

Improving Identification and Preventing Progression of Chronic Kidney Disease

April 2023 Testing Report

Project Overview

The DiscoverNOW consortium have led a project to improve early identification and management of patients with chronic kidney disease (CKD) in North West London (NWL) in order to diagnose more patients with CKD earlier and prevent progression to end stage renal failure.

The consortium set up a multidisciplinary team of patients, clinicians, experts in PPIE, health inequalities, public health, health economics, data and service design to tackle this shared challenge. The project was funded through the National Insights Prioritisation Programme with the project objective to co-design, implement and evaluate pathway improvements in North West London that could then be shared to the other 5 London ICSs via the London Kidney Network (LKN)

The project had two main goals:



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

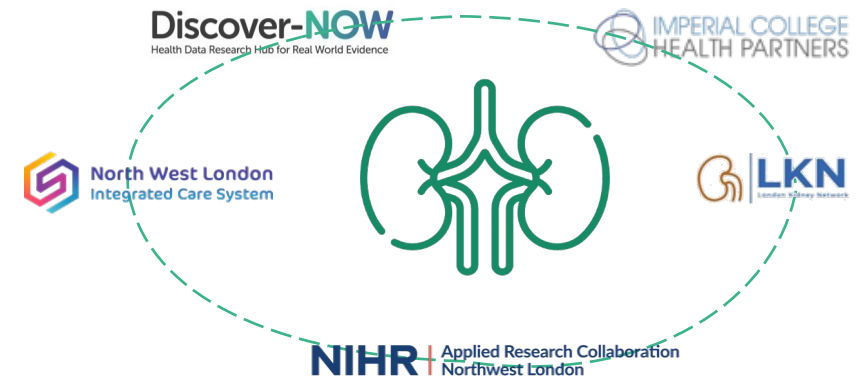


Goal 2: Increase the number of patients who are treated according to latest guidelines

We also aimed to identify and address health inequalities throughout the project. See page 10 for more details

We are running a retrospective study using the linked DiscoverNOW dataset to run to understand the cost burden of the CKD over a 10 year period. This involves mapping patient cohorts through the pathway and identifying their comorbidities, population health risk factors and health outcomes.

The following report covers the testing phase of the project. For the discovery & co-design phase please see report 1.



The design process

How did we get to the ideas

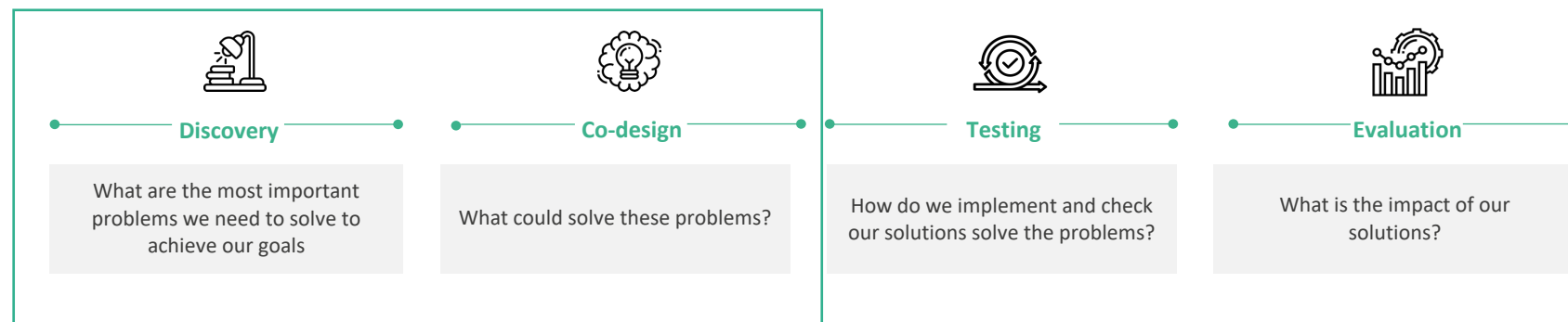
In the Discovery phase we gathered insights from **12 clinician, 5 at risk patient and 7 CKD patient interviews, 4 pathway mapping sessions, a literature review of 24 studies** and other data sources to understand how the current NWL CKD pathways operate and what the main challenges were in increasing early identification and management of patients with CKD

We prioritized the insights into **6 opportunities** for patients and clinicians to use as a basis for ideation in two virtual co design workshops.

