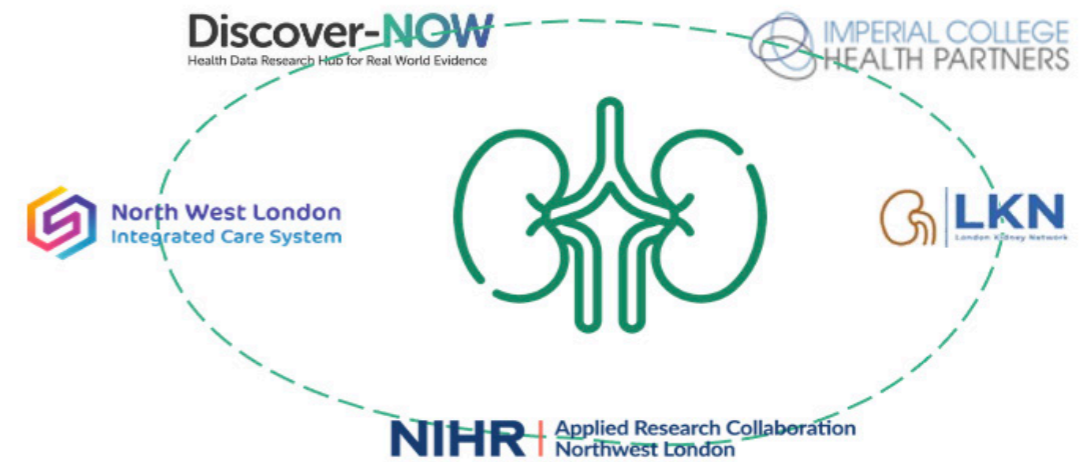

Chronic Kidney Disease

Improving early identification and management

November 2022

Contents

At risk patient interviews	pg 5
CKD patient interviews	pg 10
Clinician interviews	pg 14
Co-design workshops	pg 21
Scoping review: key findings	pg 31



Preface

Chronic kidney disease is a huge, often unseen population health problem. It is a stronger factor for all cardiovascular events than type 2 diabetes and can lead to dialysis and kidney transplants. This costs the NHS an estimated £1.45 billion annually, more than breast, lung, colon and skin cancer combined.

An estimated 15% of UK population over 35 have CKD and this is predicted to double over next ten years. Black, asian and minority ethnic communities are five times more likely to develop CKD stage 3.

Despite this only 10% patients with early stage CKD are diagnosed and treated in a timely manner.

Project overview

The DiscoverNOW consortium has been leading a project to improve earlier identification and management of patients with chronic kidney disease (CKD) in North West London (NWL). The consortium set up a multidisciplinary team of patients, clinicians, clinical research fellows and experts in PPIE, health inequalities, public health, health economics, data and service design funded through the National Insights Prioritisation Programme.

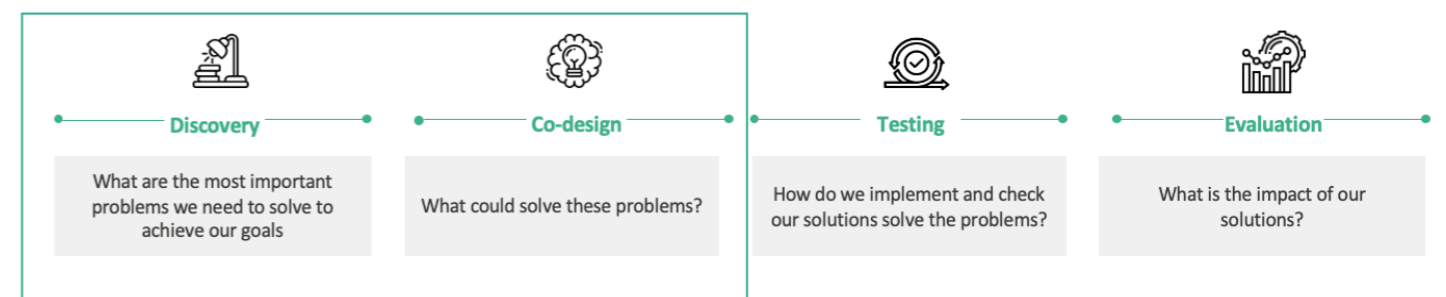
The project's objectives were to co-design, implement and evaluate pathway improvements in North West London that could be shared to the other 5 London Integrated Care Systems (ICSs) via the London Kidney Network (LKN)

The project has two main goals that the pathway improvements should achieve:

- 1) Increase the number of patients identified, tested and diagnosed with CKD
- 2) Increase the number of patients who are treated according to latest guidelines

We also aimed to identify and address health inequalities throughout the project.

The following report covers the discovery and codesign phase of the project.



Who we spoke to

At risk patient interviews

CKD patient interviews

Clinician interviews

Co-design workshops

Understand how CKD is currently diagnosed and managed in NWL from multiple viewpoints

Identify the pain points and drivers in the current pathways

Prioritise problems to solve and co design solutions together through workshops

Goal 1: Increase the number of patients identified, tested and diagnosed with CKD in NWL

1. Why is knowledge around CKD risk factors so variable, particularly about rather than to those known to be at risk?
2. What are the health inequalities + wider circumstances that affect the CKD and at-risk population?
3. Which user groups are most important to engage about CKD and what do they need to know?
4. What drives at-risk patients to get tested, what are the barriers + how they can be reduced?
5. How do patients and clinicians feel about the CKD diagnosis process?

Goal 2: Increase the number of patients who are treated according to latest guidelines

1. Who is involved in treating CKD, what are the other LTC pathways it touches on and what are staff's responsibilities?
2. Who is best placed to manage patients according to guidelines?
3. What are the barriers (especially health inequalities) to following guideline directed treatment?
4. What is needed to ensure clinicians are supported to identify, prioritise and treat patients according to the guidelines?
5. What do clinicians need to make guideline directed treatment simple and easy to follow?
6. What do patients know about treatment for CKD, how do they feel about it and are the barriers to them taking medication?
7. What Staff/Practice/PCN motivations and priorities can we tie our changes into?

All interviews and workshops were conducted prior to the new chronic kidney disease management guidelines being published in North West London

At-risk patient interviews

Overview

We interviewed 5 at-risk patients from across London who have hypertension (HTN) or hypertension and type 2 diabetes (T2D). Additional interviewee information:



2 participants had hypertension, and 3 had both hypertension and type 2 diabetes



3 participants were male, 2 were female



Participants were between 38-69 years old



All participants were London based



All participants were from an ethnic minority

What do patients know about CKD in relation to their at-risk condition?



“The last blood test I had I didn’t know what the numbers meant.” - At-risk patient

Patients had extremely low levels of knowledge around how their health condition(s) might affect their kidneys. Of those interviewed, only two mentioned that kidney issues could be a challenge for them in the future, however they did not perceive it as a high risk. This was due to kidney issues running in the family (1/5) or what their health professional highlighted as one of many potential risks in a T2D review (1/5). However, all interviewees were unaware that by having T2D or HTN, they had an increased chance of being affected by CKD. This could be happening because:

- Patients receive an overwhelming amount of information about T2D and HTN when first diagnosed. CKD information might be easily missed or given a reduced priority. Many patients don’t understand the function of the kidneys and don’t think to discuss them with their primary care clinician. This is unlike eyes and feet, which some T2D patients cited as concerning for them.
- Patients described being confused and scared when they got their initial T2D or HTN diagnosis, making it more challenging for them to take in or remember information.
- Patients described not fully understanding the purpose of ongoing screening and tests such as bloods as well as not understanding the test results and their implications.

What are the barriers to getting tested and how they can be reduced?



“I can never find the right time to make an appointment with all the busy scheduling that I had” - At-risk patient

What are the barriers?

When looking at barriers that patients have when it comes to a) attending any GP appointment and b) booking an appointment to discuss their T2D and/or HTN diagnosis, it needs to be noted that for all at-risk patients interviewed, health was a low priority before they got a diagnosis for T2D and/or HTN.

Patients did not seem to anticipate getting a serious health diagnosis such as T2D and/or HTN and therefore deprioritised health appointments before they were diagnosed in favour of more pressing issues. The most common of these being:

- Lifestyle getting in the way (4/5) such as: Work or having a busy schedule.

Other barriers included:

- Finding it difficult to get appointments (1/5) such as: Parking at surgery, getting hold of a GP, tech issues with the GP app.
- Personal preferences (1/5) such as: Fear of invasive tests or prefers face to face appointments.
- Illnesses getting in the way of booking appointments (1/5).
- Knowledge about at-risk condition (1/5) such as: Understanding what symptoms to look out for.

How can the barriers be reduced?

Awareness and understanding play a large role in catching any health condition early. By helping patients to understand the risks of their condition developing into CKD, we hypothesise that it will increase the likelihood of them attending ongoing health checks and being proactive regarding their health, helping them to overcome barriers.

In addition to this, external forces such as a GP or a friend/relative acknowledging or commenting on a patient’s at-risk symptoms increased their likeliness to go to an appointment. Given that those with CKD often do not get symptoms, this insight is not directly transferable for CKD patients. Further research is required to understand the role GPs and nurses play when it comes to relaying information around risks and the relevance of blood (eGFR) and or urine (uACR) tests (see CKD patient interviews page 13).



“It wasn’t communicated the importance that I think the condition demands.” - At risk patient

How did patients find the at-risk diagnosis process?



“Our [surgery] was very friendly one and literally was next door to us. So, we knew all the doctors and everyone there.”
- At risk patient

Getting a diagnosis

When it came to diagnosis for their T2D and/or HTN , 4/5 patients were diagnosed by their GP with one patient going straight to secondary care (A&E).

