A visit to the doctor: shared decision making supported by outcome information in chronic kidney disease

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PART THREE

A novel way to discuss outcomes during care visits – the CKD dashboard

6

Optimizing the use of patients' individual outcome information – Development and usability tests of a Chronic Kidney Disease dashboard

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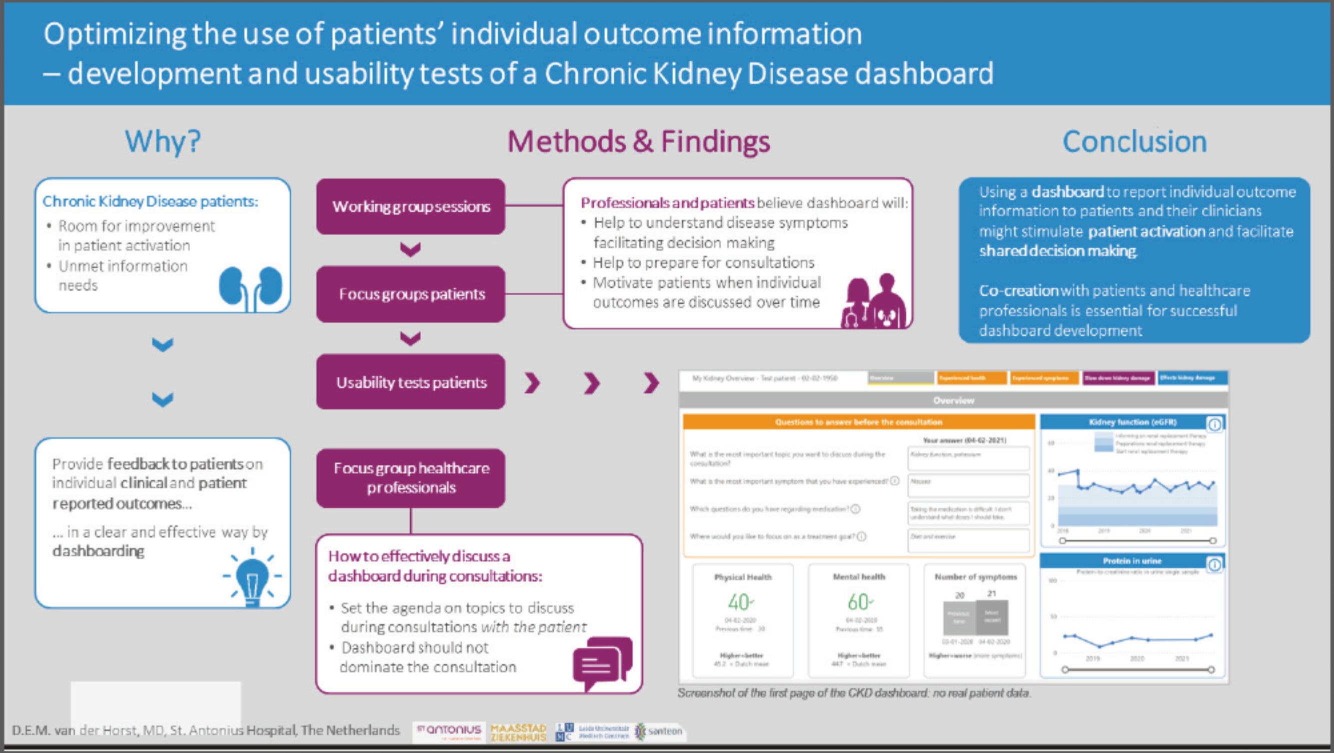

Optimizing the use of patients' individual outcome information – development and usability tests of a Chronic Kidney Disease dashboard

Why?

Chronic Kidney Disease patients:

- Room for improvement in patient activation
- Unmet information needs

Provide **feedback to patients** on individual **clinical** and **patient reported outcomes**...

... in a clear and effective way by **dashboarding**

Methods & Findings

Working group sessions

Focus groups patients

Usability tests patients

Professionals and patients believe dashboard will:

- Help to understand disease symptoms facilitating decision making
- Help to prepare for consultations
- Motivate patients when individual outcomes are discussed over time

Focus group healthcare professionals

How to effectively discuss a dashboard during consultations:

- Set the agenda on topics to discuss during consultations *with the patient*
- Dashboard should not dominate the consultation

Screenshot of the first page of the CKD dashboard: no real patient data.

Conclusion

Using a **dashboard** to report individual outcome information to patients and their clinicians might stimulate **patient activation** and facilitate **shared decision making**.

Co-creation with patients and healthcare professionals is essential for successful dashboard development

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Graphical abstract

Abstract

Background

individual clinical and patient-reported outcomes to patients during consultations may add to patients' disease knowledge and activation and stimulate Shared Decision Making (SDM). These outcomes can be presented over time in a clear way by the means of dashboarding. We aimed to systematically develop a Chronic Kidney Disease (CKD) dashboard designed to support consultations, test its usability and explore conditions for optimal use in practice.

Methods

For development a participatory approach with patients and healthcare professionals (HCPs) from three hospitals was used. Working groups and patient focus groups were conducted to identify needs and inform the dashboard's design. Usability was tested in patient interviews. A focus group with HCPs was held to identify conditions for optimal use of the dashboard in daily practice.

Results

A dashboard was developed for CKD patients stage 3b-4 visualizing both clinical and patient-reported outcomes over time for use during consultations and accessible for patients at home. Both HCPs and patients indicated that the dashboard can: motivate patients in their treatment by providing feedback on outcomes over time; improve consultation conversations by enhanced preparation of both HCPs and patients; better inform patients, thereby facilitating shared decision making. HCPs and patients both stated that setting a topic agenda for the consultation together is important in effectively discussing the dashboard during consultations. Moreover, the dashboard should not overshadow the conversation. Lastly, findings of the usability tests provided design requirements for optimal user-friendliness and clarity.

Conclusions

Dashboarding can be a valuable way of reporting individual outcome information to patients and their clinicians as findings suggest it may stimulate patient activation and facilitate decision making. Co-creation with patients and HCPs was essential for successful development of the dashboard. Gained knowledge from the co-creation process can inform others wishing to develop similar digital tools for use in clinical practice.

1. Introduction

Chronic Kidney Disease (CKD) is a significant public-health problem worldwide. It is increasing in incidence and associated with high morbidity and mortality rates, especially when it progresses to end-stage kidney disease (ESKD) [1,2]. Early treatment of CKD can slow down kidney function deterioration and postpone or prevent progression to ESKD and the need for kidney replacement therapy [3,4]. Long-term medications and lifestyle interventions are the pillars of treatment in attenuating kidney function deterioration [3,5], highlighting the active role needed from patients for effective treatment.

However, particularly patients in earlier CKD stages, appear to have limited awareness and knowledge regarding CKD and its treatment goals [6–10]. Accordingly, patient activation, conceptualized by Hibbard as '*having the knowledge, skills and confidence for managing your own health*' [11], is reported to be low in CKD populations [12,13]. In chronic conditions, high patient activation levels have been linked to better health outcomes [14–18], lower health utilization [19–22], lower costs [18] and better self-management behaviors [16,17,23]. The latter can affect the pace of progression from CKD to ESKD substantially, emphasizing the need to improve CKD patients' activation levels. However, studies showed that CKD patients experience that necessary information regarding their disease is often unavailable or incomprehensible, possibly preventing to attain sufficient activation levels. The information received during consultations with their healthcare professional (HCP) is perceived as unclear, untailored to their situation and either too much or insufficient [24].

Using outcome information in a meaningful way might address these CKD patients' information needs and enhance patient activation levels. Outcome information is increasingly collected since the introduction of Porter and Teisberg's value-based healthcare principle and the standard set of outcomes for CKD by the International Consortium for Health Outcomes Measurements (IHCOM) [25–27]. We hypothesize that effectively reporting individual outcome information to patients can stimulate patient activation and ultimately self-management behavior in four ways (**Fig. 1**). First, according to self-regulation theory, for patients to engage in self-management behavior, they continuously monitor and evaluate their own actions and how it affects their health. Providing feedback on outcomes in treatment plans (e.g. regarding lifestyle interventions or long-term medication) can lead to patients having a more adaptive understanding of their condition affecting their behavior [28,29]. Providing feedback on outcomes is especially important in early-CKD populations, where symptoms are often absent making self-evaluation on actions difficult [30]. Second, reporting individual outcome information to patients can enhance patients' understanding of their condition, an important element of patient activation [11]. Third, collecting and discussing patient-reported outcomes (PRO's) with patients, adds to patients' condition understanding and level of perceived control over their health [31–34]; both are components of patient activation [11]. Lastly, discussing PRO's and clinical outcomes is expected to facilitate Shared Decision Making (SDM) [35–38], which in itself has a bidirectional relationship with patient activation. Involving patients in decision making results in more activated patients by ensuring treatment decisions fit patient preferences and circumstances. Conversely, patients with high activation levels prefer and experience more SDM [39,40]. However, it is yet unclear *how* to present individual outcome information to patients effectively.

