Remote monitoring of kidney function:

What matters to patients and healthcare professionals?

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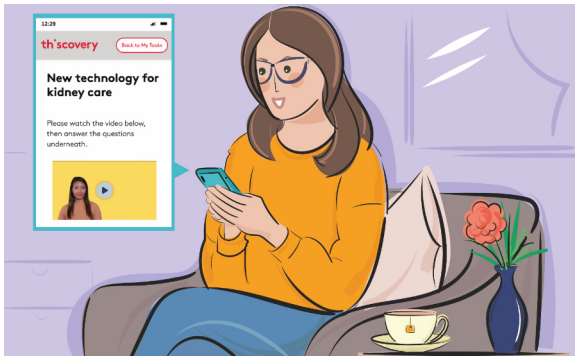

Statements that describe what good remote kidney function monitoring looks like for people living with kidney disease and kidney health professionals providing their care

Q is led by the Health Foundation and supported by partners across the UK and Ireland

this labs th'scovery

Kidney Research UK

UKKA UK Kidney Association

cúram SFI Research Centre for Medical Devices

NHS South Tees Hospitals NHS Foundation Trust

Foreword

Sustained advances in innovation and technology make remote monitoring of kidney function a real possibility in the near future. The NHS Long Term Plan (2019) proposes a widespread and funded programme to upgrade technology and digitally-enabled care across the NHS, to support patients and their carers to better manage their own health and condition. It also aims to better utilise healthcare technologies to help reduce unnecessary clinic visits for patients and limit NHS clinic expenditure.

Within the UK Kidney MedTech Research Network, our patient consultation demonstrated that many people living with kidney disease recognise the importance of self-monitoring and of positioning healthcare around patients' lives, rather than vice versa.[1] The burden from living with kidney disease is significant, and addressing health system issues has been clearly identified as a priority.[2] However, our research suggested that an ideal solution can look very different from one individual to the next. Maximising benefit, while minimising potential harm or inadvertently increasing test and treatment burden, represents a complex and important challenge.

From November 2021, we have been working with Q Lab, supported by the Health Foundation and NHS England. Together we have been exploring how to build staff and patient trust and confidence in technology-enabled remote monitoring. This document summarises our findings and sends out very clear statements about what patients and clinical teams want from technology enabled remote monitoring in kidney disease. These service principles and the rationale underpinning them can support technology development that could make a real and sustained difference in how care is delivered and how it is experienced.

This project is uniquely important because it looks at remote monitoring through the dual lenses of people living with kidney disease and multi-professional renal healthcare clinicians. It focuses on what remote monitoring features are most important to consider when thinking about people's wellbeing, life satisfaction and quality of care perspectives.

The evidence base underpinning this approach is strong: kidney disease is a risk factor for poor mental wellbeing; and poor mental wellbeing is a risk factor for worse outcomes for people with kidney disease.[3] Although people working in healthcare generally find their work meaningful and satisfying, they are at high risk of burnout.[4] NHS staff survey data shows the current workforce often feels undervalued, stretched and unwell.[5]

NHS England, NICE and the MHRA have clear roles in assessing clinical safety, data protection and technical security of new remote monitoring devices. This work demonstrates how evidence-informed and user-led approach to the design and deployment of new technologies can further support wellbeing. The challenge now for device developers, evaluators and commissioners is to utilise this information to ensure future development and use of medical technology for remote monitoring of kidney function, enables tailored and personalised care which fits within patient care pathways, whilst taking account of health professional job demands, resources and needs.

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Views of people living with kidney disease

For many patients, quality of life is just as important as quality of treatment

The prospect of remotely monitoring kidney function is very exciting. It will be less disruptive, and perhaps more importantly, it will give patients more control over their health leading to better outcomes.

In this work, I like the fact that the views of patients are being sought at a very early stage. The comprehensive responses we've received have highlighted clearly what patients would value about remote monitoring, the diverse needs they have and the issues that have to be overcome to get a smooth introduction. Early involvement of a representative group of patients is really important in so many projects like this.