Patients had mixed responses about how they felt around contacting their GP when their symptoms first presented. A few patients had close relationships with GPs which made this process easier, however one patient was ‘reserved and scared’ about contacting a GP, mainly due to the fear of what they might find. A patient’s relationship with their GP (2/5) was highlighted as being important when it came to their willingness to go to an initial diagnosis session.



“It is a little bit confusing. Because they’re looking at the numbers, and they know what the bands of what needs to be ...For me, it’s really just being told what that is.”
- At-risk patient

Diagnosis

4/5 patients described feeling confused or scared when they got their diagnosis of either T2D or HTN, which impacted their ability to take in information about their new health condition.

Most patients felt that the severity of the disease or its impacts weren’t properly communicated, with the patient who was diagnosed in A&E being the most vocal about this.

How are patients managing the early stages of their condition?



“I didn’t take [it] seriously. I was pissed, I wasn’t happy... I shrugged it off”
- At-risk patient

Every patient expressed regret around their behaviour at diagnosis and wished they had taken their condition more seriously when it was first diagnosed. Some of the key challenges that came up from at-risk patients around barriers to managing their condition were:

- They found it hard to reduce the stress in their life and focus on their health (4/5).
- They found it hard to make lifestyle changes such as losing weight (3/5).
- That they didn’t need to improve their diet or exercise as they already felt they had a healthy lifestyle (2/5).
- They were in denial about the risks of their disease and its severity (2/3).

How are patients managing the later stage of their condition?



“In terms of my stress level, I’m a Muslim so pray five times a day... I find that to help me a lot thing in managing stress.” - At risk patient

Patients struggled to adopt lifestyle changes after their diagnosis. The biggest changes in lifestyle choices came when individuals were proactively self-educated about their condition.

We collected some hypotheses that require further validation to be applied to improving patient self management:

- If patients who have created personalised ways to manage their condition have better health outcomes than those that don’t e.g., using prayer to relieve stress.
- If patients would find it easier to keep on top of their condition if they had access to their health records and understood the information on it.
- If a shift in life outlook - such as a desire to leave a legacy or realising the importance or impact their condition has on them - spurs patients to take more action around their health.

What drives people to manage their condition?



“I didn’t take this seriously... I wasn’t sat down like, listen, listen to me now. This is over make or break now. If you solve this, you can be fine. If not, it’ll be in tatters.”
- At-risk patient

Initial diagnosis drivers

Helping patients understand the severity of their condition impacts how invested they are early on in managing it. This can be impacted by:

- How the information about their diagnosis is delivered to them - with one participant mentioning the need for more ‘emotion’ in how his condition was relayed to him for him to understand the severity of his diagnosis.
- Ensuring that the diagnosis and the information about it is presented in an accessible way, for example using simple language that the patient understands.
- Having a connection with the HCP relaying the information was also believed to help a patient be more likely to grasp the severity of their condition.

How are patients finding their ongoing care?



“Regular appointments have been six months, but again, some of them haven’t occurred. I think the last one I had was almost an annual one.” - At-risk patient

Health is often a low priority for patients which can mean they are less prone to chasing appointments such as ongoing check-ups and wait for their GP practice to contact them. For one patient that was engaged in their health care but found the ongoing support minimal, they actively reached out to their GP to ensure that reviews would happen.

Patients described how the quality of care varies across health professionals and in particular GPs. For one patient, this meant that they chose a favourite health professional (their GP) and connected with them to answer any health issues.

The overall process of booking appointments and attending ongoing appointments seems to be universally stressful for patients for a variety of reasons. These ranged from connecting with a GP/nurse, taking time off work, being fit enough to go, the amount of time you have with the GP and the quality of care from a practitioner.

In addition to this, patients found lifestyle changes hard to implement, meaning that after their first diagnosis they needed to be checked up on and potentially put on medication when they aren’t committing to changing old habits which were detrimental to their health.

What wider circumstances impact their at-risk condition?



“My day from the minute I get up is just full-on stress.” - At-risk patient

Overall circumstances

Participants cited having a ‘busy schedule’ as a barrier to them being able to focus on their health. This was the case even if they knew it was a key part of managing their treatment, such as eating regular meals when diabetic. Every patient mentioned stress as a lifestyle factor that impacted their ability to manage their health day to day.

Health management

When initially diagnosed, patients all had a period where they ‘got to know’ their condition, the impacts of it, and finding suitable and realistic lifestyle changes which can help lessen its effect. The speed in which this process can be done seemed to depend on how clearly the implications of their diagnosis was communicated at the start, their own family experience of the disease, and how important health was to them as an individual.

What health inequality factors impact at-risk patients?



“It was communicated like it’s quite common in the black community... It wasn’t like something that was delivered to me like it was that important.” - At-risk patient

Further work needs to be done to understand the impact of health inequalities as insights were limited from the at-risk patient interviews. There were however, two key areas that were highlighted and require further validation:

- Is there a ‘playing down’ of a patient’s diagnosis if they are from an ethnic minority as it’s perceived that certain minorities are more likely to get a health condition such as T2D?
- What impact does having mental health issues (diagnosed or not) or a learning difficulty (such as dyspraxia or ADHD) have on a patient’s outcomes when it comes to being at risk of CKD and/or managing their CKD?

How do patients feel about being put on medication?



“I don’t like taking medication as much as possible unless it’s urgent.” - At risk patient

When asking questions around about medication, two areas were raised that we review in more depth in our next round of interviews:

- Medicine adherence
- Understanding the purpose of the medicine prescribed

Insights requiring further validation:

- Every patient mentioned their busy lives being a barrier to them having health as a priority, does this get in the way of medication adherence?
- 3/5 did not fully understand what the medication they were given was for, does this lack of understanding impact their adherence?
- At-risk patients described feeling confusion around the time of their diagnosis, does this cloud their understanding of why they are being given medication and for what purpose?
- One patient disliked the idea of being on any form of medication, is this a common view among patients?

Which staff are best placed to optimise patients on guideline directed treatment or deliver ongoing care to patients for their CKD?



“The last blood test I had I didn’t know what the numbers meant.” - At-risk patient

Insights around identifying which staff are best placed to deliver guideline directed treatment to patients can be broken into two areas:

- Who patients feel most comfortable with currently.
- What needs to be considered around wider health professional involvement.

Who patients feel most comfortable with currently

GPs were by far the group that were referenced the most by patients in terms of trusted health professional roles. However, the same patients who preferred to speak to their GP around health issues, also highlighted multiple challenges around getting appointments with them. (See Barriers section) Due to this, we need to look wider than GPs when it comes to ensuring patients receive guideline directed treatment.

What needs to be considered around wider health professional involvement

Patients highlighted three things that were important when getting a diagnosis from a health professional:

- That the patient feels listened to and supported by the person giving the diagnosis.
- For them to explain how diet and other lifestyle factors can impact their condition and lead to CKD.
- For them to understand the family history risks and highlight their importance to the patient.

CKD patient interviews

Overview

We interviewed seven chronic kidney disease (CKD) patients from across England.

Additional interviewee information:



4 participants were female, 3 were male



Participants were between 30-56 years old



4 participants were from an ethnic minority background and 3 were white

CKD diagnosis timeframes:



4 x had had CKD for 3+ years.



2 x had had CKD for 2 years.



1 x had had CKD for 1 year.

Patient health profiles prior to CKD:

- Participant 1: T1D, HTN
- Participant 2: HTN
- Participant 3: Heart failure
- Participant 4: polycystic kidney disease
- Participant 5: AKI/HTN
- Participant 6: T2D and HTN
- Participant 7: Heart Failure

Why is knowledge around CKD risk factors so variable, particularly to those known to be at risk?

Problem areas:

Family history and risk factor education, awareness about CKD severity, assumption that GPs will highlight risks, lack of clarity around test purposes and results.



“I certainly hadn’t made the linkage with the hypertension with my kidneys.” - CKD patient

It is not clear to patients that having risk factors and/or a family history increases their likelihood of getting CKD.

- Even when a patient was aware that CKD ran in their family and had had health as a priority from a young age due to having an at-risk condition such as hypertension, the link between the two isn’t being made by the patient.



“Have no clue. I don’t know what the causes of chronic kidney disease are.” - CKD patient

Patients don’t think they were warned enough about the risk of CKD by health professionals.

- Patients had low knowledge about CKD and its risks before they were diagnosed, with many of them still being unsure about what the condition meant for them and their health. One patient still had no idea what caused their CKD and seemed unsure of how they could manage their condition.



“The GP knew our family history, and they never said anything, is it worth getting tested or anything like that.” - CKD patient

Patients assume GPs will clearly highlight any health risks they should be aware of due to their family history or medical conditions.

- Patients are assuming that their GP will inform them of any risks that they should be aware of, however we know from clinician interviews that GPs and nurses are not always highlighting these risks to patients clearly and can sometimes be reluctant to tell a patient even if they have been diagnosed with CKD (see Clinician interviews page 16). Reasons for this were: they didn’t want to scare the patient, they didn’t have the right language to easily describe CKD or they didn’t want to tell a patient if they already have another health condition that they saw as more problematic for example T2D.



“Told we’d be seeing once a year for blood pressure checks, weights, and blood tests. And see you again next year.” - CKD patient

Patients don’t understand what their regular health tests are for or what their results mean.

- Most patients weren’t aware what their health tests were for or had the technical language to decipher their test results. This meant that if it was not explicitly mentioned by the health doing the tests, patients didn’t realise what conditions they were at risk of and how much closer they were to getting them.

What are the health inequalities and wider circumstances that affect the CKD and at-risk population?