Since most patients struggle to memorize spoken information, providing visual aids to present outcome information seems needed [41]. Currently existing (yet underused) strategies to visualize individual patients' outcomes include: 1) visualizing data in the Electronic Health Record (EHR), for example visualizing laboratory results in a graph, however this does not provide an overview of different relevant outcomes and is limited in data visualization options, and 2) listing individual outcomes in the post consultation letter available to patients, however this doesn't show the outcomes over time and doesn't incorporate data visualization for optimal clarity. A more effective strategy can be the use of dashboarding. A dashboard provides a visual display of complex or extensive data with the aim of improving clarity and comprehension[42]. Although the use of dashboards in clinical settings increases, literature on dashboards reporting on individual patient level is scarce[43]. In literature on visualizing PRO's, guidance is offered on displaying outcome information to patients and healthcare professionals (HCPs). Visual analogies plus texts are recommended [44–46] and graphs with higher-better directionality and threshold lines appear to be most fitting for presenting data over time [47,48]. The longitudinal data collected during a CKD trajectory may benefit from these data visualization techniques in providing clear disease overviews.

Thus, the aim of this study was to systematically develop a dashboard for CKD patients stage G3b-4 designed to visualize individual outcomes to patients during consultations, test its usability and set conditions for optimal use in daily practice. By following a participatory development approach, findings of this study bring forward both patients and HCPs views on the potential value of dashboarding outcome information. Findings of this study have implications beyond nephrology and can inform similar initiatives in other conditions.

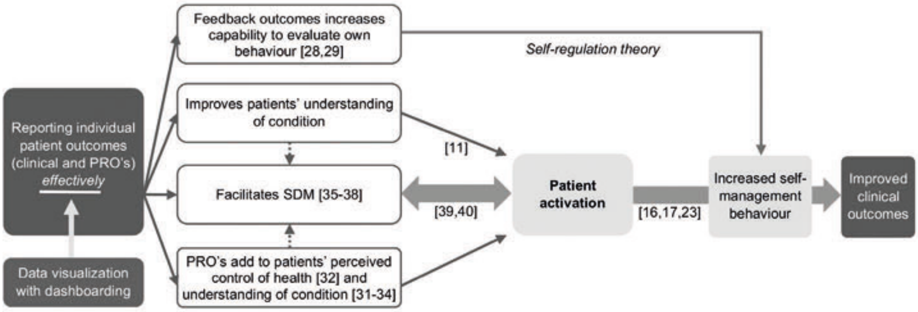


Figure 1. Conceptual model of how reporting individual patient outcomes can increase self-management behaviour and ultimately clinical outcomes. PRO's=patient-reported outcomes, SDM=Shared Decision Making

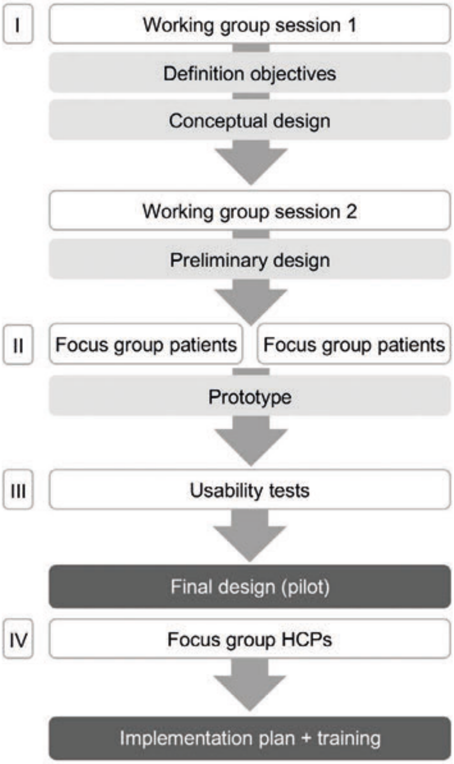
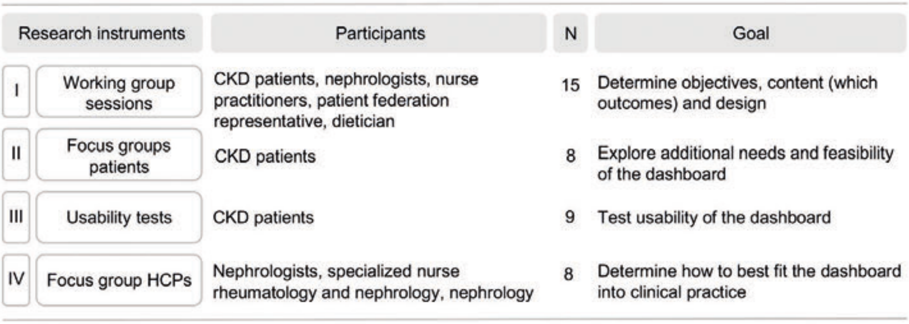


Figure 2. Overview of dashboard development, HCP=Healthcare Professional

2. Methods

The CKD dashboard was developed by means of an iterative co-creation process with both HCPs and patients, as detailed in **Fig. 2** and **Table 1**. The development was initiated by Santeon, a collaboration of seven independent large Dutch teaching hospitals. The dashboard was developed for patients with CKD stage 3b-4, treated by a nephrologist. Dashboard development drew upon theory (**Fig. 1**) and experiences from a best-practice example: a dashboard used in rheumatology consultations [49].

Table 1. Details on research instruments used in dashboard development. HCP=Healthcare professional, CKD=Chronic Kidney Disease



Research instruments		Participants	N	Goal
I	Working group sessions	CKD patients, nephrologists, nurse practitioners, patient federation representative, dietician	15	Determine objectives, content (which outcomes) and design
II	Focus groups patients	CKD patients	8	Explore additional needs and feasibility of the dashboard
III	Usability tests	CKD patients	9	Test usability of the dashboard
IV	Focus group HCPs	Nephrologists, specialized nurse rheumatology and nephrology, nephrology	8	Determine how to best fit the dashboard into clinical practice

2.1. Working groups

The multidisciplinary working group that directly informed dashboard development consisted of HCPs of three hospitals, two kidney patients (recruited by the Dutch Kidney Patient Association) and a representative of the Dutch Kidney Patient Association (**Table 1**). The project leader (EP) and researcher DH, led the working group. Topics discussed in the working group sessions concerned the dashboard objectives, content and design. Dashboard variables were selected from a longlist of outcome information (both PRO's and clinical data). Variables were included when the working group members agreed on them being informative regarding disease trajectory or CKD treatment goals, and when they are frequently discussed during consultations. Prior to the sessions, participants received assignments to stimulate their thoughts on which outcomes they find relevant to include in the dashboard.

2.2. Focus groups with patients

Two focus group interviews were held with patients (n = 8, mean age 56 years, range 38–71 years, three male and five female). One focus group had three participants and the other five. The kidney function varied from 15 to 45% and one patient received peritoneal dialysis. Patients were recruited from the Dutch Kidney Patient Association; informed consent was obtained. Focus groups lasted 1.50 and 1.20 h and were led by an experienced moderator with a background in psychology and a member of the working group (JB). Part one of the topic list included the exploration of current experiences in consultations and identifying information needs. More specifically, patients were asked what information was discussed during consultations, what information they deem important to discuss and what they missed what had not been discussed. In part two, feedback on the preliminary design was collected.

2.3. Usability tests

Usability tests were performed with patients (n = 9, mean age 52, range 25–73 years, five male and four female). Nephrologists of two hospitals recruited patients purposively, aiming for patients of different ages and estimated digital skills. The participating patients reported digital skills that varied from poor to excellent and more than half of the patients had high education levels. An external user experience expert led the usability tests. In the tests, patient did a 'walk-through' of the dashboard and performed three user tasks, while asked to think out loud. In the first task, patients were asked to orient themselves in the dashboard and explore different parts of it. In task two, patients had to imagine to visit the nephrologist in the near future. While navigating through the dashboard they had to identify two topics from the dashboard that they would want to discuss with the nephrologist. In task three, patients were asked to navigate through the dashboard and identify aspects they could work on themselves to slow down kidney function deterioration. After the tasks, patients were asked additional questions regarding the added value of the dashboard and the willingness to use it (for the interview questions see **Supplement 3**).

2.4. Focus group HCPs

A focus group was held with HCPs working in kidney care of two hospitals (n = 8, **Table 1**) to identify conditions for optimal use of the dashboard in daily practice of nephrology care. A specialized nurse of the rheumatology department was also present to share experiences with the rheumatology dashboard. The focus group lasted 1.30 h and was moderated by researcher DH. The findings of the focus group informed content of the training for HCPs on using the dashboard in clinical practice.