Successful remote monitoring revolves around two core principles: choice and independence. Some patients opt for as much independence as possible. They are willing to take on significant monitoring responsibility to maintain this independence and have minimal interaction with their hospital and clinical teams.

At the other end of the spectrum are patients who choose, for many different reasons, not to move to new models of shared care. Fears of being left to their own devices, not being able to speak to a healthcare professional and over medicalising the home, are all concerns we heard expressed strongly in this research. Of course, most patients fall somewhere between these two extremes and getting the balance just right, for each patient is so important.

Projects like this can only contribute positively to patient choice, our ability to live as 'normal' a life as possible and allow patients to have both choice and independence.

David Forsdike
Patient Researcher

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Patient Researcher

Introduction

Technology-enabled remote monitoring is the use of technology, devices, or apps to support patients to monitor and manage their health or long-term conditions. This technology makes it possible to safely and securely exchange health information between a person living with kidney disease and their clinical team, to assist in monitoring their health status and quality of life.

As yet, there aren't devices approved for use in the NHS that allow this to happen in kidney care. However, we know there are devices in development that will ultimately enable remote monitoring of key measures of kidney function, such as levels of potassium, creatinine and potentially immunosuppressants like tacrolimus.

In this project, we set out to understand how remote kidney monitoring devices could be designed and deployed to maximise patient and staff trust and confidence. We also explored how using wellbeing evidence could enable better design. Importantly, this guide isn't specific to a particular device or technology platform; it describes the experiences health professionals and patients want from remote monitoring of kidney function within patient care pathways.

Who is this guide for?

- **Device developers** - to understand the experiences people living with kidney disease and kidney health professionals want to have using this technology. This guide can be used as a standard for design factors e.g. usability and accessibility, and deployment considerations e.g. interoperability.
- **Evaluators** - to inform decisions on evaluating, authorising and/or funding remote kidney monitoring technology e.g. the Medicines and Healthcare products Regulatory Agency (MHRA) and UK Approved Bodies for the certification of the performance and safety of medical devices.
- **Healthcare organisations** - to inform procurement processes and assess the extent to which suppliers of this technology provide a person-centred approach to care, and take account of health professionals' job demands and capacity, to ensure their engagement is feasible and sustainable.

What does this guide cover?

The guide is in two parts:

- **Experience statements** that describe what good remote monitoring of kidney function looks like. There are five themes for people living with kidney disease and five for health professionals providing kidney care.
- **Service principles** that bring attention to what is important when making decisions about how to design and deploy a service for remote monitoring of kidney function.

Complementing existing frameworks

We purposefully designed this guide to complement two existing frameworks:

NHS England Digital Technology Assessment Criteria (DTAC)

- Clinical safety
- Data protection
- Technical security
- **Interoperability**
- **Usability and accessibility**

Our guide informs these two standards

NICE Evidence Standards Framework for digital health technologies.

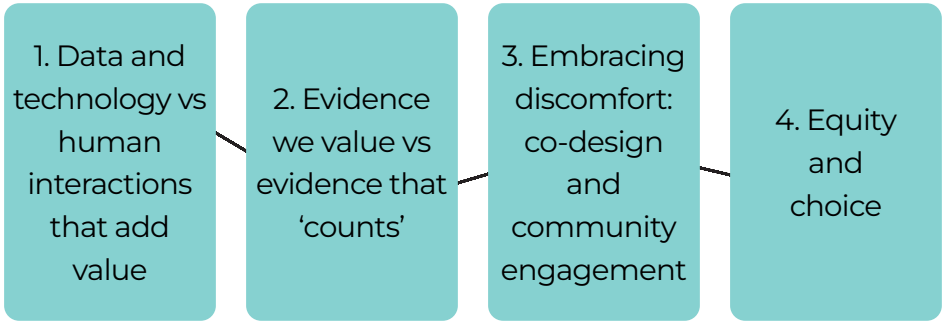
1. **Design factors** — Our experience statements can be used here
2. Describing values
3. Demonstrating performance
4. Delivering value
5. **Deployment considerations** — Our service principles can be used here

Scope

- We captured the experiences of those over 18, we didn't explore care pathways for children and young people.
- Our focus was patients currently attending hospital check ups for kidney function, not those solely in contact with Primary Care.
- Our health professional engagement was with renal consultants and renal specialist nurses providing care to patients in the NHS.