“Sometimes I can get a little bit overwhelmed with the CKD and the hypertension.” - CKD patient

When interviewing the CKD patients, the following points came up as issues:

- Fatigue of the condition gets in the way of ‘normal life’ making it harder for at-risk patients to manage their condition (2/5).
- For patients who have multiple chronic health conditions, managing them can be stressful - which adds to the impact that they have on a patient’s health (1/5).
- The effects of their condition can make it hard for patients to hold down a job (1/5).
- Mental health issues can also make it challenging to manage for patients to manage their CKD (1/5). This also came up as a challenge in the at-risk interviews.



“I’ve got anxiety and depression, so [my CKD] is just another added concern” - CKD patient

What drives at-risk patients to get tested, what are the barriers and how they can be reduced?



“My partner, she said, look, you need to go and get this seen to. She’s quite influencing when it comes to me getting things done.”
- CKD patient

CKD patients reflected on their experience of getting tested for CKD and shared the following as barriers:

- If patients don’t feel like they’re getting the support they need from a clinician, they are unlikely to attend appointments (1/5). When the relationship with a GP improved, one patient started to attend appointments more.
- If patients have co-morbidities, they are likely to prioritise the ones that are causing them the most issues. (1/5) As CKD tends not to have symptoms, and often seen as a ‘by-product’ of other conditions, patients are less likely to address it or prioritise coming to the practice for testing or appointments.
- Feeling physical symptoms spurs patients to get tested (1/5).
- Family and friends are a driver for patients getting tested initially (1/5). In the at-risk interviews, having external forces such as the GP or a friend/relative acknowledging or vocalising patient’s condition increased their likeness to go for tests.
- If patients don’t understand the point of the tests they are less likely to attend (1/5).
- Some patients could be wary about booking tests online and data sharing (1/5).



“I’ve got a lot going on, health wise. I tend to prioritize the things that are causing me the most issues.” - CKD patient

How do patients and clinicians feel about the CKD diagnosis process?

Problem areas:

The severity of CKD isn’t being properly communicated, the profile of CKD is too low, CKD stages aren’t understood, there aren’t clear treatment plans at diagnosis.

Note: of the five patients interviewed, two were diagnosed outside of primary care - one by a cardiologist and one by a nephrologist after a GP referral.

The severity of CKD isn’t being understood by patients or being clearly explained by clinicians.

- Patients felt that clinicians weren’t highlighting the severity of CKD to them during screening and diagnosis. This led some patients to not take their condition as seriously as they later did once their condition had worsened, or they had done further independent research or spoken to a specialist.

The profile of CKD is so low that the gravity of the condition is being overshadowed by other conditions.

- When it comes to diagnosis, if a patient has other co-morbidities such as hypertension or type 2 diabetes, the more common conditions can take priority for patients over CKD for treatment. These conditions are more well-known and patients have had them for longer, meaning they’ll prioritise treatment and knowledge of them over CKD.
- In addition to this, the lack of symptoms for CKD, combined with the fact that its impact is not as ‘visible’ as other conditions, means patients tend to demote it as a risk. For example, in round 2 of clinician interviews, a pharmacist highlighted the fact that patients often with T2D will frequently ask about getting foot problems and will never ask about the risk of CKD.



“I’m a sucker for a plan. This is what we need to do going forward. This is how we can monitor things.” - CKD patient

Patients are unsure what the stages of CKD mean or what stage they are.

- From our clinician interviews, we know that health professionals have differing views on the importance of the CKD stages. Primary care do not focus on diagnosing or managing CKD stages 1 & 2 (see Clinician interviews page 16). However, nephrologists want to see patients diagnosed earlier as they are often referred too far down the line, making it harder to control their condition. This confusion between risk and CKD stages is impacting patients understanding of their condition, with them not understanding the importance of the stage they are at or what it means for their health.

Patients want a clear plan for treatment at diagnosis.

- Patients want to know what’s happening next, how their condition will be monitored and what treatment they will be given and why. This was echoed by the at-risk interviews, where interviewees felt that they were being asked to do tests or take medication without understanding the purpose of them.

At risk patient interviews

CKD patient interviews

Clinician interviews

Co-design workshops

What do patients know about treatments for CKD, how do they feel about it and what are the barriers to them taking medication?

Problem areas:

****Low levels of knowledge around treatment****, understanding test purposes and results, medication and its purposes, and shifting patient's lifestyle habits is challenging.



"No, there is no treatment for CKD 3. Is there?" - CKD patient

Overall, patients had low levels of knowledge about CKD treatment (5/5). This is unsurprising as the clinician interviews also highlighted the same for issue for health professionals. When it came to patient treatment, there were two areas that were highlighted as a challenge:

- Patients don't understand what their tests are measuring and what their results mean (2/5). This insight also came up in the at-risk patient interviews, with patients being unsure about if or why their condition was worsening.
- Patients are confused about the medication they are taking and why (2/5).



"I didn't really have an incentive to be better"
- CKD patient

Only two potential barriers to taking medication came up in interviews, and both were from the same participant:

- Having to eat something before taking medication in the morning is a barrier (1/5).
- Experience of a medication affecting a family member negatively (1/5).

When it came to barriers and drivers for getting patients to change their lifestyle habits, two insights that came up in the CKD patient interviews and were also echoed in the at-risk patient interviews:

- It's hard to incentivise patients to change their health habits before it's too late (1/5).
- There was a shift in perception and raising health as a priority once patients realised the severity of CKD (or an at-risk condition).

Clinician interviews

Overview

We interviewed 12 clinicians across primary and secondary care working in CKD related pathways in NWL and collected insights from weekly pathway mapping sessions with our core clinical team



4 x GPs



2 x GPs



5 x Nephrologists



3 x Nephrologists



2 x Pharmacists



1 x Pharmacist



1 x Nurse



Why is knowledge around CKD risk factors so variable, particularly to those known to be at risk?

Problem areas:

Too much reliance on GPs picking up issues, varying primary care knowledge around CKD and being able to notice it in test results



“It relies on skill of GP picking up the reading.”- GP

Clinicians felt there is a lack of awareness around CKD within at-risk groups and that patients assume any new health conditions, such as CKD, will be picked up by their GP. However, whether an at-risk person gets noticed depends heavily on the clinician reviewing their tests. Knowledge around CKD and how to treat it varies between primary care health professionals and seems to be limited.



“The knowledge about why you should do it and what the benefits are haven’t been well formulated and socialized amongst GPs.”
- GP

What drives at-risk to get tested, what are the barriers + how they can be reduced?

Problem areas: patients are nervous about tests, urine samples

Urine samples were a particular problem area with challenges being: Patients are reluctant to bring in samples, surgeries relying on people coming in to do them which happens less often nowadays, HCAs aren’t always available to support, testing was seen as resource intensive, there was confusion around tests and lack of clarity around what results mean.



“Patients are reluctant to bring in urine samples.”- GP

Patients trust that GPs will pick up changes in their health or new health conditions. However, knowledge around CKD and its treatment among health professionals is limited and varies between clinicians.

When it came to getting tested, clinicians believed patients get nervous and are particularly reluctant to bring in urine samples. Surgeries still struggle to get patients uACR tested despite there being a NWL payment attached to doing annual urine tests for T2D patients. Within GP surgeries, clinicians identified the following reasons for why urines were less likely to be done by at-risk patients:

- **No CKD screening pathway:** patients will only be asked for a urine test as part of a few existing annual reviews in other pathways and/or conditions namely; T2D, hypertension, medication, >40 review and for rheumatoid arthritis.

- **Relying on patients coming in:** A practice relies on people bringing their urine in to then be sent off for analysis, however lots of patients don’t come into the practice for their annual reviews as they are being done virtually. For example, HTN patients might be asked to get their blood pressure checked remotely so don’t come into practice and many patients are managed through telehealth appointments.
- **HCAs are too busy:** Even if a patient brings their urine the practice, HCAs might not collect it as they are busy with other work that is a higher priority eg QOF activities.
- **Urine dip is resource intensive:** The process of testing patients’ urine via urine dip in practice is seen as extremely laborious. It has many steps to it and is seen as a burden by clinicians. Clinicians do not want all their HTN and T2D patients bringing their urine in as their practices (receptionists and staff) will not be able to process them.
- **Confusion around tests:** There is confusion amongst clinicians about when the urine needs to be taken, with a number of clinicians not using patient’s urine if it’s not the first of the day. One GP explained that eGFR >60 is also not that well understood as the lab used to not report these numbers and suddenly started doing so without an explanation. It is suspected some labs still do not report >60.
- **Lack of clarity around results:** It is rare for uACR testing to be done outside of T2D so when it is, primary care are often unsure of how to interpret the results.
- **A feeling of not burdening the patient with more possible conditions:** For the co-morbid stable patient, it is the belief of some GPs that there is little benefit in burdening them with a CKD patient unless it is a late stage (stage 4 is generally what is mentioned). The same is true for elderly patients, many of whom have CKD but due to their age are not seen as needing intervention specifically for their CKD.



How do patients and clinicians feel about the CKD diagnosis process?

Problem areas:

Patients unlikely to be diagnosed and coded pre stage 3 (stage 1-2) due to lack of incentives and knowledge about patient risk, primary care clinicians struggle with telling patients they have CKD. There is confusion about the coding process.

Secondary care feel patients are not being appropriately motivated to make lifestyle changes. Primary care feel secondary care could support with patient education once diagnosed with CKD.



“Patients don’t want to be told about another condition” - GP

When it came to patients being diagnosed and coded, as stage 1-2 are not seen as a condition they are less likely to be identified. Clinicians tend to focus on identification around stage 3. And as there are no payments attached to early diagnosis of CKD, primary care do not have an incentive to try to diagnose patients earlier than that.

Clinicians struggled with how to tell patients they had CKD when they already had other health conditions or when they felt patients might not react well to hearing their diagnosis.

