the renal service every three months, look at how staff are managing them to see if they need more training to promote it, and look at what percentage of people have had an assessment done. Hopefully now that we've got a new consultant and we're having monthly meetings, that's going to be really useful to start discussing it as a group and looking at what we want to do with this data."*

Karen's story

Karen Stevenson is a transplant and vascular access surgeon at NHS Greater Glasgow and Clyde hospital. Her transplant unit is using two PROMs as part of routine transplant assessments and with acute renal transplant patients. Both measure quality of life: the EuroQol- 5 Dimension (EQ-5D) and the Renal Dependent Quality of Life (RDQoL).

Karen explained that patients complete the PROM on paper and then a staff member transfers the results to the hospital's electronic health record system. Karen noted that while EQ-5D data is relatively easy to interpret and enter electronically, the RDQoL is much more of a challenge. She explained that once the RDQoL has been entered into the electronic health record system, it is difficult to retrieve the ePROM results in a form that is interpretable at an individual patient level.

The following quotes illustrate some of Karen's experiences:

> *It's not particularly clinician-friendly for using in routine clinical practice, and part of that is because we're not quite sure of the role of it [...] It's something we have to report in the aggregate to our commissioners on a yearly basis, but it's not reported at an individual level."*

> *Sometimes you share a screen with a patient if you were looking at a scan, you'll point something out but actually [the ePRO data] is uninterpretable to them. I view it as something that needs to be visually interpretable by both sides."*

> *Actually, the vast majority of people, even older people, are way more tech savvy than you'd think and they're fine with [electronic questionnaires] as long as there's somebody to ask for help. But for the paper version, I think it's fairly universally filled in. The only folk who would struggle with that are those who have limited literacy, and I don't think either method helps them particularly."*

Appendix 2: Suggestions for roadmap report from public consultation

We conducted a public consultation to request feedback on a draft version of the roadmap report. People could provide feedback and share their concerns and suggestions via email, by completing an online survey, or during online meetings with key patient and professional organisations. The nine groups/organisations that sent us feedback were:

- UK Kidney Association Patient Council (UKKA PC)
- UK Renal Registry (UKRR)
- Kidney Research UK (KRUK)
- Kidney Care UK Patient Advocacy Group (KCUK PAG)
- Kidney Patient Involvement Network Patient Advocacy Group (KPIN PAG)
- Polycystic Kidney Disease Charity (PKD Charity)
- South Eastern Kidney Patient Association (KPA-SE)
- Kidney Quality Improvement Partnership (KQuIP)
- Renal Service Transformation Programme (RSTP)

Together, they provided more than 100 suggestions and questions, which are listed in the Table below. We used these to refine report, with a focus on the recommendations.

Table: List of suggestions from patient and professional organisations on a draft version of the roadmap report