The workshop participants produced **32 potential ideas** which were consolidated and refined them into **4 key ideas** to take forward into testing. The core project team of patients, clinicians and experts in health inequalities and PPIE assessed the ideas based on feasibility and scalability.

In our third workshop, a group of patients and clinicians refined two of the ideas into solutions that would be taken forward into live testing within NHS services in NWL.

The other two ideas, which were focused on clinical pathway changes, were developed further by a multi-disciplinary group of clinicians who met on a weekly basis. Patients were later involved through a series of co-design workshops. More detail to follow from page 23



The testing process:

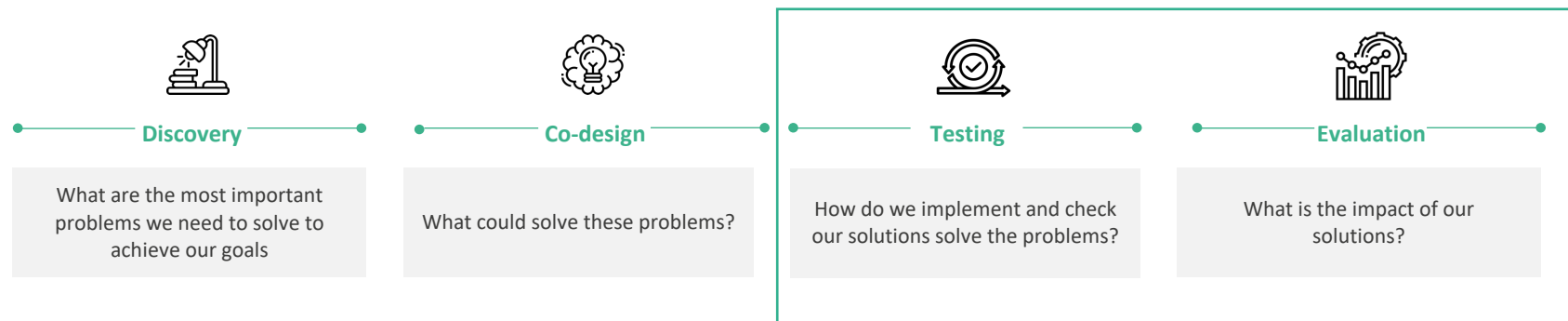
Test 1

How we went about testing the ideas

We divided our testing into two testing phases. For the first testing phase we developed simple prototype versions of our ideas and tested them individually with a small number of patients and clinicians over a defined period to answer the following questions:

1. To what extent does the idea address the hypothesis or hypotheses?
2. What changes would need to be made for this to better address the hypothesis?
3. How else does this idea impact clinicians and primary care ?
4. What other changes do we need to make to ensure this meets patients and clinicians need in a sustainable way?

Following this first testing phase, we will develop the ideas based on test findings and implement updated solutions in more practices and PCNs so we can then evaluate how the ideas work together as a part of a more cohesive service.



An overview of the ideas and our testing hypothesis

The idea

IDEA 1

A CKD diagnosis pathway with an education programme for patients.

The insights

1. Many patients with results indicating CKD stage 3 or worse are not coded or given formal diagnosis in primary care which leads to a delay in treatment
2. CKD patients have low understanding about what the diagnosis means and how to manage their condition
3. GPs and nurses lack time, confidence and/or knowledge when it comes to describing CKD to early stage patients

The hypothesis

By introducing the ability to signpost earlier stage patients to a CKD education program, patients will receive timelier, appropriate diagnoses and learn to advocate for their own care



GOAL 1

IDEA 2

Enhancing primary care test results with CKD clinical advice and management guidelines

1. At risk patients do not always get a uACR test which can delay their diagnosis
2. Many patients with results indicating CKD stage 3 or worse are not coded or given formal diagnosis which can lead to a delay in treatment
3. Primary care clinicians responsible for filing results find coding confusing and are not all aware of latest guideline changes for CKD management

By adding clinical guidance to eGFR and uACR results, primary care staff will increase ACR screening, improve CKD coding and refer appropriate patients to secondary care earlier



GOAL 1



GOAL 2

An overview of the ideas and our testing hypothesis

The idea

IDEA 3

A risk stratification search and contact process that enables primary care to identify high risk CKD patients

The insights

1. There are many patients whose results indicate their CKD is progressing who aren't appropriately managed
2. Primary care are not sure which patients need to be prioritized and want support from secondary care on identification

The hypothesis

By flagging and supporting primary care to manage patients at high risk of CKD progression in primary care, more patients will be managed according to the latest guidelines



GOAL 2

IDEA 4

An improved annual review pathway for T2D patients to encourage identification and management of CKD.