Others struggled to explain the condition in a way that patients would find easy to understand. GPs felt there wasn’t CKD specific advice available to them. This conversation was sometimes done over the phone.

Additionally, GPs do not always tell a patient they have a diagnosis, and this can lead to challenges later on if a patient has had a condition for a while but it had not been raised before.

Once they got a diagnosis, clinicians noted that some patients were not motivated to make changes to their lifestyle. This echoed what we heard in patient interviews. One patient wished that they had been directed to peer support groups upon diagnosis to help them learn how to manage it from the start.

One suggestion from a GP was to get secondary care to focus on educating patients newly diagnosed with CKD.

There was agreement from primary and secondary care that a shared language needed to be created to explain CKD to patients



“Language used to explain CKD too scientific and not relevant to the patient” - Nephrologist

Who is involved in treating CKD, what are the pathways it touches on and what are staff’s responsibilities?

Problem areas:

GPs are working at full capacity, Nephrologists want earlier diagnosis, uACR timing and result challenges, No CKD specific review, CKD referrals to secondary care.



“We’ve been told to minimise referral to renal.” - GP

Primary care challenges

The burden of CKD identification and testing falls on primary care, and in particular GP and HCAs. However, GPs are working at full capacity with many of them feeling that they are managing CKD to the level that is expected of them. Additional challenges include:

- **Workforce:** GPs, HCAs and nurses are seen to be working at full capacity. Nephrologists and GPs wanted pharmacists to be used to diagnose and manage CKD patients as they have the right skillset and potentially capacity.
- **Earlier diagnosis:** The focus for GPs is around diagnosing CKD at stage 3 but nephrologists would like them and the rest of primary care to diagnose and optimise high risk patients earlier

- **uACR challenges:** Primary care is not systematically getting uACR tests for at risk patients except for T2D and even here testing is missed. Additionally, there is some confusion among primary care practitioners if the urine sample needs to be collected first thing in the day or not.
- **No CKD specific review:** One pharmacist commented that they were responsible for running the annual T2D reviews where patients often had CKD. Their priority was to meet T2D targets and only had 10 mins to run the review, so this meant CKD was typically not discussed.
- **Referrals to secondary care:** The referral criteria for CKD to nephrologists were designed to reduce the volume of patients and GPs have also been told to reduce the number of referrals to renal. However, Nephrologists could be open to reviewing patients outside the referral criteria.

Secondary care challenges

- GPs are focusing on stage rather than risk for referral criteria (Nephrologist)
- Secondary care do not review patients until they are in advanced stages of CKD and the first review might not be with the patient present but via a virtual record review.



“Our virtual consultations generally are undertaken with people with more advanced CKD and do not involve the patient.”
- Nephrologist

Who is best placed to manage patients according to guidelines and how can we encourage patients to self-manage?



“I worry would another doctor be good enough” - GP

GPs

- GPs are working at full capacity and can't take on any more work.
- GPs might not all have the right knowledge to optimise patients according to the latest guidelines
- There is distrust even amongst GPs about their ability to manage patients with CKD.
- Patients might insist on speaking to a GP over other health professionals such as a pharmacist.

HCA's

- HCA's were seen as a potential option to shift the workload around CKD, with them reviewing patients if they have clear guidance on what to do
- However, there are currently problems recruiting HCA's and they are seen as overworked by current local requirements.
- HCA's would prioritise what their payment targets are and there is currently no incentive around early diagnosis of CKD.

Nurses

- Nurses are seen as overworked by current local requirements but do have some of the required skills that could support with CKD diagnosis and are involved with T2D reviews.

Pharmacists

- Pharmacists were seen as having the right skill set to support with diagnosing and optimising patients on treatment for their CKD.
- Pharmacists are used for T2D and medication reviews and have to focus on delivering DES related activities so their time is limited
- They might not be being used to their full capacity in some PCNs

Nephrologists

- GPs think secondary care would be best placed to educate patients newly diagnosed with CKD.
- Nephrologists could be open to being involved in patient care outside of referral criteria as they feel their knowledge could help stabilise at risk patients – and primary care currently not doing this.
- Nephrologists find that GPs ask lots of the same questions through the Advice and Guidance portal

Patients

- Patients could do tests at home to relieve some of the burden on primary care.
- Nephrologists receive lots of incorrect referrals which they still take the time to review and send back to GP with comments. There is a mix of some GPs referring too early and others too late

What are the barriers (especially health inequalities) to following guideline directed treatment for patients and clinicians?

Problem areas:

No clear guidance around risk assessments, difficulty knowing what guidelines to follow due to co-morbidities, networks of care, CKD treatment (particularly SGLT2is outside T2D).



“HTN/DM/CKD/heart failure - many guidelines for GPs to follow but lots of overlap”
- Nephrologist

Below are the barriers identified for following guideline directed treatment for patients and primary care clinicians:

Primary care

- **Risk assessment:** GPs don't know how to assess a patient's risk level (nephrologist) and want clear guidance from secondary care on which patients should be prioritised for earlier intervention.
- **What guidelines to follow:** Patients with CKD have complex needs and often co-morbidities, making it unclear which guidelines a clinician should follow. GPs have asked for a clear care pathway.

- **Network of care:** Not all GPs have the right knowledge to optimise patients medication and team work can be poor within practices and PCNs. (Nephrologists)
- **CKD treatment:** The standard response for kidney related diseases from GPs around diet is to cut salt. Clinicians have a low level of understanding around CKD treatment and there is a lack of confidence amongst GPs when it comes to SGLT2is use outside of T2D and even within T2D when patients' eGFR fluctuates.

Patients

- **Patients prioritise other risks:** For patients, as CKD often has no symptoms, they will prioritise managing their other risk factors such as T2D or HT.
- **CKD treatment:** They might be reluctant to go on medication especially statins.

What is needed to ensure clinicians are supported to identify, prioritise and treat patients according to the guidelines?

Problem areas:

Identification – lack of incentives around early identification, challenges around CKD definition and coding

Prioritising – No standardised process for identifying patients to test, challenges around risk assessment, lack of knowledge around eGFR decline timeframes.

Treatment – Challenges around what guidelines to follow, lack of understanding around CKD medication, resource heavy to optimise patients to latest guidelines



“Can nephs create a definition of ‘at risk’ patient?” - GP

Identification

Challenging areas for Clinicians around identification of patients:

- **Lack of incentives for earlier identification:** The lack of incentives around early identification of CKD was raised by clinicians as a blocker to coding patients.
- **Coding challenges:** The definition of CKD by eGFR and uACR was seen as unclear and GPs were believed to be struggling with CKD coding.

At risk patient interviews

CKD patient interviews

Clinician interviews

Co-design workshops



“I can see the eGFR has dropped but the result doesn't have triggers for time period.”
- Pharmacist

Prioritising

Challenging areas for Clinicians around prioritisation of patients:

- **Standardised identification:** There is no standardised way of identifying which people most need what tests for CKD (GP) and it was believed that GPs aren't able to assess a patient's risk level (nephrologist). GPs want clear guidance from secondary care on which patients should be prioritised for earlier intervention as the NICE guidelines are too broad.
- **eGFR decline:** A drop in eGFR that is 'significant' was seen as something that should dictate whether a patient should be reviewed and considered for referral (nephrologist). Nephrologists want GPs to investigate the reason behind the decline. Primary care clinicians have varying understanding of what the eGFR drop and time period should be and they might have to calculate this manually in their system. They would like this to be automated.
- **Kidney Failure Risk Equation:** Nephrologists use the KFRE to assess patients' risk of developing kidney failure would like it to be used more widely in primary care when deciding whether to refer patients. However many primary care clinicians aren't aware of this equation and cannot access it in S1 or EMIS. The equation also relies on a uACR result which lots of patients will not have.

Managing CKD patients

There is a low level of understanding around CKD within clinicians, especially when it comes to management. There needs to be an increase in awareness around how best to manage CKD to reduce cardiovascular complications. The challenging areas raised by clinicians around treatment were:

- **What guidelines to follow:** Different guidelines make it hard for a GP to know what to do with patients who have multiple conditions “HTN/DM/CKD/heart failure - many guidelines for GPs to follow but lots of overlap” - Nephrologist
- **CKD treatment:** The standard response for kidney related diseases from GPs around diet is to cut salt. Clinicians have

a low level of understanding around CKD medicines. “I thought SGLT2is were bad for kidney function” - Pharmacist.

- **Incentivising medicine:** Clinicians expressed dislike at being financially incentivised to prescribe statins.
- **Resourcing burden:** Uptitrating RAASi therapy was seen as an intensive burden on the workforce as you need to regularly check the patient 's bloods in the first few months (typically HCA). There is also no CKD review so patients don't get a dedicated time to speak about their CKD with their GP. The conversation will take part in existing review eg T2D so is likely to be deprioritised due to lack of awareness and time as the funded activities are prioritised.



“The only treatment that I am aware of is lifestyle” - Nurse

What do clinicians need to make guideline directed treatment simple and easy to follow?

Problem areas:

Prompts around CKD coding and tests, automating the process (eg eGFR drops or at home testing), reducing GP time to explain screening process to patients (eg with a video).