Organisation/ group	Suggestion / feedback
KCUK PAG	Do kidney services see this as a priority, considering all the other changes and challenges they are facing at the moment? How are you going to convince clinical and patient leaders that this should take priority?
KPIN PAG	If there is no buy-in from senior hospital staff, e.g., consultants, it will fall upon nurses to implement ePRO collection – all stakeholders need to be on board for this to be successful. How can we persuade senior staff of the value of ePRO collection?
KPA-SE	Obtaining active participation by all renal units in the UK is a barrier
KRUK	Establishing the evidence base is an essential success factor – clarify that there is some evidence out there but that it's currently insufficient and needs strengthening. When formulating the recommendation, avoid the suggestion that we need to start from scratch with building evidence (e.g., use 'expanding' or 'strengthening' the evidence base instead of 'establishing'
KRUK	Which areas of research still need particular funding?
KPIN PAG	Showing that ePRO implementation is feasible on a smaller regional scale could help to get stakeholders on board
KPIN PAG	ePROs would have to be presented as a way to get things done quicker and more easily - Training for patients and staff would be time-consuming - Individualising the feedback and advice through ePROs would be beneficial but also time-consuming
PKD Charity	ePRO will need to be evaluated against clinical outcomes
KQuIP	The [ePRO] case studies presented within the document mainly refer to trial protocols published and I could not see data (on accessing the links provided) on how this has impacted on patient outcomes or experience or its cost effectiveness.
KPA-SE	Patient-reported outcomes are subjective, therefore difficult to measure
RSTP - CKD workstream	Establish and promote evidence for the impact and perceived value of ePROs: this is the key issue. Until this is established for patients with CKD, it will he hard to implement. The evidence base needs to be strengthened and the case made for how this adds 'value' across the whole pathway. Supportive of the content but need to make sure it is framed in a way that ensures buy in and ultimately implementation. Why should a provider which has to fix cancer recovery, mental health critical shortfalls invest in eRPOs for their patients with kidney disease? Need to make sure the narrative talks to all stakeholders with evidence.
KQuIP	Maybe add in a bit after discuss the results and plan their care goals
KRUK	Try to further clarify how ePROs are going to lead to patient benefit (i.e., say how ePROs going to help us achieve higher level aims on how to improve patient care and outcomes)
KRUK	Highlight early in the document the transformational effects that responsive communication between patient and caregiver can have on a person's life
PKD Charity	Needs to be more focused on how ePROs could actually improve health outcomes for patients, e.g., by encouraging self-management, triggering alerts & feedback, signposting to appropriate guidance, improving communication with clinicians
KPIN PAG	We don't want to burden the NHS with yet another tick-box exercise – there needs to be a clear incentive in the form of funding
UKKA PC	Burden on staff – how to ensure introducing ePROs doesn't overburden NHS staff
KPIN PAG	Implementing ePRO collection with an under-staffed and over-worked NHS workforce will potentially put extra strain on the system, especially when there are different IT systems which don't talk to each other both within and across hospital trusts.
UKRR	Concerns from health professionals about how this endeavour will be resourced (kit, people, etc.)
PKD Charity	An unintended consequence of introducing ePROs could be that there is a sudden deluge of symptom-reporting from patients which could be a burden to systems and staff
KQuIP	Widespread local implementation will require a significant increase in resource for clinical staff to respond to ePRO results, arrange earlier clinical review etc. in order for patients to experience the true benefits. This will need to be prioritised within the renal networks to ensure it is adequately resourced and it is unclear whether this would happen.
UKKA PC	Some HCPs may feel that what is reported with ePROs is not within their remit.
KPIN PAG	Patient portals are subject to change and not always accessed and used effectively by health care professionals