2.5. Data analysis

All working group sessions, focus groups and usability tests were held via video conferencing because of COVID-19 pandemic-related restrictions. Focus groups were recorded and transcribed. Thematic analysis was performed by coding the transcripts and identifying themes related to the topics in the topic list. Atlast.ti 9 was used for analysis. The researcher (DH) conducted the primary analysis. A second coder (CU) checked this analysis for accuracy and missing themes. The usability tests were recorded and analyzed by both the researcher (DH) and the user experience expert. Reporting the qualitative findings was guided by the criteria for Reporting Qualitative research (COREQ) [50].

3. Results

3.1. Working group sessions

3.1.1. Objectives

The working group reached consensus over the formulation of the objectives to be achieved by the CKD dashboard, see **Box 1**. The fourth objective was proposed by HCPs because of the increase of tele-consultations during the COVID19 pandemic. The dashboard will be used during the consultations between CKD patients and their HCP in the hospital as well as during tele-consultations, supported by videoconference software.

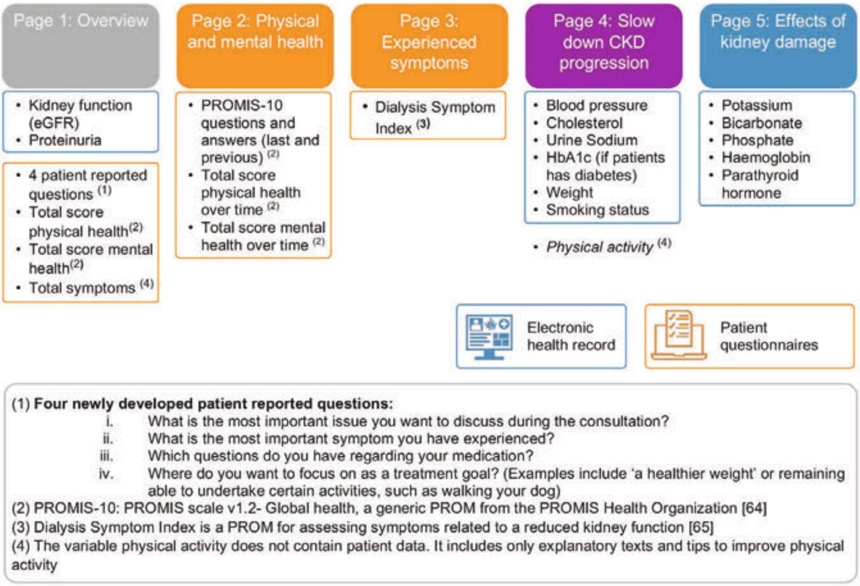
Box 1. Objectives CKD dashboard

- Provide feedback on the CKD trajectory over time and treatment goals to help activate patient self-management and thereby fostering **slowing down disease progression**;
- **Facilitate SDM** by enhancing the two-way flow of information during the consultation; better informing both patients and HCPs
- Provide **a complete and clear overview** with relevant data from multiple data sources
- Help ensure **effective information** exchange during teleconsulting

However, the patients in the working group stated that the dashboard should also be accessible for patients at home. They argued that reviewing the dashboard at home and discussing it with relatives/ partners, would help in processing the information and preparing for consultations. It was agreed upon that the dashboard used during (tele-) consultation and at home should be the same to ensure patients can recognize what is discussed during consultations.

3.1.2. Content

A set of items was chosen to include in the dashboard from a list of outcome information (**Fig. 3**). Because of the wide range of included items, working group members reported a need to explore what patients find most important to discuss in upcoming consultations. To that end, four newly developed patient-reported questions, to be completed before the consultation, were added in the dashboard (**Fig. 3**).



(1) **Four newly developed patient reported questions:**

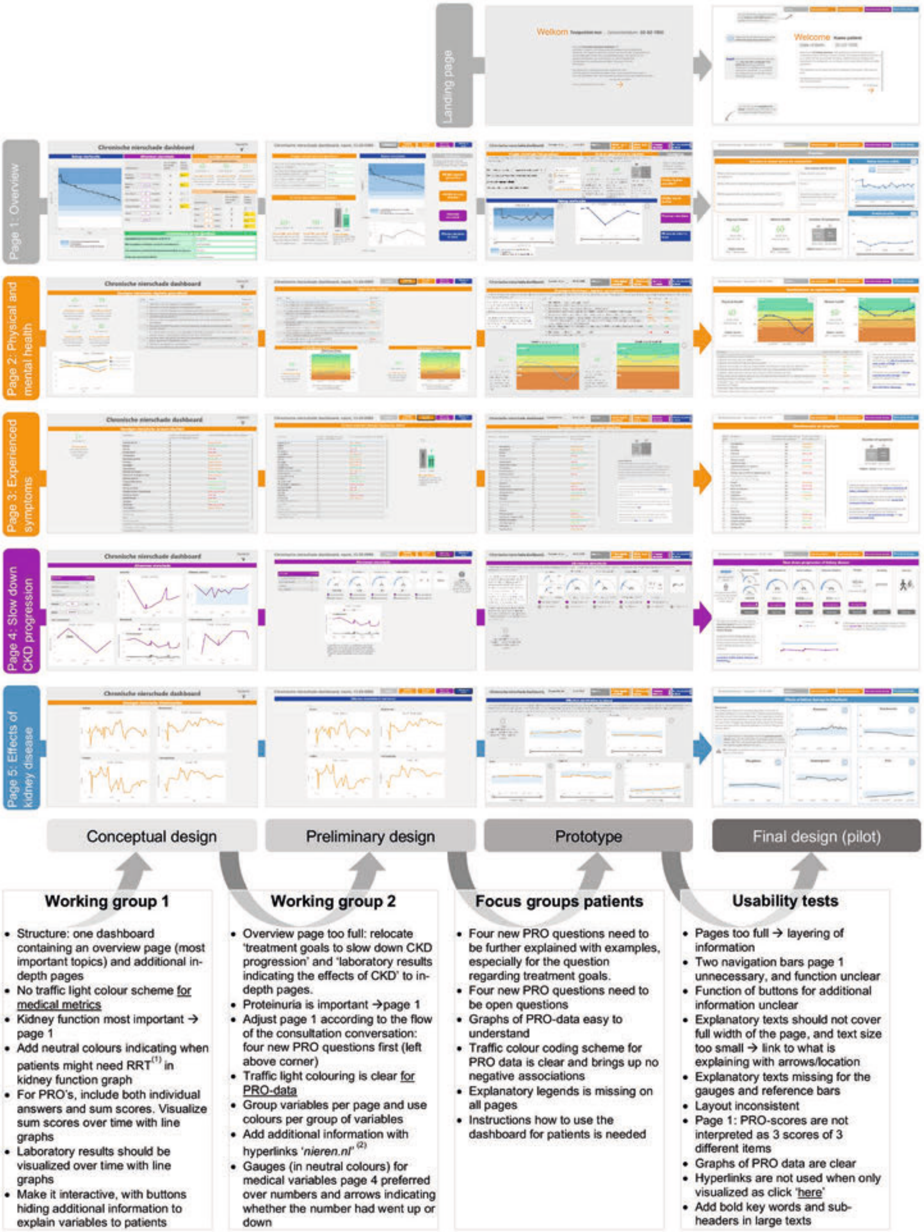
i. What is the most important issue you want to discuss during the consultation?
ii. What is the most important symptom you have experienced?
iii. Which questions do you have regarding your medication?
iv. Where do you want to focus on as a treatment goal? (Examples include 'a healthier weight' or remaining able to undertake certain activities, such as walking your dog)

(2) PROMIS-10: PROMIS scale v1.2- Global health, a generic PROM from the PROMIS Health Organization [64]
(3) Dialysis Symptom Index is a PROM for assessing symptoms related to a reduced kidney function [65]
(4) The variable physical activity does not contain patient data. It includes only explanatory texts and tips to improve physical activity

Figure 3. Overview of the variables included in the dashboard and their data sources

3.1.3. Design

The working group agreed on a design with multiple pages in order to group information effectively. The 'overview-page' was designated as the main page to be discussed during consultations. The other four pages were designed as in-depth pages visualizing health status and treatment goals. Patients in the working group discouraged the use of traffic light colour-coding for clinical outcome information, since it can be demotivating if everything is 'red' while the patient is fully commited to their treatment plans. It was emphasized that explaining clinical outcomes and providing additional information on what patients can do themselves to achieve treatment goals, is essential for the dashboard. Therefore, an interactive interface was built including informative buttons and hyperlinks that open webpages on specific topics on *nieren. nl*, the informative platform of the Dutch Kidney Foundation and the Dutch Kidney Patient Association. See **Fig. 4** for an overview of the feedback of the working group on the dashboard's design. The dashboard was built in PowerBI (Microsoft). The clinical metrics were automatically retrieved from the EHR. The PRO-data originates from digital patient questionnaires (per e-mail) collected with the software 'Questmanager' (Philips) twice a year before patients' their consultation (**Fig. 3**). The PRO-data was directly imported from Questmanager. Data from both data sources had a refresh rate of 30 min.