“There is no prompt from lab to code” - GP

Knowledge around CKD treatment and management is low among clinicians. NICE guidelines are lengthy and challenging for a clinician to read while they are pressed for time. A few suggestions that came out of the interviews about how this process could be made easier are:

- **Prompts:** Two clinicians suggested attaching prompts to eGFR and uACR lab results to get clinicians to follow up with uACR tests, code and diagnose patients.
- **Automation:** A GP suggested some of the CKD process could be automated, such as eGFR drops or prompts and at home testing. Nephrologists also believe the primary care process of screening and coding needs to be as automated as possible to enable them to manage CKD better.
- **Video explanations for screening:** There could be a pre-generated patient facing video that explains CKD and the need for screening. This would be the GP explaining the screening. Clinicians felt patients did not understand the need for them to be screened and needed something more engaging to increase the chance of them coming to the surgery

At risk patient interviews

CKD patient interviews

Clinician interviews

Co-design workshops

- **Templates:** One GP suggested adding more CKD information and prompts to HTN and T2D templates. One GP said they did not want a separate CKD template as they feel they already had too many and it was unlikely to be used if not funded. Guiding content to help explain CKD diagnose and advice could be linked to these templates.
- **Patient education:** More information pre and at diagnosis; better links to diabetes groups and take home material (leaflet) peer to peer support groups post diagnosis
- **Screening outside of GPs:** At home or in the community uACR screening

What do patients know about treatment for CKD, how do they feel about it and are there barriers to them taking medication?

Problem areas:

Low level knowledge around treatment options for CKD, misinformation around impacts of sglT2is.



“I thought sglT2is were bad for kidney function” - Pharmacist

Clinicians feel patients are reluctant to go on statins and can experience unwanted side effects on RAASi therapy especially in older patients. Some patients do not want to be on additional medication if already in addition to existing medication.

Clinicians are not always aware of the treatment options for CKD or understand them. Two insights that require further validation:



- Why clinicians might not let their patient know that they have CKD if they believe their current treatment for existing conditions ‘covers’ CKD.
- What impact SGLT2is is perceived as having, and if it’s widely believed to negatively impact kidney function.

It is important for a clinician to specify the purpose of new medication they recommend and what it is for to increase patient understanding and hopefully, adherence. This was echoed in the round 1 at-risk patient insights.

Co-design workshops

Overview

We ran three co-design workshops ranging from 1.5 to 2 hours in length, with the purpose to come up with ideas to solve for the challenges highlighted by the research phase findings, and to do this in a truly collaborative way, bringing in as many perspectives and viewpoints as possible.

-  15 x patients at first co-design workshop
-  6 x clinicians at second co-design workshop
-  8 x patients and 4 x clinicians attended third validation workshop

Co-design workshops

A team of service designers and PPIE experts ran three workshops with people who experience the CKD pathway to co-design solutions for the largest opportunities identified during the discovery phase. The workshops were designed to enable diversity of opinion and provide a safe and trusted environment where every voice is welcomed and respected.

1

Patient workshop

The group came up with ideas for three of the main opportunities from the discovery phase.

Opportunity A:

How could CKD be better explained to people when they are diagnosed so they are able to understand their condition and what it means for them in terms of their daily lives?

Opportunity B:

How could CKD patients be made more aware of how to manage their condition so that they can be proactive about their care?

Opportunity C:

What can be done to enable people with CKD to better understand how their condition might develop and affect them over time, and what they can do to prevent or slow this if possible?

2

Clinician workshop

The group came up with ideas for three of the main opportunities from the discovery phase.

Opportunity A:

How could primary care staff be given confidence to code patients when their results indicate stage 3 CKD and ensure patients receive their diagnosis as soon as possible?

Opportunity B:

How could primary care clinicians be enabled to manage CKD patients on top of their existing long-term conditions?

Opportunity C:

What could help primary care staff identify and manage CKD patients who are fast progressors?

3

Patient & clinician workshop

The group build out details of the two of the four ideas:

What should the experience be for a patient or clinician?

What are the key features it should have?

What should it avoid?

Idea 1:

A CKD session for patients via a healthcare professional right after diagnosis and ongoing peer support around living with the condition.

Idea 2:

Enhanced prompts around lab test results that help primary care follow guidelines for CKD patients.

1

Patient
workshop

2

Clinician
workshop

3

Patient &
clinician
workshop

Patient workshop report

Attendees:

- 15 patients with varying stages of CKD
- 3 Facilitators
- 3 Notetakers
- 2 patient representatives
- 1 nurse representative

Project team roles included people from the following organisations:

- The London Kidney Network
- Imperial College Health Partners
- The Applied Research Collaboration Northwest London
- AstraZeneca

On September the 6th 2022 from 1830 to 2030, fifteen CKD patients attended a two-hour virtual ideation workshop looking at ways to improve early identification and prevent progression of chronic kidney disease (CKD) in the UK, starting in North West London.

The workshop was run in three groups of five, each tasked with coming up with ideas around an opportunity that had surfaced from the extensive research done prior to the workshop by the project team. These opportunities are as follows:

1. How could CKD be better explained to people when they are diagnosed so they are able to understand their condition and what it means for them in terms of their daily lives?
2. How could CKD patients be made more aware of how to manage their condition so that they can take more control of their care?

3. What can be done to help people with CKD to better understand how their condition might develop over time and what they can do to slow this if possible?

In their smaller groups, the participants each completed a solo ten-minute time-boxed activity to come up with as many ideas as they could to solve for the challenge. Participants were provided with an ideas template for them to write these ideas into and send to us after the workshop. They were sent this template and the opportunity via email ahead of the workshop to give them the chance to start thinking beforehand.

The ideas:

Below are the main ideas that were recorded in this solo activity by the groups:

Glossary of CKD terms	CKD nurse focused on support and conduit to specialist team	mental health support	A 'how to' to understand blood test results	An understanding of all medications for the co-morbid patient (polypharmacy)	Tailored lifestyle advice around work, diet and exercise
Tailored lifestyle advice around work, diet and exercise	Symptom alerter so those with CKD know what to look out for	A DESMOND for CKD	A guide for progression	1-1 CKD info session at diagnosis with patient and carer	Printed CKD info packs for GP surgeries
Online and offline (inc Social media) channels explaining what to do as a CKD patient to avoid progression and development of other co-morbidities	Information on buses and at train stations for CKD awareness	youtube channel explaining CKD and endorsed by kidney care UK?	Clear diet advice particularly around potassium rich foods	Medication info at each appointment explaining the what, the why and the dosage	Patient information group sessions at diagnosis
information evenings with trusts to share info and learnings	patient-friendly language and glossary explainer	at home testing and self-management (urine and bloods)	re design the diagnosis process. Involve families in initial diagnosis moment. stretch out info over longer period	visual explainer of ckd stages, symptoms and where to go for help eg slides or video	An App showing stages of CKD and what develop at different stages; also, in it, diet and medication advice

1

Patient workshop

2

Clinician workshop

3

Patient & clinician workshop

The next activity was for each participant to feedback their two to three top ideas to their group and to discuss their reasons behind these ideas.

Once each participant had presented their ideas, the facilitator revealed and explained a few more ideas that had come up throughout the project with patients and clinicians from the project team. The group were asked to each vote on their top idea.

Once the voting was completed, the facilitator tallied up the votes and announced the winning idea(s). These were then broken apart and discussed in depth as a group.

Throughout these activities, a notetaker from the project team made notes of the ideas and the outcomes from each activity (in online workshopping tool miro) and a facilitator made sure the activities were clearly explained, that each participant had a chance to speak and that the group kept to time.

Below is an example of the ideation and voting activity from one of the three groups. The blue dots represent one vote:

TASK 1
[10 mins] Solo thinking time
Use the template we sent you to write down any ideas you have

TASK 2
[15 mins] Share top 3
Choose the three best ideas you've written down and share them back to the group

TASK 3
[5 mins] Facilitator shares previous ideas

TASK 4
[10 mins] Ideas voting
Dot voting, one vote per person

TASK 5
[15 mins] Discussion
What did you like about the top idea(s)?

Share top 3...

1 Support and knowledge around the condition	2 App to easily monitor the blood pressure and send to HCPs	3 Measure urine and colour of it and the uACR (practical at-home tests)	4
5 Patient to do own measurements and tests, blood pressure, urine and using a medical device with a cloud of the averages to send on to HCPs via their patient app (PDA)	6 Social media platforms and support groups. Ability for each knowledge and connection with others, particularly stages	7 creatinine measures at-home	8 Community groups to understand the reality and learn from one another in real life (job, finances, benefits, housing etc)
9 A DESMOND for CKD patients (or connect them?)	10 early engagement: Patient to patient networks/events/office mornings	11 A simple clear guide/care plan for renal patients to engage with	12
13 Social cultural support programmes taking into account dynamics (class, predisposition to CKD etc)	14 Community GDN support. Encourage emerging the App to do ongoing support the opportunity to speak, hear and engage. (PDA) This is a feature	15 mental health support	16
17 Simple one pager at diagnosis including symptoms to look out for/when to report back. As a young person in particular	18 Information and support around the importance of bloods and urine tests before the appointment and the appointment and the person discussion around the results	19 Better joined-up care between other departments for other conditions. Take the burden off the patient being in the middle.	20

Previous ideas...

21 CKD peer to peer programme for patients to share experience and tips

22 Printed material on CKD management for local community pharmacists to share with patients when they pick up medications

Could be woven into group A's idea >

Simple one-pager/care plan

At-home testing

DESMOND or equivalent for CKD

Support networks and community groups

Improved joined-up care support between departments

Pharmacy medication explainer

Mental health support programme for CKD

1

Patient workshop

2

Clinician workshop

3

Patient & clinician workshop

Once the three groups were brought back together, we had three top ideas to feedback and share with everyone else. There was just time for the group facilitator to play back each idea before the workshop closed.

The next steps are to run the same workshop but with clinicians to gain three solid clinician ideas to combine with the patient ideas. We then will be running a co-design workshop with clinicians and patients together to review all the ideas that have come out of the two workshops (patient and clinician) and to go deeper into them with a practical lens. The aim is to come out of this joint co-design workshop with a clear idea of what idea(s) make the most sense to develop and test in direct care in settings across Northwest London.

Patients were informed of these next steps and assured that they will receive communication from this project team as soon as the final idea has been confirmed.