Organisation/ group	Suggestion / feedback
UKKA PC	ePROs can be long and repetitive – patients may disengage if they don't have much/any changes to report
KCUK PAG	Many patients are demotivated and do not want to be involved in their care
KPIN PAG	Agreement that peer-to-peer support and mentorship programs for patients would be a good way to get people involved
UKRR	Is there an approach that may take us 80% of the way there by creating a social movement and using the technology as a system disrupter?
UKKA PC	Addition to the recommendations: Initiating a social patient-led movement to emphasise and communicate the importance/benefit of ePROs
KCUK PAG	How will you ensure that all patients will be able to benefit and that nobody will be left behind
KPIN PAG	Use a regional approach to implementation, and tailor this to the barriers that are most commonly experienced in particular localities, e.g., language & cultural barriers, social deprivation, internet access
KPIN PAG	Older people may need special support for using Internet-linked devices. However, many of them use video communication programs to interact with family and friends so it may be possible to build on that.
RSTP - CKD workstream	Need a much greater emphasis on reducing health inequalities - this is particularly important for our population. Was this explicitly discussed as it doesn't really come out in the case studies.
KCUK PAG	How to ensure that patients are motivated to complete it and that you select ePROs that are relevant to the individual, and how does that relate to nationally-coordinated data collection.
UKKA PC	ePROs do not necessarily communicate what matters most to patients
UKRR	Has a front-end been developed/made available that can minimise the questions patients need to complete?
PKD Charity	We lack PROMs that appropriately capture all of the symptoms experienced with different types of kidney disease, especially rare diseases
KPIN PAG	Patients completing ePROs may assume that little can be done for symptoms so be become disengaged.
KPIN PAG	There should never be a system where data is collected and no follow up/message to the care team/provision of resources is triggered - Patients should be made aware of the purpose of data collection and whether is purely for the knowledge of professionals and researchers or whether it will have a direct impact on their individual care
UKKA PC	Follow up ePRO results with suggestions for referrals to other parts of the system, facilitated by, e.g., system navigators.
UKRR	Crucial to incorporate recommendations on how ePRO data will flow back to patients and units so that it can inform individual patient care.
PKD Charity	Needs to be made clear that through completing ePROs, patients will actually get something back – if patients are reporting their symptoms something needs to be done about it rather than it just being a data point
KQuIP	It would be important to manage individual patient expectations on how their symptom reporting will be responded to at an individual centre level depending on centre resources and other constraints. we should facilitate routine collection of ePRO data for the dialysis population (integrated into current electronic health records) via registry returns to develop a national picture of the symptom burden and understand any centre variations. Clinicians will then have the option of using such individual patient reported data as part of their routine clinical review to help guide management.
KPIN PAG	In the case of multimorbid patients (which is very common in CKD), there would be difficulty in getting different departments to coordinate with each other effectively
KPIN PAG	With regard to multimorbidity, an ePRO collection system needs to be 'intelligent' enough to be able to triage different diseases and symptoms in order to direct people to the most appropriate treatment/support
PKD Charity	Have people with rare kidney diseases been considered? ADPKD is a multi-system disease – more than just kidneys are affected
KCUK PAG	Case studies are interesting but some seem very specific and make you wonder how this aligns with a vision of nationally-coordinated data collection
KPIN PAG	They need to be introduced and contextualised. Additional case studies needed to represent a broad range of people.
KRUK	No doubt they are genuine stories, but they feel perhaps slightly contrived to get across some salient points. Perhaps more direct quotes would make bring them to life a little more.
UKRR	This is purely anecdotal. They were nice but don't get across well how (e)PROs have had an impact on people's lives/care. Voice of younger patients missing in current version.
RSTP - CKD workstream	Health inequalities again - consider the message this document runs the risk of sending out - the stories include Karen, Brian, Mary, Keeley and Judith. I know it sounds a bit like a tick box exercise but this is important.
KPIN PAG	There needs to be a national steer, from organisations like the UKKR, to work towards buy-in across all stakeholder groups
KPIN PAG	Political (government endorsement and commitment), systemic (NHS and ICS structures, especially commissioning), financial (national and local/ institutional) and technical (access, and system interoperability).
KRUK	Be more explicit about how your recommendations align with current policies and priorities
UKRR	ePROs align well with kidney care policy priorities around transitions (between stages/modalities), shared decision-making at the start of advanced kidney care (see GIRFT), and around re-engaging haemodialysis population in their care (because many see this group as a 'lost' group who have become disengaged from their care)
PKD Charity	NICE have quality standards that could be pulled into PROs and could be measured through PROMs – we should cross-reference these
KQuIP	It would be useful to integrate ePRO discussions into all the national RSTP workstreams and KQuIP projects so it is built into the improvement and measurement process.
KPIN PAG	We don't want to burden the NHS with yet another tick-box exercise – there needs to be a clear incentive in the form of funding
PKD Charity	"Specialised commissioning for kidney care can mandate ePRO collection as part of the service specification for kidney services" - This part of the recommendations should form a more central part of the document as it is of key importance - There is a requirement to demonstrate that ePROs can be linked to meaningful improvements in clinical and quality of life outcomes in order to attract the necessary funding for implementation - Pharmaceutical companies could provide a potential funding source
KPIN PAG	There needs to be support from NHS commissioners to work towards buy-in across all stakeholder groups
UKRR	The case studies of ePRO initiatives are helpful, but they don't provide evidence on the value and cost-effectiveness of ePROs – e.g., how it impacted on patient outcomes, and whether they are cost-effectiveness. If there is any evidence available about (cost-) effectiveness (either from kidney disease or other clinical areas), it's worth adding it because it will strengthen the case for healthcare providers and commissioners.
KQuIP	The case studies presented within the document mainly refer to trial protocols published and I could not see data (on accessing the links provided) on how this has impacted on patient outcomes or experience or its cost effectiveness.
UKRR	Renal IT systems need to develop ePRO functionality and it will come at a cost.
PKD Charity	There needs to be health economics work done to provide evidence of the financial benefits of rolling out ePROs and justify the costs
KQuIP	Once the renal community is familiar with ePRO and its interpretation, we could consider some regional QI projects on how best to implement this to maximise its effectiveness and make it cost effective and consider expanding it to non-dialysis population.
KRUK	We were curious to know what the graphs being shared with patients were. These suggest something beyond individual patient care. Is this aggregated data for all the patients in a unit, or national data? Is this comparing an individual patient with other patients in the unit? Or their own data over time? Some examples of good practice in data visualisation might illustrate the point well
KRUK	In the first part of the roadmap, have a section on secondary use of ePRO data beyond direct care (e.g. for service improvement, research) and to what extent this is part of/related to your vision
UKRR	Minimum ePRO data set crucial for national Registry-led collection