Who is this guide for?

This guide was developed by a team, led by the What Works Centre for Wellbeing, as part of an improvement project with Q Lab supported by the Health Foundation and NHS England. Between November 2021 and May 2022, we took part in six workshops collaboratively exploring the topic of technology-enabled remote monitoring. You can read the detailed insights from this work here. Four tensions and challenges were identified as part of this work:



From April - September 23, we refined our area of opportunity, designed and tested our research questions with device developers, patients, renal health professionals and regulators. In October 23 we partnered with THIS Labs whose online platform Thiscovery provided an engaging way for people living with kidney disease and renal health professionals to share their views. Ethical approval for the patient element of this work was secured from Foundations. The healthcare professional survey was considered to fall outside the scope of ethical review.

Patients were recruited through the network of kidney patient associations and with support from the National Kidney Federation. Renal healthcare professionals were approached through the NHS Renal Service Transformation Platform and regional clinical networks. In our first task, participants were asked to imagine that remote monitoring devices were available and approved for use within the NHS. Participants were asked how the availability of this technology might change their experience of kidney function monitoring. What would be the biggest benefits? What concerns would they have?

We heard from 80 people living with kidney disease and 40 renal health professionals. We summarised what we heard into draft experience statements and service principles. In April 24 we went back to participants to further refine these and gauge strength of support. The information presented on the following pages is the result of this work.

> **Interesting technology. Prior to completing the survey, I had more scepticism for the use cases and now feel differently.**
>
> Renal consultant

> **I can't stress how excited, and almost tearful(!) the idea of these kinds of innovations make me!**
>
> Kidney patient

Patient Experience Statements: five themes

People living with kidney disease described their ideal experience of remote kidney monitoring. We grouped these into five themes:

1. **Trusted relationship with my kidney care team**
2. **Feeling safe**
3. **Confident involvement in my care**
4. **Tailoring my device and kidney care**
5. **All in one place**

The statements with the highest levels of support are presented first in each theme.

Trusted relationship with my kidney care team

- I can have **an open and honest conversation** with a member of the renal team, where we **both have the same, up to date information** on my kidney function.
- I am a **known and visible patient**; my relationship with the renal team is preserved.
- I am **listened to**, and when I have questions or raise concerns, **I am heard**.
- I can discuss aspects of my kidney health with **a real person** by telephone, or secure online communication.
- My kidney team **ask and respect what matters to me** in my care.
- My kidney team ensure my kidney care plans are **shared appropriately** with other healthcare teams.
- My carers and I can have an **ongoing dialogue** with the renal team.

> **I like speaking to a consultant and being reassured that my kidney function is ok.**
>
> Kidney patient

Concerns

- It will be difficult to **get hold of a person** to discuss my results with.
- I won't have an assigned consultant or renal specialist. It will be **whoever picks up my readings**.
- I'll feel **isolated** from medical support.

Feeling safe

> **Continuity of care is important. Often I am seen in clinic by someone who only looks at my last set of blood results and does not place those results into the context of my medical history.**
>
> Kidney patient

- I am confident that my remote monitoring device is **accurate, reliable and easy for me to use**.
- I am **contacted quickly** if there is a problem with my results. I am assured that any declines in my kidney function will be noticed.
- I am **informed promptly of my test results**, even if they are normal.
- Core **costs** for remote monitoring, for example device maintenance, **are covered**.
- I have **confidence to live a 'normal life'** and not worry about my kidney function.
- I feel **in touch with my kidney health**. I don't have the stress of waiting several weeks or months for my results.
- I am treated with **dignity, compassion and respect**.
- Those **who care for me** are adequately supported too.