Working group 1

- Structure: one dashboard containing an overview page (most important topics) and additional in-depth pages
- No traffic light colour scheme for medical metrics
- Kidney function most important → page 1
- Add neutral colours indicating when patients might need RRT(1) in kidney function graph
- For PRO's, include both individual answers and sum scores. Visualize sum scores over time with line graphs
- Laboratory results should be visualized over time with line graphs
- Make it interactive, with buttons hiding additional information to explain variables to patients

Working group 2

- Overview page too full: relocate 'treatment goals to slow down CKD progression' and 'laboratory results indicating the effects of CKD' to in-depth pages.
- Proteinuria is important →page 1
- Adjust page 1 according to the flow of the consultation conversation: four new PRO questions first (left above corner)
- Traffic light colouring is clear for PRO-data
- Group variables per page and use colours per group of variables
- Add additional information with hyperlinks *'nieren.nl'* (2)
- Gauges (in neutral colours) for medical variables page 4 preferred over numbers and arrows indicating whether the number had went up or down

Focus groups patients

- Four new PRO questions need to be further explained with examples, especially for the question regarding treatment goals.
- Four new PRO questions need to be open questions
- Graphs of PRO-data easy to understand
- Traffic colour coding scheme for PRO data is clear and brings up no negative associations
- Explanatory legends is missing on all pages
- Instructions how to use the dashboard for patients is needed

Usability tests

- Pages too full → layering of information
- Two navigation bars page 1 unnecessary, and function unclear
- Function of buttons for additional information unclear
- Explanatory texts should not cover full width of the page, and text size too small → link to what is explaining with arrows/location
- Explanatory texts missing for the gauges and reference bars
- Layout inconsistent
- Page 1: PRO-scores are not interpreted as 3 scores of 3 different items
- Graphs of PRO data are clear
- Hyperlinks are not used when only visualized as click 'here'
- Add bold key words and sub-headers in large texts

Figure 4. Development of the design based on the feedback on the dashboard from the participatory methods.

(1) RRT = renal replacement therapy

(2) Throughout the dashboard, per topic, hyperlinks can be found forwarding to the informative website of the national Kidney Foundation and Kidney Patient Federation for additional information (nieren.nl).

3.2. Focus groups patients

3.2.1. Part one: Current way of consultations

Patients reported that during their consultations mainly laboratory results and symptoms were discussed. Outcome information was already being visually presented to some patients during consultations; four patients were shown graphs from the EHR of their kidney function and one patient was also presented graphs of blood pressure and proteinuria. Most of the patients indicated to be satisfied with the way consultations were going. However, two patients stated that they felt overwhelmed with the amount of (unclear) information provided at the start of their CKD trajectory:

> *Patient 5: When I went to the nephrologist there was a bit of an assumption that I knew what I had, but it wasn't obvious to me. So, you actually have to look things up and read things yourself. It might be good if the nephrologist explained everything properly at the start, what those values are, what the values do, what everything means. What should be happening with everything? (…) Yes, I actually think that there is no place where you can find that information clearly. In addition, some patients indicated to have missed information on what you can do yourself to improve CKD:*

> *Patient 7: Earlier in my CKD trajectory, I never talked to a dietician or attention was given to diet and things, and that is something I missed, since that is now something I know can keep my kidney function stable.*

3.2.2. Part two: patients' vision on the preliminary design of the dashboard

After being shown the preliminary design of the dashboard, patients differed in which dashboard topics they deemed most important. Some patients indicated the mental health components to be highly important, whereas others were mostly interested in laboratory results. All patients agreed that the dashboard content was clear and comprehensive. Patients' preferences for comparing their individual data with aggregated data varied; some patients argued it would help to see others' progress to motivate themselves, although others said not to be interested in other people's data, because '*every kidney patient is different (Patient 1)*'.

The four newly developed PRO questions

The four newly developed PRO questions, aimed to prioritize issues to be discussed (see **Fig. 3**), were believed to help patients structure their thoughts on what they want to discuss during consultations. A patient added that this could also stimulate patients to engage in decision making. Furthermore, patients mentioned that discussing treatment goals and monitoring them when using the dashboard could help them to actively engage in treatment plans and adjust them when needed:

> *Patient 4: Asking a patient for their treatment goal can be a reminder, people can see for themselves which diets help and which don't. Then you naturally also set a goal and you can keep coming back to it each time. [...] you can see with your measurements whether you've had results.*

All patients agreed that the four questions should be open ended questions. Providing answer-examples was suggested, because not all patients understood what was meant with 'treatment goal'.

Pages reporting PRO's

Regarding the other PRO's included in the dashboard, patients pointed out that the symptom-related PRO's could help to better understand CKD – *Patient 3: I think this [DSI] is a good addition, because there were issues that I hadn't connected to renal function*. The benefit of visualizing PRO's over time was also emphasized:

> *Patient 1: I think that it [PRO's in dashboard] could definitely contribute to the consultation because it's clear whether the line is going up or down. I think it's helpful for yourself too, because you can also see the difference compared to a year or two years ago. Kidney disease often progresses very slowly which you don't really notice.*

Visualizing the PRO's of experienced mental and physical health over time with line graphs were easy to understand according to the patients. Patients indicated to find the traffic light coding for the PRO-data clear and useful to identify what to discuss. No negative associations with this colour use were mentioned.

Pages reporting treatment goals to slow down CKD progression and the effects of kidney damage

Visualizing the treatment goals in slowing down CKD progression was deemed relevant. Particularly, being able to see progress over time in graphs can help to stay motivated for treatment, as a patient reported:

> *Patient 5: To me, these kinds of things are very interesting, I work on my progress and everything's improving. I'm still working on it. (...) Knowing how that progress can manifest, you can clearly see that in these kinds of graphs. I want to see this in the consulting room, that would motivate me.*

The additional explanations of the medical variables (e.g. laboratory results) in the dashboard behind buttons were also received positively because patients experienced that these variables were often mentioned, but not fully explained during consultations.

Added value of the dashboard as a whole

Patients emphasized the value of being able to access the dashboard at home and use it to prepare for consultations. The easy access to additional information by way of the informative texts and hyperlinks was also deemed of added value, as this information had been missed at the time of onset of CKD.

> *Patient 5: I definitely missed having it [the dashboard] at the start to help me prepare properly for the consultation with my nephrologist, because I think you get really overwhelmed in the beginning with all the numbers and things and now you can ask really focused questions.*

In addition, patients indicated that the dashboard provided a good overview of their disease and believed it might increase patients' involvement in their treatment by getting better informed and stimulated to think about their own disease.

Patients' concerns regarding the dashboard

Patients' expressed concerns regarding privacy and the applicability of the dashboard towards elderly, non-native speakers and patients with limited digital skills. A potential barrier mentioned by multiple patients was that discussing the dashboard might exceed the regular consultation time. On the contrary, one patient suggested the consultation might be more time-efficient:

> *Patient 4: I think that both the nephrologist and the patient will be well prepared heading into the consultation and when you can see everything beforehand, I also think that for the things that aren't so important at that moment, you can get through them more quickly. So, I don't even think it would take longer, because both are so well prepared.*

Another concern was that patients could focus too much on their dashboard resulting in increased worrying. The most-frequently mentioned concern was that the dashboard should not overshadow the conversation:

> *Patient 2: I think it's really useful, but it shouldn't dominate; that it needs to be filled in otherwise the consultation won't be good and we can't assess everything properly. Then, it can steer away from what really matters. It's a supportive tool, not a primary goal.*

Patients' views on how to use the dashboard in practice

Patients mentioned that the dashboard requires sufficient explanation, both in the dashboard itself (by adding legends and visuals) as well as having a HCP explain the dashboard the first time. In addition, a patient mentioned that to effectively discuss the dashboard both HCPs and patients have to align their perspectives on what to discuss.

For a full list of identified themes and related key citations see **Supplement 1.**

3.3. Usability tests

During task one, *orientation,* patients reported an information overload on most pages. Patients differed in what information they found most important and in their needs for additional explanations. This highlighted the importance of 'layering information' in order to address these varying information needs and reduce information overload. Most patient stranded on the overview page and did not use the navigation tabs. Additionally, patients did not read explanatory texts and the buttons for additional information were not used. In task two, *navigating through the dashboard and identifying topics that you would want to discuss during the consultation*, patients succeeded in picking the topics relevant to them to discuss. The four newly developed PRO questions and kidney function were most often chosen. A learning curve was observed; the more time patients spent navigating through the dashboard, the more acquainted they got with it. In task 3, *finding out what you can do yourself and how you can do it*, patients did not fully succeed in identifying where they can work on themselves, since they were not always able to find the information buttons and hyperlinks on how to implement treatment plans. Thus, it was suggested to explain on the landing-page how to use the dashboards' functions (e.g. navigation, i-buttons, hyperlinks). In addition, it was advised to position explanatory texts more closely to the visual it's explaining, using arrows to correctly annotate. Other remarks were made on design and user-friendliness, such as enlarging text size and being more consistent in lay-out (see **Fig. 4** for other remarks on design).