1. At-risk patients with relevant long-term conditions such as type 2 diabetes are often unaware of the importance of annual renal screening and don't always get a uACR test
2. CKD patients are not always having their CKD reviewed and managed as part of their existing T2D annual reviews, which is problematic as it is very uncommon for GP practices to run CKD specific reviews



GOAL 1



GOAL 2

Applying a health inequalities lens to testing

Health inequalities considerations by idea: Idea 1

IDEA 1

A CKD diagnosis pathway with an education programme for patients.

How might our ideas affect health inequalities positively or negatively?

The group acknowledged that this idea could affect health inequalities negatively as one of the education options was only available in English, patients with disabilities might struggle to access education due to digital exclusion and it could benefit patients who were already more engaged with their health

What steps can we take to address these during our tests and project?

The group discussed a number of options that could address health inequalities in a positive way. These included creating a YouTube video with translations, leaflets in additional languages, ensuring tech options were accessible such as through font and captions, translating existing information that had proven successful and having peer to peer supporters who are representative of other patients which has been demonstrated before in the 'patients like me' initiative

What we were able to take forward?

- ✓ Provide non digital education options and in different languages
- ✓ Recruit a diverse patient group to the workshops for review of this idea in testing

For the next testing phase

- Get a breakdown of the invitees and participants by ethnicity, sex, language, age
- Explore accessibility support options with/without tech to tackle data poverty
- Translating videos into different language

Health inequalities considerations by idea: Idea 2

How might our ideas affect health inequalities positively or negatively?

The group acknowledged that this idea could affect health inequalities negatively as it could benefit patients who already get tested in the first place and could miss patients who aren't seen as typically clinically at risk. There were positives noted such as helping GPs with limited time and clarifying some outdated clinical recommendations for patients from ethnic minorities related to their eGFR results.

What steps can we take to address these during our tests and project?

The group suggested ensuring patients were aware of purpose and optimal frequency of the tests and calculating the impact of who we will miss by focusing on those already getting tested

What we were able to take forward

- ✓ Create clear patient messaging for the reason behind their test
- ✓ Remove outdated clinical recommendations for ethnic minority patients and eGFR results

For the next testing phase

- Review how patients access results
- CKD data study will assess impact of non clinically at risk CKD patients and those who do not get screened and diagnosed

THE IDEA 2

Enhancing primary care test results with CKD clinical advice and management guidelines

Health inequalities considerations by idea: Idea 3

How might our ideas affect health inequalities positively or negatively?

The group acknowledged that this idea could affect health inequalities positively as it could provide a safety net for patients who are currently being missed. On the other hand, this idea could give more resource to a concentrated group of patients by taking it away from a group not indicated in the risk stratification. The group also thought that the search could increase referrals to secondary care which might increase appointment wait times. This could then affect patient groups disproportionately.

What steps can we take to address these during our tests and project?

The group suggested identifying and quantifying which patients would benefit most from this idea and measuring the impact on clinicians' time.

What we were able to take forward?

We are using the CKD data study to identify the highest cost cohorts including clinical and population health factors. This is due to read out in September but we will be able to use interim data to make patient cohort suggestions.

THE IDEA 3

A risk stratification search and contact process that enables primary care to identify high risk CKD patients

Health inequalities considerations by idea: Idea 4

How might our ideas affect health inequalities positively or negatively?

The group acknowledged that this idea could affect health inequalities negatively if focused only on people who usually turn up to GPs for their annual checks.

What steps can we take to address these during our tests and project?

The group suggested ensuring offering a virtual and in person appointment and looking into how patients can be encouraged to attend tests and appointments

What we were able to take forward

- ✓ Improve messaging to encourage patient to attend review
- ✓ Create additional materials to explain importance of annual testing to patients and make readily available to patients in different formats (paper and electronic)

THE IDEA 4

An improved annual review pathway for T2D patients to encourage identification and management of CKD.