Concerns

- My **care plan won't be reviewed** in a timely way by a healthcare professional.
- **My results will go missing** and/or will go unseen.
- **Too much will be expected** of me, my family and those who care for me.

Confident involvement in my care

- I am **engaged, motivated and enjoy** being involved in my kidney care.
- The information I receive about my kidney function is **presented in a way that makes sense to me**.
- **I can choose to see** exact results and/or a traffic light system that tells me if my results are normal for me, and when review may be needed.
- I know which parts of my kidney care I am **confident** with, and where I might like **more support**.
- I understand **how I can take action** and proactively manage my kidney health. I am **confident** to do this.
- I can **track my results over time** and know what's good/normal/for me.
- Remote monitoring means I can **ask better questions** and have **better conversations** with my kidney team.
- I can take an **active role in shared decisions** about my care.

> **What works well for me is understanding the blood tests, allowing me to ask better questions**
>
> Kidney patient

Concerns

- I am tempted to check my kidney function every time I feel 'a bit off'.
- I worry about taking an incorrect reading, fluctuations in my readings and misinterpreting results.

Tailoring my device and kidney care

- My kidney care is **convenient**. I spend less of my time waiting and travelling to deal with my kidney disease. I can book an appointment at a time that works for me.
- Life is a lot simpler. I can work my tests around my job. I don't have to **cancel work or social activities**. I don't miss out on as much as I used to.
- I trust that, whenever possible, my care will be tailored to meet **my individual needs and preferences**.
- I can take on **as much or as little of my monitoring** as feels right for me.
- I have **choice and control** over the care I receive.
- My care covers my **quality of life and the quality of treatment**. We talk about emotional wellbeing and my physical health.
- My **partner, family and friends** who support and care for me can tailor their involvement in my remote monitoring too.

> **It is often hard to get medical professionals to understand how you are feeling, or how symptoms are affecting your life.**
>
> Kidney patient

Concerns

- I might prefer it if the data is transferred directly to the renal team and I'm not always expected to check.
- Home monitoring makes the disease ever present; the current system confines chronic disease to the hospital.

All in one place

- I can view **all my kidney function information in one place**.
- I can **easily and safely share my kidney function information** with other health professionals providing care, for example my GP or a healthcare professional from a different speciality.
- I get an alert when my results are ready to view.
- I can **see my personal health information**, for example blood pressure, exercise levels and weight **alongside my hospital kidney data**.
- My kidney function monitoring is part of **a coordinated approach** across health providers to my care.
- I can use my remote monitoring app to **capture my day-to-day health**, so I have a diary to share with a member of the kidney team during care reviews.

> **Other health care professionals should be able to access this information routinely. My diabetes nurse at my GP surgery should know how my kidney care is impacting my diabetes and vice versa. At present, she only tends to find out when I tell her.**
>
> Kidney patient

Concerns

- Kidney function is only one of the tests performed at my regular appointments. If I can't do other tests at home, I will still need to come into hospital.

Health Professional Experience Statements: five themes

1. **Increased capacity**
2. **Better consultations**
3. **Safety**
4. **Integration**
5. **Training and technical support**

Increased capacity

- I can more **effectively triage** those who would benefit from a face-to-face appointment, longer appointments and those who could have a video or telephone consult.
- I have a **reduced administrative workload**; I spend less time chasing blood results.
- I have **up to date renal function data** when I need it. I have access to trend data, and can make decisions and changes in patients' care **before problems arise**.
- I can **review vulnerable patients** quickly and easily for example those in residential care settings or those vulnerable to clinical deterioration.
- I can use **software and artificial intelligence** features to support clinical decision-making, analyse patterns in a patient's data and predict potential risks.