Most patients expected that the dashboard can motivate patients, because of the possibility to see progression in treatment goals over time. All patients would recommend the dashboard to others, especially since the dashboard provides a clear overview of a lifelong disease. See **Supplement 3** for an overview of the findings of the usability tests.

3.4. Final design CKD dashboard

Findings from the patient focus groups and usability tests were incorporated in the final design (**Fig. 5**). Visual and textual clarifications were added to make the dashboard self-explanatory for patients. To help prevent information overload and to meet the varying information needs, a variety of interactive buttons were used to 'layer information'. Changes were made in contouring, colours, text size, and consistency of functionalities, to improve visual clarity and user-friendliness.

3.5. Focus group healthcare professionals

The HCPs believed that the dashboard would improve consultation conversations by facilitating patients' priorities/concerns better. Two nephrologists argued that sensitive topics such sexual disfunction, might be discussed more frequently. Additionally, HCPs indicated that being able to provide visual feedback to patients regarding their outcomes over time can work motivating:

> *HCP7: Showing sodium excretion can be motivating. If people have to follow restrictions, you can show that they can actually have an effect and what the consequences are and that they can lead to an improvement. It's nice to be able to show people that improvement. I think that it can help with motivation. Using the clinical course as a motivator.*

Moreover, participants reasoned that better informing patients on their condition can increase their involvement in decision making and their treatment plans:

> *HCP8: It would save a lot of time if people knew what they were talking about. This dashboard actually gives you an insight into how things are going, and they can see how things are compared to last time and whether things are better, the same or are actually getting worse. And the accompanying explanations they can see make it much easier to think about setting treatment goals, and thus also much easier to think about what steps you have to take to reach those goals.*

The HCP already experienced with dashboarding in rheumatology, emphasized the importance of discussing the main treatment goal with patients, as patients and HCPs might have different perspectives:

Explanatory texts on dashboards' functions with consistent lay-out: grey, bold key words in text, arrow/image to annotate

Added explanation how to navigate through dashboard

Added explanation i-buttons (for additional information)

Added explanation hyperlinks to *nieren.nl* (1)

Instruction on how to use the dashboard included in welcome text

Changed background to white, grey text front, text size increased

Four new PRO questions left right corner (first to discuss during consultation)

Both kidney function graph and proteinuria on overview page

Added legend (in neutral colours) in kidney function graph visualizing when patients reach the need for RRT (2)

Buttons showing examples to clarify the four PRO questions

3 different PRO sum scores visually separated by use of white space and lining

Numbers clarified with concise textual explanations

Colour use based on type of data, PRO's=orange, laboratory=blue, measures related to treatment goals CKD=purple

Line graphs to show PRO sum scores over time

Mean compared to Dutch population added in PRO graphs

Traffic colour coding for PRO data

All PRO answers last- and previous measurement in table

Titles above visualisations

Symptoms that patients experienced in darker grey

All informative texts similar lay out (white with grey lining)

Icon added indicating that the hyperlink leads to external webpage

Hyperlinks linked to main terms instead of 'click here'

Added explanation gauges

Gauges simplified, blue=reference, pointer=last measurement

Button for showing graphs of variable over time

Button for additional information regarding the variable

No traffic light colours for medical values/measurements

Example graph of variable (behind button) + explanatory text

All informative texts simplified and written according to the B1 level of the CEFRL (3)

All graphs supported with i-buttons with informative information on the variables and if more information is preferred hyperlinks to *nieren.nl*(1)

i-buttons made more visible and lay-out consistently applied throughout dashboard

Added explanation reference bars

Reference /general normal values added based on guidelines (in blue)

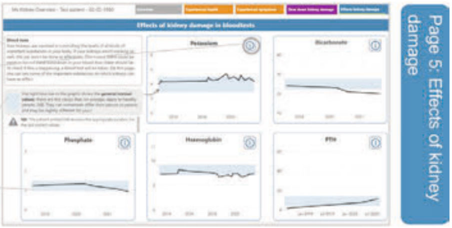


Figure 5: Final design of the dashboard including the most important design choices

The images are screenshots of the CKD dashboard (translated from Dutch) containing data of a non-existing patient. Normally, the dashboard is interactive revealing explanatory texts or graphs when clicking on buttons. Throughout the dashboard, per topic, hyperlinks can be found forwarding to the informative website nieren.nl. The dashboard can be directly opened by HCPs through a link in the patients' EHR.

(1) Nieren.nl = informative website of the national Kidney Foundation and Kidney Patient federation for additional information

(2) RRT = renal replacement therapy

(3) CEFRL = Common European Framework of Reference for Languages

> *HCP1: In the questionnaires you ask about the treatment goal. That's pretty complicated. (…) For rheumatology, our treatment goal is to reduce disease activity and for kidney disease it's slowing the progression of the kidney damage, but for a patient it might be different, for example being able to play with grandchildren.*

A frequently mentioned potential downside of using the dashboard in practice was the time-constraints of consultations. However, one HCP argued consultation time might be shorter because you already know what patients want to discuss. Participants expressed concerns that the dashboard could raise the unrealistic expectation that all topics would be discussed during the consultation. Other participants suggested these high expectations might be resolved by collaboratively setting the agenda with the patient and prioritizing what to discuss.

One nephrologist worried that too quickly 'diving into' the dashboard at the beginning of the consultation might result in missing important topics. The participants argued that leaving room for a 'real conversation' would help prevent this:

> *HCP3: You just have to allow space to have a conversation before you get into the dashboard. Depending on how you feel that goes and what the patient says, you should be able to work out what else is going on and whether there is something the patient wants to talk about. In my opinion that's no different to what we do now; I think we already start with a conversation before we discuss the results.*

Another HCP added that not the dashboard, but the conversation should remain central during the consultation: *don't make it [discussing the dashboard] the goal, make it a tool to support the conversation* (HCP 4).

Other tips for using the dashboard in practice were mentioned, including: getting sufficiently acquainted with the dashboard before using it, and always check the dashboard before the consultation to identify unexpected findings. Lastly, two HCPs argued that applying motivational interviewing combined with the dashboard's visual feedback on treatment goals over time can strengthen the effect of the dashboard on patient activation. For a full list of identified themes and related key citations see **Supplement 2.**

3.6. Training HCPs in using the dashboard

Based on findings of the HCP focus group and literature, a training was developed for HCPs on how to use the dashboard effectively in practice. The content of the training includes: 1) communication tips on setting the agenda with the patient and how to the discuss individual PRO's and clinical outcomes, 2) how to incorporate SDM and motivational interviewing when discussing the dashboard, and 3) technical instructions for using the dashboard.

4. Discussion

In this study, we propose dashboarding as a strategy to present individual outcome information effectively to patients and HCPs, with the aim of optimizing patient activation and meeting patients' information needs. This study reports on the participatory development of a dashboard for CKD patients stage G3b-4, visualizing both clinical and PRO-data over time, designed for use during the consultation and at home. We identified the potential value as viewed by patients and HCPs, conditions for design and factors affecting use in clinical practice.

Our qualitative results show that both HCPs and patients agree that the dashboard could enhance patients' activation by monitoring and providing feedback on outcomes. In particular visualizing the outcomes *over time* was considered key to activating patients. In line with earlier findings, [31–34] both HCPs and patients expected that measuring and presenting PRO's, especially the Dialysis Symptom Index, may improve understanding of one's condition and increase perceived control over health. Furthermore, both patients and HCPs acknowledged the added value of the four PRO questions designed to assess what patients want to discuss during the following consultation. They expected these questions to enable both HCPs and patients to prepare the consultation and align the topic agenda, making the consultation efficient. The four PRO questions share similarities to 'question prompt lists', of which studies show it can increase patient involvement in consultations and improve knowledge transfer [51]. In our study, the importance of setting the consultation agenda *together* was reported, which resembles how agenda setting is posed as collaborative work in literature [52].

With the different participatory methods we identified how to visualize the relevant outcomes for HCPs and patients. In the working group sessions it was decided that the dashboard would be used in two ways: during the consultation and accessed by patients at home. This twofold way of using the dashboard made the design requirements complex since it had to be concise as well as self-explanatory for patients. The interactive design, as proposed in the working group, offered a solution for this difficulty. It provided the possibility to 'layer information', thereby preventing information-overload, while still being able to offer in-depth information regarding different topics. The latter also helps to meet the variation of information needs of patients as identified in this study and in literature [24]. Moreover, studies have shown that an interactive design in which users can tailor which information they want to receive can positively affect users' information processing, attitude towards presented health issues and even affect their health behavior [53].