Testing plans

Test Plan for Idea 1: A CKD diagnosis pathway with an education programme for patients

Hypothesis:

By introducing the ability to early stage CKD patients to a CKD education program, patients will learn to advocate for their own care and might receive more timely diagnoses in primary care

Test site 1: Pimlico Health @ The Marven

Lead clinician: Dr Raakhee De Silva

Participating staff: 7 GPs

Testing dates: November 16th to December 1st

Test site 2: Brook Green Medical Centre

Lead clinician: Dr Kat Walton

Participating staff: 1 Pharmacist 2 GPs

Testing dates: November 21st – December 1st

Test protocol

1. GP identifies appropriate patient from incoming pathology results
2. GP contacts relevant patients to discuss their new CKD diagnosis and offers patient the Know your Kidneys session or signposts patient to other material if patient not able to access the session.
3. GP tasks admin to send patient template text message signposting the patient to the education programme “Know your Kidneys virtual session” and to other useful online and offline diagnosis education materials
4. Patient registers for Know Your Kidneys session via a registration page which will then trigger the sending of an MS Teams link
5. Patients receive an automated reminder from Teams
6. Patients attend Know Your Kidneys session and/or accesses other materials
7. Imperial Trust admin team and nurse to track Know Your Kidneys session attendees via their usual methods (spreadsheet and Teams)
8. Imperial Trust team will send patients a feedback survey
9. GPs will complete a survey
10. Data will be reviewed and assessed for test 2

Test materials:

- Education programme 1 pager for primary care & accessibility protocol
- Template text invitation for patients + code

What will we measure?

Reporting on invitation and attendance

- How many patients were invited to the session (AccuRX code or verbal)
- How many patients attended the session (Teams)

Clinician survey

- How easy did GPs find it to refer appropriate patients
- How easy it was to follow the patient referral criteria
- If GPs would like to be able to refer to the education session in the long term
- If having an education programme to direct patients to has made clinicians more comfortable speaking about diagnosis
- Suggestions to improve the process

Patients survey

- How they found out about the session
- How valuable they found the session
- How useful it was in helping them to understand and manage their CKD
- How confident it has made them about understanding their care needs
- How it has impacted their understanding of CKD treatment options
- How easy the sign-up process and digital access to the session was
- How likely they are to recommend it
- Who they attended with
- How they found the content covered

How and when will we collect data

1. Questionnaire sent to GPs at end of test
2. Survey sent to patients at end of education session
3. Data from patient facing text message to indicate how many patients were referred
4. Reporting from primary care system and Teams

Test Plan for Idea 2: Enhancing primary care test results with CKD clinical advice and management guidelines

Hypothesis:

By supporting primary care with CKD clinical guidance alongside eGFR and uACR results, primary care staff will increase appropriate ACR screening, CKD coding and be able to manage patients to latest guidelines (LKN 3 in 3).

Site 1: Pimlico Health @ The Marven

Lead clinician: Dr Raakhee De Silva

Participating staff: 7 GPs, 1 GP trainee, 1 hospital doctor (FY2), 1 x pharmacist

Testing dates: November 16th to December 1nd

Test protocol

1. Clinicians will complete a baseline survey
2. Clinicians will review a paper or online information sheet with CKD guidance when filing and coding eGFR and uACR results during the defined time period
3. Clinicians will complete a post-test survey and data will be analysed from the practice system
4. Data will be reviewed and assessed for test 2

Test materials

- Paper prototype of clinical guidance
- Baseline & post test survey

What will we measure?

Reporting on clinician activity

- EPR search to capture clinician activity if all clinicians in practice involved

Survey before and after for clinicians

- How useful clinicians found the guidance wording on test results
- If this addition changed how they managed patient care
- How they felt about the hyperlinks to guidelines
- If the CKD guidance affected their clinician decisions
- How their confidence changed around screening CKD patients
- If the guidance on results impacted their uACR testing

- If the guidance on results impacted their coding decisions
- If the guidance on results made them more confident about coding based on eGFR and uACR results
- If the guidance on results made them feel more confident about diagnosing the cause of CKD
- If the guidance on results made them feel more confident about diagnosing the cause of CKD
- If it changed their diagnosis decision
- If it made them feel confident about managing their patients according to guidelines
- If it gave them the information about making different patient management and optimisation decisions
- If it increased their confidence about referral and the role eGFR results play in it

How and when will we collect data

1. At baseline before the test
2. After test
3. Raakhee to send and collect responses

Test Plan for Idea 3 & 4: A risk stratification search and contact process that enables primary care to identify high risk CKD patients that also have type 2 diabetes

Hypotheses:

Idea 3: By flagging and supporting primary care to manage patients at high risk of CKD progression in primary care, more patients will be managed according to the latest guidelines
Idea 4: By improving the T2D annual review process more patients will be screened for CKD and managed according to the latest guidelines