Organisation/ group	Suggestion / feedback
UKRR	National collection of ePROs will require standardisation to be centrally submitted to the UKKA.
PKD Charity	Developing a core set of standardised ePROs that everyone uses is crucial - Look at kidney PROs on MAPI trust as a starting point - An expert group would need to be set up to achieve this - The core set of ePROs would need to include disease-specific questionnaires, e.g. for PKD, which represents a large portion of the kidney disease community - There's a need to collaborate internationally with the groups that are trying to develop PROs across specific conditions
KPA-SE	One difficulty would be the different types of ePRO that are used. There should be a single standard ePRO
KCUK PAG	How to ensure all trusts have the appropriate infrastructure to offer PROs in electronic format, acknowledging that each trust has their unique set-up
KCUK PAG	Be aware that many more (local) systems in addition to PKB and MyEpic are currently in use across the country for asking patients to contribute data about their health (e.g., home-measured blood pressure)
KPIN PAG	Implementing ePRO collection with an under-staffed and over-worked NHS workforce will potentially put extra strain on the system, especially when there are different IT systems which don't talk to each other both within and across hospital trusts.
UKKA PC	Integration of ePROs into existing IT systems – this is very challenging and far from current reality
UKRR	Systems for ePRO collection: good idea for starting from currently available systems but there will be substantial barriers and challenges to further configuring and developing these systems to make them suitable for large scale ePRO data collection linked to the Registry.It is also unclear how long some systems will be around.
UKRR	New EPR's and some renal systems may not have the functionality to accommodate ePROs
KCUK PAG	Patients Know Best (PKB) may be replacing PatientView but many patients are not necessarily happy with the functionality PKB has to offer – this requires a wider improvement effort with input from patients
KPIN PAG	Patient portals are subject to change and not always accessed and used effectively by health care professionals
KRUK	It would also be helpful to show an example or two showing ePRO portals and what is being collected. As patients, neither of us have been asked to fill one in and we are left wondering what they might look like!
KPIN PAG	Concerns expressed about data security and who would have access to it - The recommendations should make it clear that data security would be paramount in any ePRO data initiative and personal data is protected under UK GDPR regulations - The IT systems in use need to be trust-worthy and not have ulterior motives for collecting medical data
KRUK	ePROs can be collected for a number of different reasons and it wasn't clear which of these the road map was intended for. We gather from reading the document in its entirety that this roadmap is primarily for individual patient care, reflected in the vision but the document also states or implies their secondary use in local service improvements, national improvements, audit, data analysis and research.
PKD Charity	Document mainly gives context for the use of ePROs in clinical management settings rather than for clinical trials - Is the intention that ePROs will also be used for audit purposes?
KRUK	ePROs are beginning to be used widely in clinical trials which are not mentioned. It would be helpful to set out these intentions at the beginning of the document.
PKD Charity	PROs are now included in the clinical outcomes assessment set which regulators are accepting, so it's important that we define the PROs being used because this data could be vital for clinical trials. This could make the UK an attractive place for pharmaceuticals to run trials in
KRUK	Coming at the topic fresh, and being two kidney patients alongside our roles in Kidney Research UK, we felt that the roadmap would benefit from some additional context at the outset.
UKRR	Emphasise the patient voice behind this vision more and make it more visible in your Introduction – to set the scene better for the recommendations and align with the fact that ePROs are not a thing but a process that involves people.
KPA-SE	For someone unfamiliar with ePROS, the introduction given on page 9 is too brief.
PDK Charity	Is it for England only – what are the plans to connect with Scottish and Welsh patients, and how do we integrate this across nations
PDK Charity	There is no consideration of children – there's a big cohort of patients there & their parents who could benefit. ePROs could be a good way to monitor the transition stage between paediatrics and adulthood
PDK Charity	Have people with rare kidney diseases been considered?
RSTP	Is this ePRO for all patients with kidney disease or RRT or advanced kidney disease? Does the evidence need to match the population e.g. outpatient clinic optimisation with digital tools is very different to distress on dialysis. The outcomes are also very different. Do we need to segment by cohort? This then provides potential providers, patients and commissioners a clearer view on how/which ePRO systems/evidence is relevant to their areas.
KPIN PAG	Importance of GPs having access to ePRO data was emphasised – the recommendations and roadmap as a whole are very secondary care focused. There is a need to consult with renal professionals who work in primary care.
KRUK	Be clear that the roadmap focuses on secondary care while acknowledging importance of and link to primary care
RSTP	The document is also secondary care centric which is probably appropriate but need to ensure the population is clearly defined.
KPIN PAG	As the 10-year vision is quite aspirational & high risk, it might be useful to lay out a clear contingency plan for if the barriers are too great to overcome
KPIN PAG	Over the long term, but the barriers are too great at the present time. A timetable is needed and especially a flow chart indicating prerequisite actions for each successive stage of the process
UKRR	Might be a bit too broad? Emphasise that it's a long-term vision.
UKRR	Not clear for many delivery principles who is supposed to pick them up, and what the timelines are – could you add the who and when to them to increase their actionability? Could you cut them up in stages and order in sequence of what needs to happen first.
KRUK	The time and funding that key kidney organisations will be able to contribute in order to achieve the vision
UKRR	Clarify who should 'own' and drive the 10-year vision
UKRR	Not clear for many delivery principles who is supposed to pick them up, and what the timelines are – could you add the who and when to them to increase their actionability? Could you cut them up in stages and order in sequence of what needs to happen first.
KQuIP	Mentions coordinated ODN's but the commissioning will sit with ICS level who will set priorities
UKKA PC	highlight recommendations that will make the most difference/will get us a long part of the way there
KCUK PAG	Could we think of a different, less technical term for 'ePROs'
UKKA PC	Clearly explain difference between PREM and ePROs (and emphasise that PREM is not within the scope of the roadmap)
KRUK	Explain what you mean with a 'national ePRO system'. Else people may think you want one system rolled out nationally, rather than having local ePRO systems feeding into a national repository.
RSTP	RePROM links through to the trial design paper rather than the results paper.
KQuIP	Can the holistic approach to care and partnership working be emphasised a bit more on page 10.