Some design choices based on findings of this study differed from literature on visualizing outcomes, such as the decision to visualize PRO's over time with higher-better oriented line graphs including threshold lines and explanatory texts. Although patients in this study seemed to understand them well and different studies suggest this is the best choice of visualization [46,48], a recent review showed that bar charts might have a slightly higher interpretation accuracy [54]. Furthermore, the use of traffic light colour-coding for clinical metrics is advised by studies [55] and frequently used in medical dashboards [43]. However, based on comments from the patient members in the working group, it was decided against its use for clinical metrics, because it can have a demotivating effect. Surprisingly, for PRO-data, patients did not have negative associations with this colour scheme and found it clear, resembling patients' and HCPs views in other studies [54]. The different views on using traffic light coding for medical metrics and PRO data as seen in this study may be explained by the progressive nature of CKD. Although patients might be fully committed, the disease is still progressive, which can be (negatively) emphasized by using traffic light coding for medical metrics. PRO-data on the other hand, might be considered more changeable and reactive to patients' own behavior and feelings. Lastly, during the usability tests the importance of textual explanations for visuals was recognized. Although this is no new insight and already recommended [46,54], we found that such textual explanations only work when correctly placed (near the visual or including an arrow) and the texts are large enough and concise.

An important finding, mentioned by both patients and HCPs, is that the dashboard is a tool to support the conversation during the consultation, and using it must not be a goal in itself. The HCP-patient relationship and the conversation between them should remain central, in order not to miss relevant topics. Such worries about digital tools taking precedence over the conversation during consultations have also been reported in studies with decision aids [56–58] and screen sharing of the EHR [59].

A principal limitation of this study is the selection bias in the sample of participating patients. The focus groups' patients were recruited from the Dutch Kidney Patient Federation, who may be more involved than patients of the general CKD population. Additionally, the patients who participated in the usability tests had relatively high education levels. Furthermore, due to the COVID19 pandemic, all research methods were performed via videoconferencing. This required a minimum of digital skills, which may have affected participants' views on the dashboard. Thus, caution should be taken in generalizing the results to the whole CKD population and all HCPs providing kidney care.

This study has implications for everyone developing digital tools that aim to visualize outcome information in healthcare. The participatory approach with both HCPs and patients, being involved in the early phases of development, has proven its worth. This approach resulted in an early change in the objectives of the dashboard (i.e. extending to accessibility for patients at home), and altering its design drastically. Participation of HCPs in development also helped to ensure a solid base for implementation of the dashboard [60,61].

For others planning on following similar steps in developing a dashboard, we recommend to include all potential end-users in the working group, ideally including multiple participants per function. As this study shows, conducting additional focus groups and usability tests with end-users can provide useful insights. For focus groups, four to eight persons per group is generally advised [62], which worked well in this study for exploring different views in depth. For usability tests, including five participants can already help to identify a large part of the usability problems [63]. Ideally, the number of participants is dependent on when data saturation is reached, which was the case in this study after conducting nine usability tests. Preferably, characteristics of the participants, that are relevant to how the developed dashboard might be received, vary (e.g. age or education level), which can be achieved by purposively sampling.

Next, we will implement the CKD dashboard in a pilot. A mixed-methods observational evaluation study will be performed to assess the effect of the dashboard on patient activation and SDM. For this end, patient questionnaires and audio-recordings of the consultations will be collected pre and post dashboard implementation. In the questionnaires patients will be asked to provide feedback on the information presented in the dashboard. In addition to the study, feedback-sessions will be held with HCPs who are using the dashboard in order to explore first experiences and identify possibilities for improvements. Other next steps include scaling up to other hospitals and continuously improving the dashboard based on feedback retrieved from its use in clinical practice.

5. Conclusion

A CKD stage 3b-4 dashboard was developed in co-creation with HCPs and patients. Both patients and HCPs acknowledged the added value of the dashboard when used during consultations, and when it is accessible for patients at home. This study shows the potential of dashboarding as a strategy to report individual patient outcomes to patients and their clinicians effectively. Our findings suggest that using a dashboard for this end may facilitate patient activation and SDM, which will be investigated in future work. The participatory development approach offered valuable insights for dashboard development and implementation, which can inform others wishing to develop similar digital support tools. In trying to improve care in this era of digital possibilities, continued efforts should be made to report on the development of similar tools to allow learning from each other's experiences.

Summary table

What was already known on this topic

- Dashboards can enhance information transfer by optimizing clarity of the data.
- Dashboards are increasingly used in healthcare, especially on aggregated level to inform healthcare professionals' quality or clinical decisions. The use of dashboards for reporting individual clinical and PRO-outcomes to patients during consultations is limited.

What this study added to our knowledge:

- This study shows that dashboarding might be a useful tool to report individual patients' outcomes to patients and their clinicians

- This study provides design and content requirements for a dashboard visualizing patients’ individual outcomes designed to be used during the consultations and accessible for patients at home
- Enablers are provided how to best use a dashboard during consultations

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Supplements

Supplement 1. Identified themes and key citations focus group patients

	Focus group HCPs	
Topics topic list	**Identified themes/findings**	**Key citations**
	Part 1: How consultations are currently being done	
How consultations are currently being done: - *What is being discussed?* - *What information is deemed important to discuss?* - *What information is missed that is not discussed?*	• Mainly blood tests, urine tests and symptoms discussed (FG 1+2) • Treatment goals not discussed (FG 1) • Four nephrologist show graphs of kidney function of which one also shows graphs of blood pressure and proteinuria from the EHR (FG 1) Identified needs in current state of doing consultations • Information on what you can do yourself to slow down CKD progression i.e. dietary advices (FG 1+2) • Missed general explanations about CKD; patients had to look things up themselves in beginning (FG 1)	*P4 When I saw those lab results for the first time they didn't tell me much, I had to find a few things out before I understood what it all meant.* *P4: When I went to the nephrologist there was a bit of an assumption that I knew what I had, but it wasn't obvious to me. So, you actually have to look things up and read things yourself. It might be good if the nephrologist explained everything properly at the start, what those values are, what the values do, what everything means. What should be happening with everything? (...) Yes, I actually think that there is no place where you can find that information clearly.* *P5: In the beginning, I had no idea what something like that [kidney damage] meant and suddenly I was confronted with it and I got no information at all from the hospital.* *P7: earlier in my CKD trajectory I never talked to a dietician or attention was given on diet and things, and that is something I missed since that is now something I know can keep my kidney function stable*
	Part 2 patients' vision on the preliminary design of the dashboard	
Individual data comparison aggregated data	Patients differed in opinion: • Arguments in favour: a mean as guidance or helps to motivate if others can get better (gives hope) (FG 1) • Argument against: everyone is different (FG 1)	*P4: On one hand I think you are your own person and you have your own problems, but on the other hand I think it's really good to see what's possible or where you might end up. If I hear about people with improved kidney function that gives me hope. Maybe if you can compare yourself to people in a similar situation, that might be useful.* *P1: I wouldn't want to have to see myself compared to others. Because I think that's a very complicated issue, because, um, what I've learned up to now is that no person's kidney disease can be compared with another person's kidney disease, because if you look at groups on Facebook for example, at people with the same kidney disease, one person's taking medicine, the next is on a diet, another one isn't on a diet yet, someone else is already having dialysis with a kidney function of 20 and for others dialysis has been postponed again because they're not suffering. That makes it really difficult to compare yourself to other people, I would only want to know about myself. I think that's very important to know – how things are going for me.*

Supplement 1. *(Continued)*

Focus group HCPs		
Topics topic list	**Identified themes/findings**	**Key citations**
4 newly developed PRO questions (1)	• Asking patients their treatment goals helps not to miss important treatment goals that matter to patients (FG 2) • Explicitly discussing treatment goals can be a reminder and work motivating (FG 1+2) • Questions structure what patients want to ask the nephrologist and prepare the consultation (both for patients and nephrologists) (FG 1+2) • Questions should be open-ended but to increase understanding of the questions examples should be added	*P4: Asking a patient for their treatment goal can be a reminder, people can see for themselves which diets help and which don't. Then you naturally also set a goal and you can keep coming back to it each time. Then for example the goal might be to avoid using certain products, and then you can see with your measurements whether you've had results* *P3: And I think it's great that what you want to ask about is already there, for the nephrologist it's good being able to see it already. I normally have this in my notebook; now the nephrologist knows it all already.* *P7: the question regarding the treatment goal, for who is this question? [P8 provides example:] for instance a patients who wants to keep walking the dog, that can be a treatment goal. [...] P7: more explanation is then needed for this question, that it is aimed at the patient. Only saying treatment goals in the question is not clear enough, examples should be provided.*
Page 2: Physical and mental health (2)	• Importance visualizing PRO's over time (FG 1+2) • Importance of mental health to be included emphasized (FG 1) • Seeing what can be improved helps to address problems and alter therapy plans (FG 2) • Graphs and tables presenting PRO's are well understood (FG 1+2) • Traffic light colour use for PRO data is clear and useful	*P1: I think that it (PRO's) could definitely contribute to the consultation because it's clear whether the line is going up or down. I think it's helpful for yourself too, because you can also see the difference compared to a year or two years ago, for example. Kidney disease often progresses very slowly which you don't really notice.* *P5: I definitely missed having it [dashboard] at the start to help me prepare properly for the consultation with my nephrologist, because I think you get really overwhelmed in the beginning with all the numbers and things and now you can ask really focused questions.* *P8: Yes, it could certainly help, where am I heading? Because if I see this now and I'm heading into red that just gives me a reason to discuss the red things, and the doctor and I can look at what we can do about it.* *P1: I think the table and graphs are presented clearly, especially because of the colour use: it makes it pop and helps to identify what you need to discuss. When a lot is red, you can discuss this.*