A workshop debrief was held following the meeting with the facilitators and notetakers to discuss each groups ideas in further detail. From this discussion, it has been agreed that the ideas do overlap and it appears all three ideas centre around the development of a CKD service providing information, support and education at diagnosis as well as ongoing peer support through signposting to communities and groups when living with CKD. The final idea therefore has been summarised as follows:

A patient-focused CKD service with a healthcare professional right after diagnosis focused on clearly defining the condition and what this means for the patient as well as ongoing peer support around living with the condition.

It is important that the service will cover:

- What CKD is and what it means for the patient and their co-morbidities
- An explainer of CKD language and what these words mean
- What the process around CKD treatment and progression looks like
- Time for patients to ask question on topics that are relevant to them
- Signposting them to helpful support groups, communities and charities
- Ongoing support: Patient to be linked to peer support groups to support them with advice about the condition and build their mental resilience after diagnosis

The service could be virtual, on the phone, face to face and/ or through another digital channel and should consider the core design principles: language, inclusion, cultural background and accessibility. We will be working on the mechanisms for delivery of the service in the validation co-design session and in subsequent team design sessions. We have captured all the ideas from Miro and the ideas templates and stored them on our project workspace.

1

Patient workshop

2

Clinician workshop

3

Patient & clinician workshop

Clinician workshop report

Attendees:

- 6 Clinicians in total (2 GPs, 1 PCN manager, 1 pharmacist, 1 renal nurse, 1 nephrologist)
- 3 Facilitators
- 3 Notetakers

Project team roles included people from the following organisations:

- The London Kidney Network (LKN)
- Imperial College Health Partners (ICHP)
- The Applied Research Collaboration Northwest London (ARC)
- AstraZeneca (AZ)

On September the 16th 2022 from 1230 to 1400, six clinicians attended a ninety-minute virtual ideation workshop looking at ways to improve early identification and prevent progression of chronic kidney disease (CKD) in the UK, starting in North West London.

The workshop was run in one group discussing ideas around the following opportunities that have surfaced from the extensive research done prior to the workshop by the project team. These opportunities are as follows:

1. How could CKD be better explained to people when they are diagnosed so they are able to understand their condition and what it means for them in terms of their daily lives?
2. How could CKD patients be made more aware of how to manage their condition so that they can take more control of their care?

Please note that there is a third opportunity that the group did not have time to discuss:

3. What can be done to help people with CKD to better understand how their condition might develop over time and what they can do to slow this if possible?

Participants were provided with an ideas template for them to write these ideas into and send to us after the workshop.

The ideas:

Here are the ideas that were recorded in the session:

Once each participant had presented their ideas, the facilitator revealed and explained a few more ideas that had come up throughout the project with patients and clinicians from the project team which are as follows:

- Show ranges and coding reminders on eGFR and uACR test results
- Add CKD guidelines and coding nudges to relevant primary care templates eg HTN, T2D and CKD



1

Patient workshop

2

Clinician workshop

3

Patient & clinician workshop

The group were then asked to each vote on their top idea.

Once the voting was completed, the facilitator tallied up the votes and announced the winning idea(s). These were then broken apart and discussed in depth as a group.

Throughout these activities, a notetaker from the project team made notes of the ideas and the outcomes from each activity (in online workshopping tool Miro) and a facilitator made sure the activities were clearly explained, that each participant had a chance to speak and that the group kept to time.

The top two broad ideas were as follows:

1. Patient and clinician education service/sessions
2. Prompts and explainers highlighting what to look out for regarding CKD ranges and explainers on lab results

[The top two voted ideas are represented in the below image]

A workshop debrief was held following the meeting with the facilitators and notetakers to discuss each groups ideas in further detail. In this discussion we agreed to take forward the patient education intervention to the co design workshop as this aligns with the idea from the patient workshop. We took a next step to review our previous research and existing UK solutions to:

- Further develop the proposed interventions of lab results and streamlining CKD information for clinicians.
- Source ideas to solve the third challenge around identification and management of fast progressors/high risk CKD patients, that we did not have time to cover in the clinician workshop.

Using insights from our previous research, literature review and other data sources we were able to bring forward three other interventions to address the main research challenges

1. Patient focused CKD session right after diagnosis (idea shared also in patient workshop)
2. Enhanced lab test results that help primary care follow guidelines for CKD patients - There is potential here to also improve patient understanding of their CKD through access to their record
3. A risk stratification search and contact process that enables primary care to identify patients who are fast progressors with CKD
4. Integrate CKD guidelines and triggers into existing pathways

The core project team will be designing how best to develop these ideas into experiments through the upcoming co-design workshop on Friday 7th October and through the ongoing project codesign sessions.

1 Lab results

Lab prompt on results to code any CKD stage

Show ranges and coding reminders on eGFR and uACR test results

2 Patient and Staff Education

larger scale ckd education seminar from secondary care

Patient Group consultations to deliver CKD education at diagnosis (diet, lifestyle, similar to diabetes)

Peer to peer education is helpful. Incorporate CKD into Diabetes DESMOND programme more prominently than it is already?

HCA, pharmacist, nurse, GP: all able to help with patient education: A session with someone at diagnosis?

Checklist for primary care to know when to offer patient education and what it should be at each step

Self-refer option for patients to take the load off HCPs and engage patients

Validation & scaling workshop report

Attendees:

- 8 Patients
- 4 Clinicians in total (2 GP, 1 pharmacist, 1 renal nurse)
- 2 Facilitators
- 2 Notetakers
- 4 Observers

Project team roles included people from the following organisations:

- The London Kidney Network (LKN)
- Imperial College Health Partners (ICHP)
- The Applied Research Collaboration Northwest London (ARC)
- AstraZeneca (AZ)

On October 7th 2022 from 1230 to 1400, a mix of patients and clinicians attended a ninety-minute virtual workshop to build on two previous ideas which had been co-designed in a patient workshop (6th September) and a clinician workshop (16th September). These ideas were:

1. A CKD session for patients via a healthcare professional right after diagnosis and ongoing peer support around living with the condition.
2. Enhanced prompts around lab test results that help primary care follow guidelines for CKD patients.

Note: Two additional ideas are being developed, however as they are more technical in nature it was agreed that they would be worked on in smaller groups with clinicians.

The workshop was run in two groups, with an idea taken for each one. The groups were presented with background information and potential visualisations for their idea and asked to discuss how the idea could work. Participants were asked a series of prompts which included:

1. What does this look like for you?
 - What does it need to include?
 - Who are the patients that you think this would be most helpful for?
 - What would be your ideal way to be invited, attend and experience this session?
 - Who would you most like to deliver it and what skillsets are needed?
2. What's the most important thing to test about this idea?
 - What's the weakest part of the idea or the part we are most unsure will work?
 - Who should be involved in designing what we test and running the test?
 - What's the process for making any changes?
 - How can we make sure this is as accessible as possible for everyone?
3. How could we measure the impact of this idea?

Idea 1: A CKD session for patients via a healthcare professional right after diagnosis and ongoing peer support around living with the condition.



Patient receives a text message/email/letter inviting them to a virtual education session.



Patient registers at home for this session.



Patient attends virtual group session with their family members.



Patient joins patient recommended peer support groups.

1

Patient workshop

2

Clinician workshop

3

Patient & clinician workshop

Discussion summary

Key points from the discussion:

1. We need to know about CKD earlier

- For patients with co-morbidities that lead to CKD, there was a strong call for knowledge around CKD and what to look out for, testing info etc was very important and not currently done until it is too late
- CKD education discussions should happen as soon as a patient experiences symptoms – do not wait for a formal diagnosis

2. Information at diagnosis is key (ideally before but at the very least first thing at diagnosis)

- Everyone wanted more clear information about CKD at diagnosis. Most didn't know what CKD was and felt shocked to get the diagnosis. Some searched for it on Google it or did other research for themselves
- Everyone agreed that a session at diagnosis to explain CKD and talk to a group together of newly diagnosed patients would be a positive thing
- Many were keen to attend and give feedback about Joana Teles (renal nurse) current education sessions led by her in secondary care and this is an important next step as it makes sense to see if this session can be brought earlier in the n CKD pathway so that GP practices can refer newly diagnosed patients vs referral patients only.

3. Co-morbidities and how CKD connects and interacts with other conditions was an important consideration

- For patients with multiple conditions (which represented everyone in this group), it was requested that there be a point person to help to navigate the patients' co-morbidities better and really understand how they connect and impact one another, as well as what medication is helping what condition. Currently this is confusing and not shared well by clinicians resulting in patients now knowing what their tests were for, what their medication was helping and how their conditions relate and connect

4. Peer support and signposting is key

- The participants know there is a lot of info out there on CKD but they cannot navigate this alone. They asked for signposting to the best info/communities/guides
- Mental health and community to help this was positively discussed by all participants. It was felt that others with the condition sharing their experiences, being in live discussions and being there for support and to answer questions was the largest factor in helping with mental health difficulties related to having CKD

5. Something physical in terms of information

- A physical info pack and personalised care plan would be helpful at diagnosis. Patients and their carers like the idea of having something tangible to open and read and would help them have a better sense of control over their condition management
- Progression info and what to look out for/what to do next was cited as being particularly important in this info pack

6. What do clinicians need:

- Clinicians have limited time to support patients more around their CKD diagnosis. This was acknowledged by the patients and clinicians in the group
- Clinicians also need education on CKD management at diagnosis in primary care, if the result doesn't indicate a need for nephrology referral

Idea 2: Enhanced prompts around lab test results that help primary care follow guidelines for CKD patients.

1



Blood sent to the lab, eGFR is done, Primary care receives these results from the lab in their inbox.

2



Clinician sees that there is a standardised prompt on the results to suggest next best action.