Test 1:

Site 1: Kings Road Surgery – T2D & CKD stage 1-3 pts

Lead clinician: Laksha Satchitanathan

Participating staff: 2 pharmacists

Testing dates: November 29th – 13th December

Test protocol

1. Run search for T2D patients with CKD stage 3-5 no uACR
2. Prioritise patients who have not had a uACR test in this financial year
3. Admin check if patients already booked in for uACR and book patient in for blood test via text and give urine sample at practice add booking note diabetic review bloods, urine, mental health
4. Admin to resend text if patient does not book blood test
5. Patients might be asked to complete their mental health questionnaire ahead of their review either via text or in the surgery
6. Pharmacist checks patient results before their annual review along with a printout of the NWL CKD guidelines / LKN medication guidelines
7. Pharmacist runs the T2D review with patient and discusses changes to treatment if appropriate
8. Pharmacist change patient's medication in the review, or asks patient to book another appointment for this if more time required
9. After the test period, a short interview will be conducted with participating pharmacist(s)
10. Data will be reviewed and assessed for test 2

Test materials

- EPR search
- Protocol for T2D review
- NWL guidelines printout

What will we measure?

EPR report

- Number of pts without uACR
- Number of pts not on appropriate prognostic medication (statin, ACEi/ARB, SGLT2i)

Reporting on annual review (Idea 4)

- Number of pts invited for annual review
- Number of pts who we received a uACR result for
- Number of pts who attended annual review
- Number of pts whose medication was changed
- Number of pts initiated on RaaSi / SGLT2i
- Did you use the provided guideline material before or during the review to help you make a clinical care decision

How and when will we collect data?

1. EPR report at baseline and end of test
2. Informal interview with pharmacist at end of test

Results of testing

A CKD diagnosis pathway with an education programme for patients

By introducing the ability to early-stage CKD patients to a CKD education program, patients will learn to advocate for their own care and might receive more timely diagnoses in primary care

To what extent does the idea address the hypothesis or hypotheses?

We ran a survey after the sessions to understand how newly diagnosed patients found the seminar. Results were positive and revealed that 70% of the survey respondents said they were very likely to become involved in their own care following the session and 78% said they felt more confident about understanding their care needs and talking about them with health professionals. In addition to the survey, we spoke with 6 patients who attended the sessions and all of them said they found the session very informative and that it was delivered in an inclusive way, which they all appreciated.

“The seminar was brilliant. What it did was give me a balance cos pre the seminar I was oh god, I don’t know what I am supposed to be doing. It reassured. It’s not preachy and if people are preached at, they switch off and it wasn’t. The tone was perfect. And she sent me links which is great because you are going to the right places for information” - Stage 4 CKD patient

What changes would need to be made for this to better address the hypothesis?

Based on two main areas of patient feedback regarding the length of the session *“two hours is a bit long when you have work”* and the lack of time to discuss and ask questions *“I would have liked a little bit more time to ask questions”*, we are trialling a new shorter session format of one hour allowing for 30 minutes Q&A.

GPs provided the feedback that it could be challenging time-wise to invite patients to an education session whilst filing and coding results. To help mitigate this, we set up a CKD page on the NWL ICS website with registration information for the next 3 seminars enabling patients to self-register and reducing the workload for primary care staff.

What other changes have we made to make to ensure this meets patients and clinicians need in a sustainable way?

To ensure we are addressing health inequalities we have developed a diagnosis one-pager explaining CKD to compliment the content in the seminar and for people who prefer taking in information in their own time or who cannot attend online meetings. We have provided links to validated resources from organisations such as kidney care UK to signpost to patients, so they have more support on their CKD journey

Considering language barriers, we are working on translating resources into the top 5 languages spoken in North West London other than English. We have also arranged for there to be sign language support at the seminar if required

Enhancing primary care test results with CKD clinical advice and management guidelines

By adding clinical guidance to eGFR and uACR results, primary care staff will increase ACR screening, improve CKD coding and refer appropriate patients to secondary care earlier

To what extent does the idea address the hypothesis or hypotheses?

All 8 clinicians demonstrated improved confidence with managing patients with CKD at their practice. The areas of highest improvement being:

- Knowing when to screen a patient for CKD
- Diagnosing the cause of a patient's CKD
- Knowing when and how to refer a patient to renal

“Everyone was grateful for the guidance especially more junior GPs – GP Partner

Confidence in coding and onward management were not markedly improved, suggesting that more guidance on these areas should be incorporated into the test result comments. There was **4.5X more people coded with CKD and 1.75x more uACR tests** compared to the month prior. There could be other reasons for this increase and further evaluation is required.