Appendix 3: Patient and healthcare professional requirements and preferences for the design of ePROM systems

ePROM system feature	Requirements and preferences	
	Patients	**Healthcare professionals**
Entering ePROM information	• Have one system for everything health-related, as much as possible. • Make sure the system is compatible with tablets. Tablets are easy for most patients to use; the large display boosts accessibility[18]. • Make sure ePROM information can be entered on smartphones so people who rely on them to get online can be included[35]. • Offer alternatives for people who do not have digital access or digital skills. For example, by providing paper-based PROMs or tablets in hospitals for completing ePROMs. • Give instructions in simple and easy-to-understand language. • Include free-text sections alongside standardised ePROMs so people can mention other symptoms or issues that matter to them. • Include a quick option to report 'no change since last time' so people are not put off completing ePROMs if their kidney health is stable.	• None
Presenting results	• Present results in a large text size using bright, meaningful colours alongside simple images to aid interpretation – for example, a colour-coded bar chart with emojis[36].	• Present results within the electronic health record system so it is easier to include ePROMs in routine clinical practice[37] and shared decision-making processes. • Make the results easier to interpret by automatically analysing and summarising the information in charts or graphs[38].
Reminders and alerts	• Provide editable SMS or email reminders for when to complete the next ePROM[18].	• Send automated messages to alert kidney teams to severe issues reported by patients, so problems can be detected earlier and managed in a timely way[18].
Privacy and legal concerns	• Be clear about why ePROMs are being collected, who will use the results and how they will do so. This will manage people's expectations and build and maintain their trust. • Reassure people that the ePROM system complies with privacy and confidentiality regulations[40].	• Be clear about who is responsible for responding to ePROM results and what the responses should include

MANCHESTER 1824
The University of Manchester

The University of Manchester
Oxford Road
Manchester
M13 9PL

www.manchester.ac.uk

Royal Charter Number RC000797

recycle
When you have finished with this publication please recycle it

Supported by
The Health Foundation

The Health Foundation
8 Salisbury Square
London
EC4Y 8AP

www.health.org.uk

Registered charity number 286967