Supplement 1. *(Continued)*

Focus group HCPs		
Topics topic list	**Identified themes/findings**	**Key citations**
Page 3: Experienced symptoms (DSI) (3)	• Helps to understand condition (and related symptoms) (FG 1)	*P3: I think this [DSI] is a good addition as well, because there were intermediate issues that I hadn't connected to renal function*
Page 4: slow down CKD progression and page 5: effects kidney damage	• Monitoring on treatment goals can work motivating (FG 1) • Additional explanatory texts bring brings additional value (FG 1)	*P5: To me, these kinds of things are very interesting, I work on my progress and everything's improving. I'm still working on it. (...) Knowing how that progress can manifest, you can clearly see that in these kinds of graphs. I want to see this in the consulting room, that would motivate me.* *P4: I think it's great, seeing the explanation right there. I think it's very plain and clear. It's just nice to have an extra bit of explanation. Yes, I like being able to see it in advance or talk it through in the consulting room. There's nothing missing.* *P1: I think it's also a great addition and definitely clear. Particularly if an explanation pops up that you can click on to find out what exactly it means.* *P2: These are things that were mentioned by my nephrologist but never further explained later on in our conversations. So, this is something fairly new. I know things are measured but, in the consultations, and the treatment plans it's not obvious. Naturally, these are things that show something about yourself in more detail. It certainly helps me, getting more of an explanation.*

Supplement 1. *(Continued)*

	Focus group HCPs	
Topics topic list	**Identified themes/findings**	**Key citations**
Added value dashboard as a whole	• Added value for conversation (FG 1+2); encourages patients to think about their treatment • Helps patients to prepare for the consultation (accessibility at home therefore required) (FG 1+2) • Nephrologist already know patients' issues beforehand leading to a better, more efficient, conversation (FG 1) • Helps to increase patients involvement in their treatment (FG 2) • Helps to raise and address questions you have during consultation (FG 1 + 2) • Provides a good overview	*P3: I think that the addition really encourages me to think about things I just wouldn't think about by myself, so in that sense it really adds something to the consultation. And it also provides a good overview.* *P8: It helps me focus – what do I actually want to discuss? It would be good if it could pop a bit more, so I'd know what to focus on.* *P6: The advantage is that it acts as a kind of checklist and it improves patient engagement. It fits with the general trend of giving patients more of a say in their treatment.* *P2: I think the dashboard as a whole really adds value, it could help you dot your i's and cross the t's with your preparation and work out what you want to talk about, what questions you have and what things were like last time, I think it could make you a bit sharper.* *P4: I find it very clear; I think that both the nephrologist and the patient will be well prepared heading into the consultation and because you can see everything beforehand, I also think that for the things that aren't so important at that moment you can get through them more quickly. So, I don't even think it would take longer, because both of you are so well prepared.*
Concerns dashboard	• Digital skills elderly (FG 1) • Other languages (FG 1) • Privacy (FG 1) • Limited time consultation, might take too long (FG 1 + 2) • Should not overtake the consultation (FG 1 + 2) • Too much value in reported outcomes can lead to worrying (FG 1) • More experienced symptoms because of list of symptoms (FG 1)	*P2: I think it's really useful but it shouldn't dominate; that it needs to be filled in otherwise the consultation won't be good and we can't assess everything properly. Then it can steer away from what really matters. It's a supportive tool, not a primary goal.* *P6: One disadvantage is that the screen must not come between the patient and the doctor.* *P2: It may be that if you add too much value in the questionnaires it could have the reverse effect, people might make a certain value judgment and that might not be a good thing. But a snapshot is nice, and particularly for people who have recently been confronted with kidney disease it's important to review it from time to time.*

Supplement 1. *(Continued)*

Focus group HCPs		
Topics topic list	**Identified themes/findings**	**Key citations**
How to use the dashboard in practice	• Align both clinician and patient perspectives on what to discuss (FG 2) • Needs to be available at home (to prepare and to discuss with relatives/partner)) (FG 1+2) • Dashboards need to be explained first time by clinician (FG 2)	*P8: My first impression is that it will require some explaining. So maybe in time you will learn how to use it, but that's my initial impression; it means everything will need some kind of key or explanation. That goes for everything.* *P8: I am a patient and I have these issues and this is the focus and here are the things I want to ask about. (...) And this is probably on the doctor's screen, obviously he's prepared as well, he has a focus on what to discuss too. Then you have two things to focus on and you can align them.* *P5: Particularly if you get it a day or two in advance, you can actually go through and fill it in with your husband and look things up on the Internet so you can ask more questions.*

Supplement 2. Identified themes and key citations focus group healthcare professionals

Focus group HCPs		
Topics topic list	**Identified themes/findings**	**Key citations**
How the consultation is started currently	HCPs differ in their start of consultation: • Clear distinction between how it is going with the person and the medical - results • The question: 'did something change from when I last saw you?' • The question: 'what can I do for you?'	*HCP 3: I always ask the classic "How's it going?" And I try to make a distinction between how it's going for the person and how it's going in terms of results. I try to make sure we can discuss each of these questions separately.*
(after presenting dashboard) How can the dashboard change the consultation conversation?	• PROM answers can guide the conversation • By discussing PROMs other topics that are often not discussed are more easily brought up • Patients are more prepared for the consultations; they know what they want to discuss • Patients are more knowledgeable on their condition which leads to a better conversation • By informing patients on their own trajectory, it may support their involvement in decision making and setting treatment goals • Showing patients trajectory over time and effect of treatments can work as motivator or help to identify issues • When patients already know certain values, it saves time in discussing them	*HCP1: In the questionnaires you ask about the treatment goal. That's pretty complicated. (…) For rheumatology our treatment goal is to reduce disease activity and for kidney disease it's slowing the progression of the kidney damage, but for a patient it might be different, for example being able to play with grandchildren.* *HCP3: I think with some topics I can see added value, with some topics there's more awareness, and other topics are easier to discuss. One of the things I don't talk about enough is sexual functioning. But it quite often comes up in the questionnaire. In all honesty I think that, as doctors, we sometimes find it quite tricky to talk about this topic. (…) these sorts of tools could help with that.* *HCP8: It would save a lot of time if people knew what they were talking about. This dashboard actually gives you an insight into how things are going, and they can see how things are compared to last time and whether things are better, the same or are actually getting worse. And the accompanying explanations they can see make it much easier to think about setting some treatment goals, and thus also much easier to think about what steps you have to take to reach those goals.* *HCP7: Showing sodium excretion can be motivating. If people have to follow restrictions, you can show that they can actually have an effect and what the consequences of them are and that they can lead to an improvement. It's nice to be able to show people that improvement. I think that can help with motivation. Using the clinical course as a motivator.*

Supplement 2. *(Continued)*

Focus group HCPs		
Topics topic list	**Identified themes/findings**	**Key citations**
Pitfalls to be aware of when using the dashboard as a HCP	• Treatment goals from HCP perspective might vary from patient perspective • Patient might expect to discuss every topic in the dashboard, but this is unrealistic given the duration of consultations • Patients can worry easily over small changes in the dashboard which might overtake the conversation. There should be room enough during consultations for the HCP to discuss the topics they deem important • Data in the dashboard can be confrontational for patients • During consultation diving into the dashboard too quickly might lead to missing other important topics • Dashboard is a tool, not an end in itself • For the future when grouped data might be added: not every patient interested in comparison individual data to aggregated data with similar characteristics	*HCP1: Slowing the progression of the kidney disease is actually also a treatment goal you discuss together. In the questionnaires you ask about the treatment goal. That's pretty complicated. (...) For rheumatism our treatment goal is to reduce disease activity and for kidney damage it's slowing the progression of the kidney disease, but for a patient it might be different, e.g. being able to play with grandchildren.* *HCP3: Say that a patient wants to talk about headaches but you see in the results that they need to start dialysis, for example, then the dialysis has to take priority. That's something you have to include in your conversation.* *HCP4: Don't make it the goal, make it a tool to support the conversation.* *HCP1: On the rheumatism dashboard, it's possible to show PROM data for "patients like me", but in the focus group it emerged that they wouldn't want to see this as the default, instead, they'd like to have the option of clicking to open it. Some patients really like this feature, but they also see how it could be a source of anxiety; am I doing worse than my peers? This makes it complicated.*