> **Less likely to have wasted appointments as pre-clinic tests not undertaken**
>
> Consultant Nephrologist

Concerns

- A senior renal health professional will still need to review the results and make a decision regarding the interaction required for each patient.
- The technology will result in additional test results to review with limited clinical benefit.

Better consultations

> **It would really help with on-going care. We could measure patients with poor mobility, those with cognitive issues and those patients in care homes or out-of-area.**
>
> Lead Acute Kidney Injury Clinical Nurse Specialist

- Remote monitoring is one tool available to me to provide **personalised care** tailored to a patient's individual clinical need, circumstances and preferences.
- I can have **safe, two-way communication** with patients and/or their carer about results and give advice.
- Remote monitoring **supports patient self-management** through algorithms and interpretation so patients understand their reading [without significant input from the clinical team] and know what action to take.
- I have space for a more **coaching approach** to kidney disease health, supporting patients to develop skills and confidence and become actively engaged in their care.
- Remote monitoring actively supports me improve the care I provide to **underserved groups** and **narrow health inequalities**.

Concerns

- I have reservations about this technology for patients with health anxiety. An additional intrusion of healthcare into life. We are making home life more medical.
- I will have more computer work and less patient contact - the rewarding part of being a healthcare professional.

Safety

> **With good quality safety netting advice, this would be useful for monitoring in between regular follow up appointments.**
>
> Lead AKI/Renal Clinical Nurse Specialist

- I am **assured** of the accuracy, reliability, consistency and security of the device and results.
- I understand **clinical governance** for this device i.e. quality assurance, quality improvement, risk and incident management.
- I am confident **patients won't be lost or left unsupported**. I can see if a reading has been taken.
- As a renal team, we can **customise workflow** to deliver high quality care.
- I can use my clinical judgement and risk assessment to **set upper and lower ranges** for each patient, with alerts built in when out of range.
- **Critical results** are flagged quickly through a robust system to the relevant emergency provider.
- The device **automatically re-checks** if results are outside the patient's usual range. I can request a repeat test if I feel the results are questionable.
- I can **limit when patients can use the device** i.e. when a health professional has requested a test.

Concerns

- It will be difficult to review test results in a time-efficient, coordinated way.
- I will be overwhelmed by data, unable to process it and keep patients safe.
- I will lose an opportunistic point in the care pathway to recognise people who are becoming unwell.

Integration

- **Data is available** to any clinician likely to be involved in caring for the patient in a timely fashion. Information isn't hidden in a bespoke system unavailable to other specialities for example the emergency department.
- The device supports **care pathways across primary and secondary care**.
- Remote kidney function monitoring **'plugs into' our hospital systems**, is safely and appropriately automated, uploading data to the patient's electronic health record.
- I can use the device **alongside other remote monitoring** I request, e.g. home blood pressure monitoring.

> **Results need to be integrated into local pathology system instead of logging in to a separate system which may be less reliable or where a supplier may change**
>
> Consultant Nephrologist

Concerns

- How much value does this type of remote monitoring add? I still require a full blood count and urea & electrolytes tests.
- Remote monitoring can only provide part of the information I need to make decisions about care.
- This will be another system I need to log into; another screen displaying only part of my patient's information.

Training and technical support

- My patients and I have access to a **dedicated support team**, with people who can troubleshoot technology concerns.
- The renal team have capacity to ensure **patients have the health literacy and knowledge, skills and confidence** to self-manage their remote monitoring and take appropriate follow up action e.g. understanding readings and use relevant information to take action.
- **Training and refresher courses** are readily available for patients and staff.
- There is a dedicated person to support patients to **access to the required technology** for remote monitoring e.g. a smartphone, or laptop/tablet with affordable data/internet connection.
- There is a dedicated person working with patients to assess their **digital literacy** and understanding of how to engage with a healthcare app, website or online platform. Where required, they **adequately support patients** to develop knowledge and skills.