3



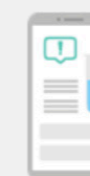
Clinician books the patient in for a uACR test based on the prompts.

4



The patient receives a notification that their results have been uploaded and are asked to come in for a urine test based on these results.

5



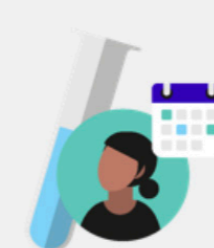
The message explains why this it is important for them to come in for this test.

6



Patient looks at their test result.

7



The message explains why this it is important for them to come in for this test.

1

Patient
workshop

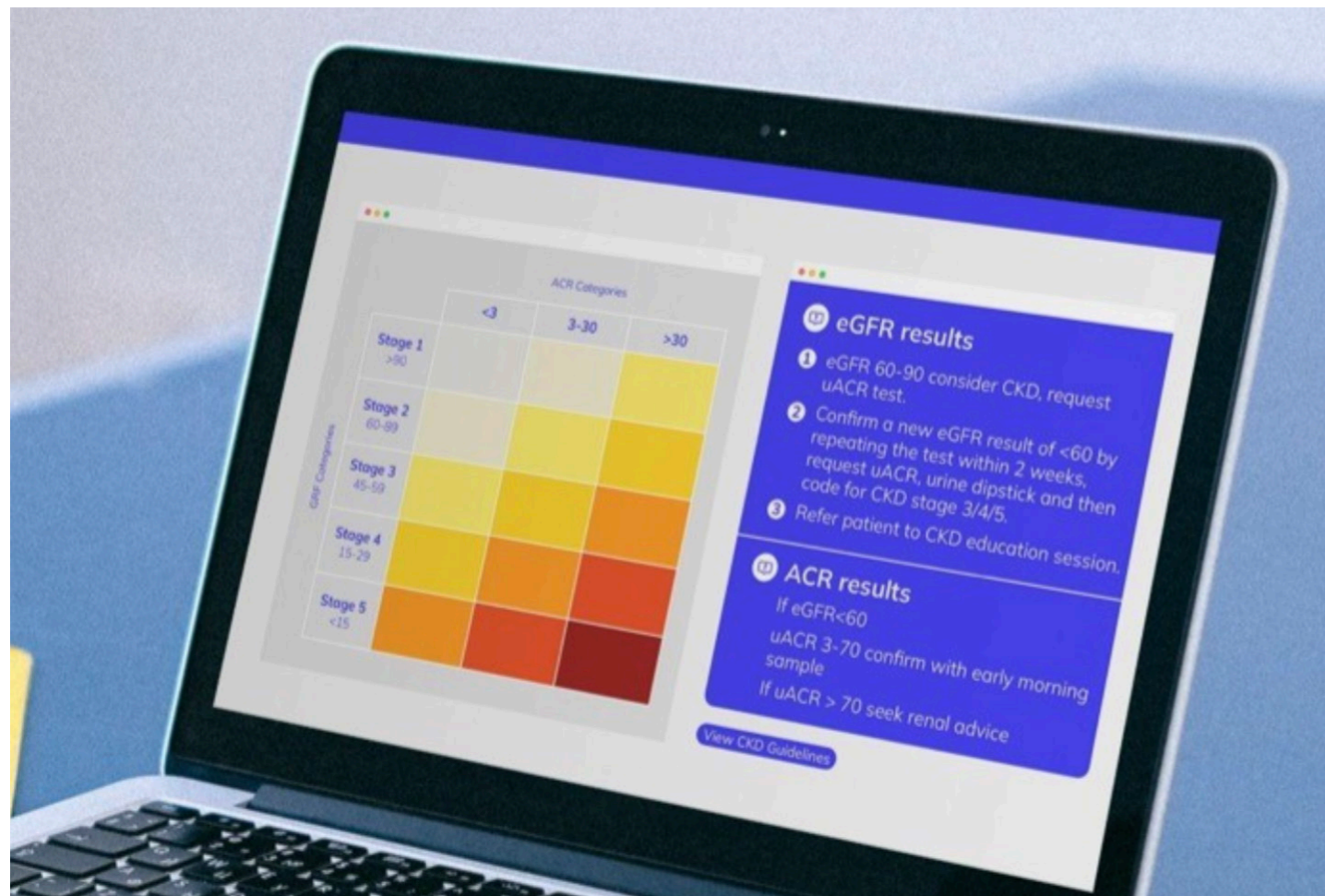
2

Clinician
workshop

3

Patient &
clinician
workshop

Clinician sees that there is a standardised prompt on the results to suggest next best action.



Discussion summary

Key points from the discussion:

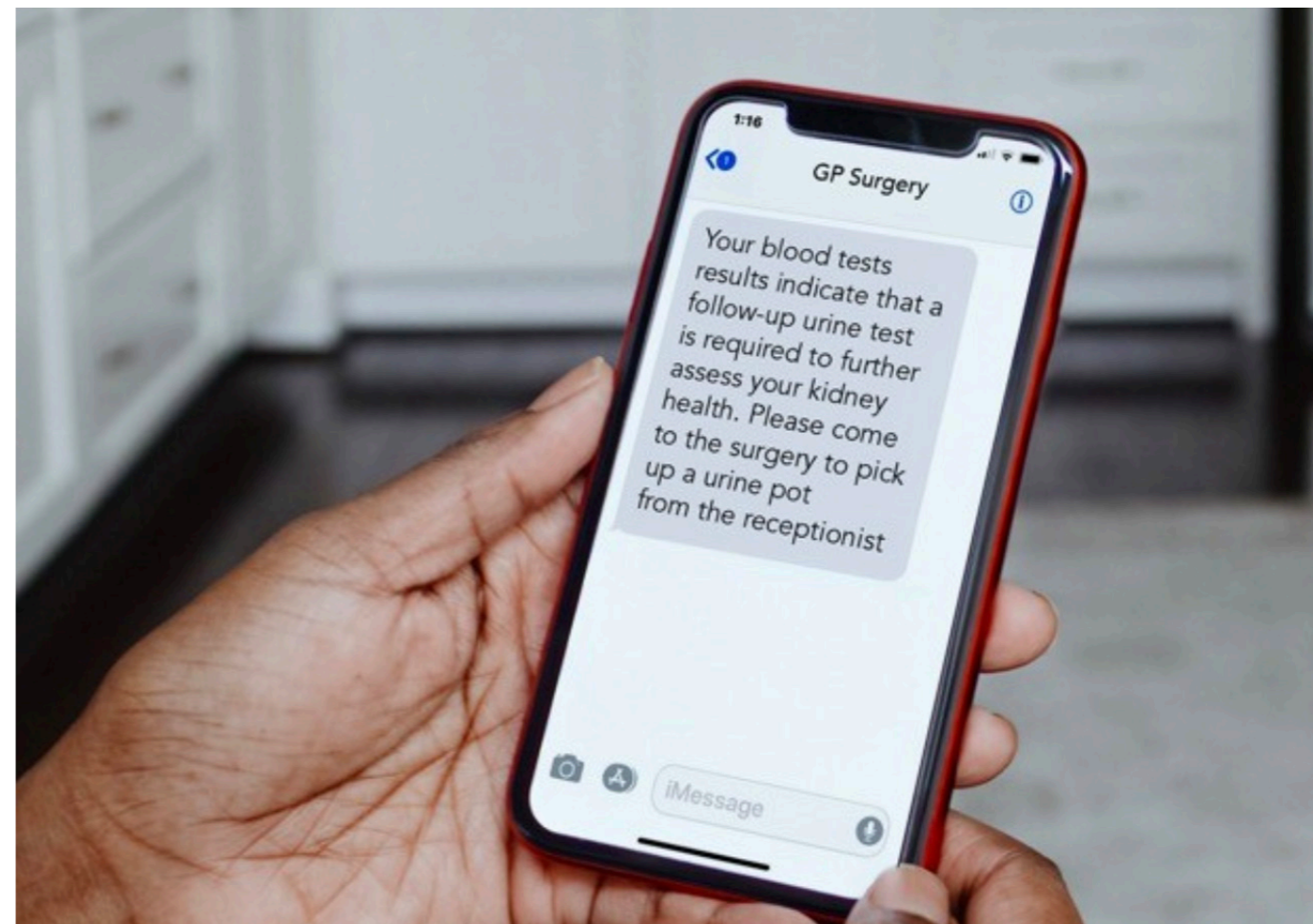
1. What prompts this test?

- The group discussion linked to idea 3 (not being worked on in this workshop) around the creation of a risk stratification tool and making sure the right people are being escalated.

2. What do we want to see with this prompt?

- Any prompt created needs to provide a clear point of action about what to do next.
- Visualising trends or colour coding was believed that it would make it easier to see drops in results.
- The group was unsure if it should be a fixed prompt (showing the same text for everyone) or something bespoke depending on the patient and their results.
- Work needs to be done to understand what would trigger a prompt and at what point of the pathway it would be triggered.

This message explains why it is important for them to come in for this test.



3. What patient group should this idea be for?

- The group agreed that it should start with CKD 3 onwards to trial the ideas effectiveness and then consider going to stages 1-2 at a much later stage.

4. How could we measure success?

- The group created a series of question to help define what would be useful to measure.
- Does it help diagnose more people?
- How useful it is to GPs? Does it help them manage workloads and make the right decisions?
- Does the prompt lead to action?

What's next

The team will be taking these ideas forward and working on them with clinicians and patients in smaller groups. We will be measuring them against two additional ideas created in the co-design sessions to see which three of the four ideas would be the best to take forward and test in November 2022.

Scoping literature review: key findings

Overview

Overarching Question:

What has been done to improve care of chronic kidney disease (CKD) patients in the UK?