Some clinicians noted that it was helpful to have a physical sheet and others said it would be more useful if it was integrated into their clinical systems

What changes would need to be made for this to better address the hypothesis?

- Implement segmented test result advice with coding and management recommendations based on the result range
- Include a shortened link to the new North West London CKD guidelines in the test results to prompt clinician to review these

What other changes do we need to make to ensure this meets patients and clinicians need in a sustainable way?

To make guidance available in pathology lab comments sent electronically to practices from laboratories and to create a printable info-sheet regarding coding and management guidance.

A risk stratification search and contact process enabling primary care to identify high risk CKD patients, and an improved annual review pathway for T2D patients to encourage identification and management of CKD

By flagging and supporting primary care to manage patients at high risk of CKD progression in primary care, more patients will be managed according to the latest guidelines

By improving the T2D annual review process more patients will be screened for CKD and managed according to the latest guidelines

To what extent does the idea address the hypothesis or hypotheses?

It was simple to create a primary care search that identified patients who were not managed according to CKD guidelines as they were missing a uACR result in the previous financial year and use this as a proxy for patients at high risk of CKD progression. A clinical pharmacist ran the search in one practice; **42 patients identified and contacted for an annual review, 7 attended the review with 9 dropping off urine for a uACR result.** 2 out of the 7 urine samples had to be requested again as there were issues with the labels that patients had filled out themselves. All the patients who had a review were also reviewed for their medication **with 3 being offered an SGLT2i and 1 increased on RaaSi in line with guidelines.** All patients needed time to consider their new medication offer as all were already on minimum 3 medications and believed that they were already on the full treatment possible for their T2D. The pharmacist would call back within the following week to check on the patients' decision.

Many patients did not come for an annual review as they were elderly, house-bound or did not have the time. The test time frame meant not all patients could be seen for a review.

What changes would need to be made for this to better address the hypothesis?

To further identify high risk CKD patients, we are creating a search that identifies patients with CKD and who have a raised uACR that can be used as a proxy for high risk of progression and are creating a protocol to accompany the search to support CKD recalls.

In patient sessions regarding uACR testing, all said they didn't understand uACR and what it means and most felt that the process of urine testing was complicated and confusing. All patients felt that any communications to patients about testing must explain the **WHY and HOW clearly, as well as the What's Next.** Taking this into account, we have created a uACR 1 pager for patients to be given or sent via text message ahead of annual reviews to increase likelihood of a successful uACR test.

Whenever she has tests done, we would like to understand the reasons why it's being done and what the outcome is' – CKD patient carer

The T2D template is being updated in EMIS and S1 to include standardised fields for CKD management aligned to latest guidelines on the Kidney page.

How else does this idea impact primary care and clinicians?

Utilising searches that identify those at highest risk helps primary care staff to manage the workload when it comes to reviewing and managing CKD high risk patients. Reminding annual review staff of CKD checks and coding guidelines in the T2D review template is a useful nudge for them to check CKD status including coding, screening and management/treatment optimisation.

What other changes do we need to make to ensure this meets patients and clinicians need in a sustainable way?

Run education sessions for clinicians involved with blood/urine testing to ensure we can opportunistically test all at risk patients

Ensure the HTN template includes the same CKD information and clinicians are prompted to access this with appropriate high risk CKD and HTN patients

Next steps

Plan for the second test phase

The ideas have been developed to incorporate the changes from the first test phase and are being implemented into the NWL primary care IT systems and pathways, as well as being promoted to primary care and patients. As we implement the solutions, we continue to gather feedback and monitor the solutions as they work together.

We are also preparing to make changes that were not possible in the first test phase and address some of the challenges raised in the health inequalities assessment.

Scaling and evaluation

Once the solutions are finalised, we will promote them through NWL channels including via NWL Kidney newsletter, GP leads, renal nurse education sessions by borough for GPs, pharmacists, nurses and virtual registry reviews with a renal consultant.

We will support practices and PCNs to set up the CKD searches and recall process. Support is not expected to be required for the other solutions as they are additions to existing pathways.

We are planning to evaluate the solutions' impact on patient outcomes and cost to the health system using health economic data from the DiscoverNOW data study (which is on track to readout in late summer 2023).