> **The key would be to couple the introduction with a comprehensive assessment and education process, to help patients get the best out of the technology and help clinicians identify the minority of patients where the technology would not work or would result in a decrement rather than an improvement in patient experience.**
>
> Consultant Nephrologist

Concerns

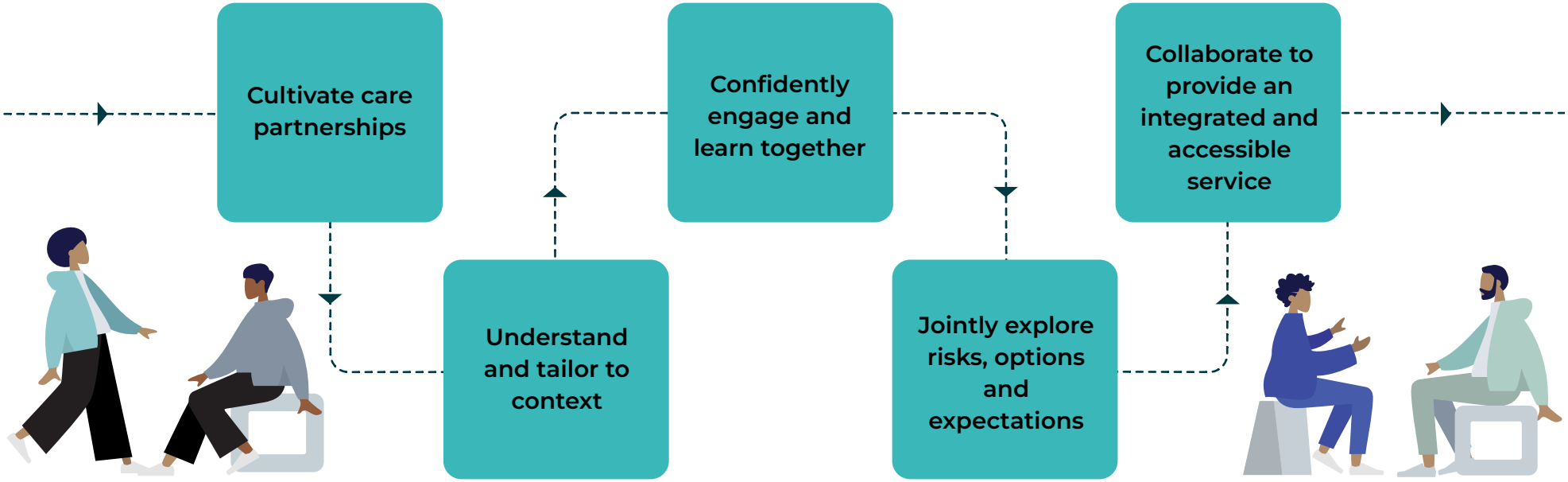
- We are generally pretty bad at providing the ongoing education and support this technology needs. It's crucial that health economic assessment includes a real budget for this aspect of development.
- I will spend a significant amount of time troubleshooting underperforming technology.

Service principles for providing remote kidney monitoring

Principles are a common way to bring attention to what is important when making decisions about how to design a service.[6] They are widely used in design to create a shared understanding of what is important, and help guide decision-making, between different groups of people using and delivering a service.

Our **five principles** bring together the insights and experience we've heard from people living with kidney disease and health professionals that provide their care. These principles are interconnected and equally important.

1. **Cultivate care partnerships**
2. **Understand and tailor to context**
3. **Confidently engage and learn together**
4. **Jointly explore risks, options and expectations**
5. **Collaborate to provide an integrated and accessible service**



Service principles for providing remote kidney monitoring

1. Cultivate care partnerships

Deploy remote monitoring to add value to kidney care pathways. Provide a secure space for interactions between a multi-professional kidney team, people living with kidney disease and those who support them. Enable health professionals to coach patients to develop the knowledge, skills and confidence to take an active role in their care and live an independent and fulfilling life.