Research Question:

What has been done for the early detection of CKD amongst patients in the UK?

Justification:

Improving care was rather a broad concept that made the scoping review very difficult and practically unachievable.

Through an iterative process involving experts and a subject librarian from faculty of medicine at Imperial College London – who is an expert in formulating research questions for reviews – we reached a consensus that “early detection” was a more objective as well as an evidence-based concept that could translate into “improving care”.

Search:

We used EMBASE database, one of the largest databases in medicine and healthcare, which covers a wide variety of biomedical subjects and literature including journals from Europe and Asia not found in other biomedical databases. We included all types of studies in our reviews.

Timeline:

We limited the search timeline between 1st January 2013 and current (2nd August 2022)

Justification:

The NICE guidelines on the management of CKD were significantly updated in March 2013.

Screening:

108 studies were screened by two independent reviewers, for title and abstract
39 studies were screened by four independent reviewers, for full text
22 studies were extracted for data/information by four independent reviewers
In addition, another 2 reports were extracted for data/information by four independent reviewers.

Key Findings

Significance & Rigor:

- The findings are based on the evidence generated from studies that investigated data from millions of patients out of which more than 400,000 were CKD patients of all age groups, in the last decade.
- These CKD patients were recruited from more than 300 primary & secondary care practices.
- Hundreds of NHS healthcare professionals (GPs, nephrologists, nurses, pharmacists) and clinical scientists from across the United Kingdom were included in these studies.

CKD as a clinical condition:

- CKD is not looked at as a standalone health condition but rather as a comorbidity in metabolic and cardiovascular diseases such as diabetes, hypertension, atrial fibrillation, congenital renal diseases (in case of children).
- Therefore, there is a need for a more individualised/ personalised interpretation of certain well-established laboratory parameters such as serum creatinine (SrCr), physiological parameters such as estimated glomerular filtration rate (eGFR), for different patient groups as a potential approach to detect CKD, early.
- There is a focus on multidisciplinary interventions at the primary care level to improve the care for CKD patients.
- Most of the interventions are “complex multisystem and multidimensional”.
- Most of the conclusions from such interventions are inconclusive and need further investigations.
- Health inequalities and reducing them are mentioned as one of the health outcomes in the extracted studies.
- CKD is acknowledged as a condition that affects racialised minorities, disproportionately.
- Acute Kidney Injury (AKI) is studied in a subgroup of CKD patients.

- There is a focus on stages 3 to 5 of CKD, stage 3 being considered as the focal point for the early detection of CKD.
- Stages 1 and 2 of CKD seem to be considered as normal, without being referred to as a clinical condition needing intervention/treatment. For example, clinicians would rather focus, in accordance with the current NICE guidelines, on managing the blood pressure and blood sugar as a priority rather than treating the stage 1 or 2 chronic kidney disease in a type 2 diabetes patient who is also hypertensive.
- We might need to look at CKD with a wide-angle lens to further push the agenda of addressing CKD care improvement, nationally and globally.

Patient characteristics (geography & demography):

- The findings are from the studies carried out in England (London borough, Greater Manchester, East and West Midlands, Southeast), Scotland and Northern Ireland.
- Overall, the racialised minorities were well-represented in these studies.

Types of studies:

- Majority of the studies were based on the “secondary data analysis” of primary and secondary care data.
- Therefore, it is important to note that “cause-and-effect” relationship claims should be cautiously interpreted.
- Other studies included a Randomised Controlled Trial (RCT) of nurse-led intervention, a few reports, quality improvement, qualitative research, literature review, health economic evaluation and audit
- A few conference abstracts had preliminary findings on potential benefits of certain innovative approaches such as retinal imaging, microsimulation economic evaluation modelling to detect CKD early. However, on manual search, the team was unable to find subsequent full papers/reports. One could speculate that the findings of these innovative approaches might have been less than ideal to be published. (This substantiates the claims that studies with positive results stand a much higher chances of either being put forward for publication or being published.)

Intervention/ Interest:

- In scoping reviews, the concept of intervention is not applicable all the time. Instead, the [concept] of “interest” is a more applicable terminology that in the context of this review would imply what was done/investigated to help with the early detection of CKD.

- Broadly, they are divided into the following categories:

a) Blood Chemistry

- Retrospective study of sociodemographic characteristics of children <18 with eGFR <60 mL/min/1.73m² from 2005 – 2009 to characterise their kidney function (5 stages). There were to peak incidences in CKD stages (3-5) i.e., age 2 and age 12-15.

b) Community support

- Peer Educator model and the subsequent impact in raising awareness of health issues within the BAME community. 10 peer educators reach 2700 members of a South Asian community to raise awareness regarding a number of health issues including CKD. The use of Peer Educators may be worth exploring as an approach of connecting with the communities that have been historically overlooked.

c) Financial incentives

- A CKD management programme in West Midlands England. The programme comprised of primary care education and financial incentives, personal clinical reports written directly to patients following every consultation, routine laboratory estimated glomerular filtration rate (eGFR) reporting, eGFR graph surveillance. The programme led to a reduction in the incidence of RRT, improved initiation of RRT and lower intensity of care at the end of life.

d) Microsimulation modelling

- To estimate the epidemiological and economic burden of CKD in the UK. Numerous clinical data were fed into the model. The model indicated that early detection and proactive management of patients with CKD and macroalbuminuria results in a cumulative £650 million direct healthcare cost saving by 2025 (in three years’ time)

e) Population surveillance system development

- A database was developed by compiling eGFR graphs up to five years of data. The graphs were reviewed by clinical scientists for patients with a low eGFR for their age. For those with a declining trend, a report containing the eGFR graph was sent to the requesting doctor. This approach allowed for a better discrimination of patients with progressive CKD, who were at highest risk of poor outcomes, which could be cost saving. However, there is a need for more investigation to establish the benefits of this system for CKD patients with mild to moderate risk of poor outcomes i.e., stages 1,2 and probably 3.
- Proactive identification and management of early-stage chronic kidney disease patients in primary care—a laboratory solution for patients with eGFR <60 mL/min/1.73m². Graphical representation and real time expert analysis was proven to improve early detection of chronic kidney disease including new diagnoses of a few cases of CKD stage 3a; and an uplift in relation to eGFR testing of patients who initially show an abnormal eGFR result for the first time.
- Passive surveillance method for early detection of CKD across various countries including England. CKD identification and management were introduced into the national Cardiovascular Disease Outcomes Strategy. Introduction of a professionally led national primary care CKD audit and quality improvement program and acute kidney injury initiatives to improve safety and medicine management in CKD. People with CKD are now also identified by the NHS Health Check program that started in 2008 and offers vascular risk assessment to all those between 40 and 75 years of age, as well as by routine care. Unplanned initiation of dialysis has fallen in the United Kingdom from 28% in 2005 to 21% in 2010.
- A community-wide CKD management programme comprising detection and monitoring in primary care, and systematic identification of patients at risk of ESRD from a database integrated with the clinical chemistry service was implemented. “Pay by results” was one of the components of the above-mentioned programme that was directly relevant to the RRT patients. The community-wide CKD management programme was introduced following the introduction of another programme (in 2003 and 2006) that comprised of primary care education and financial incentives, personal clinical reports written directly to patients following every

consultation, routine laboratory estimated glomerular filtration rate (eGFR) reporting, eGFR graph surveillance to identify and monitor patients at risk, multidisciplinary pre-RRT care and conservative care. diabetes surveillance system was extended to all CKD patients in the community by implementing it in the clinical chemistry service. Integration of nephrology and pathology services was a key part of the community-wide CKD management programme. Although this study does not measure early detection specifically, it is interesting that services have been tested to reduce progression to RRT and also that part of the study population were diabetic at-risk patients

- Assist-CKD, a lab to GP service, was developed following the success of the “community-wide CKD management programme” for patients <65 years with eGFR <50ml/min/1.73m²; and patients >65 years with eGFR <40ml/min/1.73m². The evidence of deteriorating kidney function based on the blood results were flagged out by the lab scientist; and were communicated with the primary care GP. The national intervention has proved feasible even without external funding. It has been well received and potentially added value. The intervention has the potential to slow down progression of kidney disease due to the eGFR prompts alerting GPs to review the patient record and to take action.
- Promoting Action on Research Implementation in Health Services (PARIHS) framework was adapted with two additional elements:
 - 1- multi-disciplinary teams made up of improvement facilitators, project managers, information specialists, clinicians (GPs & Nurses) and academics
 - 2- An embedded approach to evaluation and learning to ensure ongoing reflection and refinement of the improvement programmeMoreover, Plan-Do-Study-Act cycles was used to work towards established goals.
- The goals were:
 - a) to halve the gap between recorded and estimated prevalence and to ensure that 75% patients with recorded CKD had their BP managed according to the targets recommended in national guidelines (<140/90 for patients without proteinuria; <130/80 for patients with proteinuria)

b) to increase identification and improving the management of patients with CKD in primary care. Practices supported by a facilitator are almost three times more likely to implement clinical guidelines. (Practice facilitation) Complex interventions should be refined to support the identification and management of adult patients with CKD in primary care. The intervention improved the identification of CKD patients and the management of blood pressure (BP) in CKD patients

- Retinal imaging
Retinal microvascular parameters (RMPs) were assessed in association with baseline measures of renal function as a non-invasive innovative approach for the early detection of CKD in elderly patients >65 from the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA). No significant associations were found between retinal arteriolar or venular calibre and renal function. However, increased retinal venular tortuosity was associated with CKD stages 3 to 5.
- Service evaluation
A clinical audit on adherence to the early detection and management of CKD according to the NICE guidelines 2008 was carried out in a hospital in East Midlands. The findings highlighted the need to for a greater awareness regarding appropriate follow up, referrals on discharge.

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