2. Understand and tailor to context

Understand each patient's individual circumstances, their support network, and the things in their life that are important. Support healthcare professionals to tailor monitoring schedules and notifications to reflect their preference for managing risk and uncertainty.

3. Confidently engage and learn together

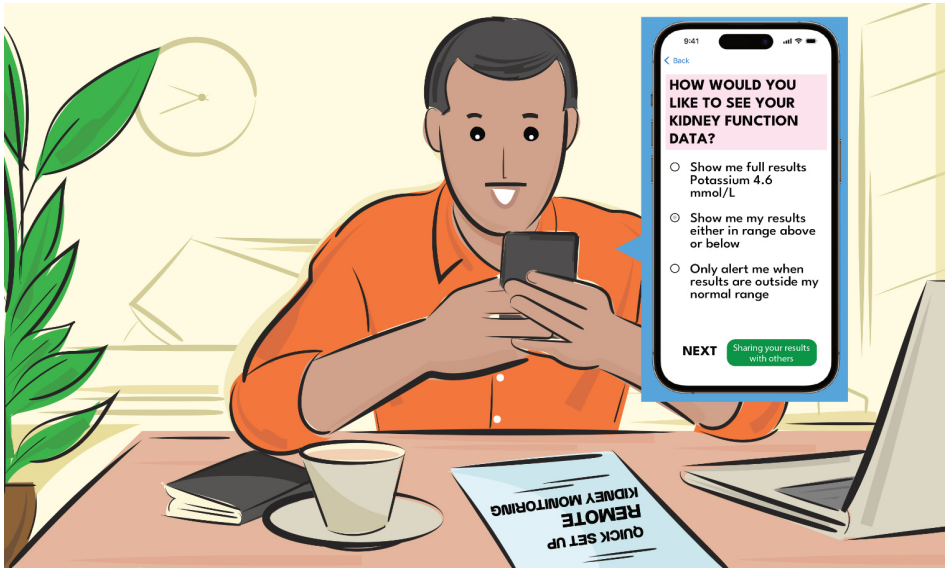
Provide assurance that remote monitoring is clinically safe and that data & information is securely stored and appropriately shared. Provide training and technology support that is accessible and responsive. Monitor and evaluate introduction of remote monitoring to understand what works, for who and in what context.

4. Jointly explore risks, options and expectations

Discuss options for maximising wellbeing, helping people to feel good and function well. Take into account clinical, social, emotional and practical needs. Balance frequency of testing with levels of assurance, anxiety and health professionals' job demands and resources.

5. Collaborate to provide an integrated and accessible service

Enable health professionals across roles, specialities and settings to interact and provide high quality, coordinated personalised care. Deploy remote monitoring to streamline systems for ordering, taking, receiving and viewing test results.



From insight to action

This guide describes how remote kidney monitoring devices can be designed and deployed to maximise staff and patient trust and confidence. It has wide ranging application across multiple settings including:

- **Developers** to illustrate how their technology responds to patient and healthcare professional need.
- **Evaluators** to inform decisions relating to evaluation and authorisation of devices and technologies.
- **NHS Trusts** where it could be used for quality assurance during commissioning and procurement, to shape development of clinical standards, and to inform audit and improvement activity.

It is important to reflect that this is a rapid, fast paced operating environment, and future changes in technology and social norms make it highly likely that these experience statements and service principles will need reviewing and updating over time.

Finally, although developed for kidney care, it is of note that this work could inform remote monitoring in other specialties, long term conditions and healthcare settings including virtual wards. We invite researchers to test, learn, pilot, and most importantly, share 'what works'.

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Acknowledgements

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In writing this guide, we drew inspiration from:
Making it real and their work with think local act personal https://makingitreal.org.uk/using-making-it-real/

The 2018/19 Q Lab project on Mental health problems and persistent back and neck pain. The Lab project, in partnership with Mind, produced service principles that describe what matters to people living with both conditions, which can be used to inform decisions about improving, designing or commissioning services.

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