Supplement 2. *(Continued)*

	Focus group HCPs	
Topics topic list	**Identified themes/findings**	**Key citations**
Tips for using the dashboard during the consultation	• Expectation management what is going to be discussed during consultations (prioritizing topics with patient) • The conversation itself can motivate patients and dashboard can support this, not the other way around. • Linking motivational interviewing to treatment goals in dashboard can strengthen dashboard's effect • Have a real conversation and do not just focus on the numbers • Explicitly mention the goal of the dashboard, which is: to have a good conversation • Leave room for a conversation next to discussing the dashboard; then you don't miss out on other topics • Get sufficiently acquainted with the information in the dashboard • Before consultations, check the dashboard on what patients have filled in • Some patients become unsettled from too many numbers in the dashboard, then don't use it with them • When patient data can be viewed at home by patients, there is additional education needed for patients in the beginning	*HCP3: The dashboard contains a lot of information; it will take a while for the patient to understand it. Then it raises an expectation that I'm going to discuss the entire dashboard, but I'm actually not going to do that. Is there perhaps also something in the design? At the beginning you can say to the patient, there's a lot of information in the dashboard, but which bit do you particularly want to talk about, because we aren't going to talk about everything.* *HCP4: I think it complements the conversation you have with your patient and you can use the dashboard to substantiate the motivation you give them, but I think it's mainly about the conversation if you want to get someone motivated.* *HCP3: I personally think you actually have to try and have a conversation and shouldn't focus on the numbers and whether they're in the dashboard or in the portal, you should just have a conversation.* *HCP2: I tend to start with the question "What can I do for you right now?", afterwards we dive into the dashboard and get started. Particularly in the beginning there's a fear that you'll spend a lot of time on the dashboard and you just have to get started with that one question, because there might be other things going on.* *HCP3: You just have to allow space to have a conversation before you get into the dashboard. Depending on how you feel that goes and what the patient says, you should be able to work out what else is going on and whether there is something the patient wants to talk about. In my opinion that's no different to what we do now; I think we already start with a conversation before we discuss the results.* *HCP4: I think that how you prepare for the conversation is also particularly important. Make sure you have some information ready before you see the patient so there won't be any surprises.*

Supplement 2. *(Continued)*

Focus group HCPs		
Topics topic list	**Identified themes/findings**	**Key citations**
Potential barriers implementation	• Lab results from outside hospital not visualized in dashboard • Limited consultation time (for the number of topics in dashboard) • Dashboard might not be suitable for every patient)	*HCP6: You want patients to understand that the consultation is aimed at them, and that the things they want to talk about can be actively discussed with them. And that's where this dashboard might be able to help, if they can enter the questions they want to talk about in advance. But I think it would be a limited group that would want to actively use the dashboard.*
Facilitators adoption dashboard patients and HCPs	• Preparation consultation HCPs enhanced, especially because of the PRO question: 'what is it you want to discuss upcoming consultation?' • In the beginning, consultation time might increase, but when both HCP and patient are more experienced it might reduce • HCPs usage of the dashboard and when they show patients how behaviour affects variables, will stimulate patients to use the dashboard as well • Support patients how to use the dashboard	*HCP1: It will take up more time in the beginning, because as a practitioner you have to dig into the dashboard first. But in the long term it might be a positive development because you'll get used to it and the patient will have seen it last time, so it will take up less time, and ultimately, you know, it should decrease.* *HCP5: By using the dashboard ourselves as professionals and showing patients that if you fill in the PROMs, things change, because yes, they can really see it. Or if as a patient I adjust my diet, then I will see things change in the outcomes. So, using the dashboard and getting patients to interact with it can really get patients engaged.*
Potential to improve dashboard	• Connect dashboard with (existing) self-management modules • Prognostic modeling could add to motivation in treatment goals CKD	*HCP2: That [prediction model for the likelihood of cardiovascular diseases] certainly has an incentive effect. But we have quite a few people who have to be confronted in a somewhat tougher way; it's not just a number, it can have real consequences for you.*

HCP=healthcare professional (participant of the focus group), PROM=patient reported outcome measure.

Supplement 3.

Main findings usability testing

Usability tests	
Tasks performed by participants	
Tasks	**Main findings**
Task 1: orientation: navigate through the dashboard freely	Observations: • Most participants strand on the overview page and do not click on the other tabs. Navigation tabs are unclear. • Most tabs are too full, participants experience an overload of information the first time they click through the dashboard. • Inconsistency in the dashboard becomes clear from remarks of patients • Text size is too small to comfortably read explanatory texts • Participants do not read the explanatory texts throughout dashboard leading to misunderstanding visualizations and graphs • Buttons for additional information or visualizing variable over time unclear Remarks participants: • Four newly developed PRO questions (Figure 3) are reported to work as mnemonic questions to discuss during consultation • Information regarding symptoms and mental health is deemed important and especially relevant to be able to see over a longer period of time • Participants recognize many symptoms in the symptoms-page from which they didn't know it could be related to their kidney disease
Task 2: while navigating through the dashboard, choose two topics from the dashboard that you would want to discuss with your nephrologist during consultation	Observations: • Learning curve in using the dashboard observed Remark participants: • The four newly develop PRO questions (Figure 3) are chosen to discuss with their nephrologist by most patients. Thereafter kidney function was mentioned most.
Task 3: where do you think you can work on yourself after viewing the information in the dashboard?	Observations: • Participants focus mostly on the overview page and need help to find the additional information buttons in the dashboard that elaborate on how to improve certain variables. • Participants need help to find the hyperlinks transferring to an informative website (including self-management tips). Remark participants: • Many participants express that they think they have little influence on their disease trajectory, but would like to have more influence. Few participants are already active in their treatment (i.e. focusing on diet)

Interview questions	
Interview questions	**Responses patients**
How can using the dashboard be of value/ useful?	• The dashboard helps to give an overview over time, which is useful especially since CKD has a long trajectory • Useful for preparing the consultation • Useful to review discussed information during the consultation and being able to discuss it with your partner/family • Useful to see where you stand; how you are doing
Which page do you think is most useful?	• Most participants agreed on 'the overview page' as most useful, displaying the kidney function and summary of what you want to discuss during the consultation • One participant found all pages equally important and useful • One patient: 'health status in general' • One patient: 'treatment goals slowing down kidney damage'
If you can change everything, what would you change?	• Make all buttons more clear in order to quickly find all the additional information • Add breathing exercises or other modules that could enhance physical experience • Have more explanations of the visuals • Introduce the dashboard with a movie with instructions or explanation by someone with experience in using it (e.g. clinician or nurse) • Change colour scheme to something less 'intense' • Enlarge text size
Would you recommend the dashboard to a friend (who has CKD)?	• Everyone would recommend the dashboard to others. Two participants added; especially when you get used to working with the dashboard it has additional value. • One participant indicated that it helps to get more grip on your situation and see the progress you make in your treatment which can work motivating.
Scale 0-10 (10 best) how would you grade the dashboard overall?	Mean 8 (min 7- max 9)

Supplement chapter 6 Images of the dashboard.

The following section provides images of the CKD dashboard as it was used during the studies. *This section is not a published supplement of the study in chapter 6. We added this section to provide the CKD dashboard as used in the studies and to present the included data, used visualization and click-through options within the dashboard.*

The link below shows a video (in Dutch) that explains the CKD dashboard by both a nephrologist and a patient.

https://www.youtube.com/watch?v=u2sulnuJ7uQ

The following images are screenshots of the CKD dashboard (in Dutch) containing data of a non-existing patient. Normally, the dashboard is interactive revealing explanatory texts or graphs when clicking on buttons. Throughout the dashboard, per topic, hyperlinks can be found forwarding to the informative website nieren.nl. The dashboard can be directly opened by clinicians through a link in the patients' Electronic Health Record. The following images contain explanatory texts explaining how the dashboard is used (in Dutch).

U kunt de onderste balk of de **blokjes rechtsboven** gebruiken om door het dashboard te navigeren

Wanneer u op deze knop klikt krijgt u **aanvullende informatie** te zien

Wanneer u in het dashboard op de links drukt, opent er een **nieuw tabblad van nieren.nl** met aanvullende informatie. Het dashboard blijft geopend in het huidige tabblad. Om terug te gaan klik je op het tabblad waar 'Microsoft powerBi' staat (of heropen je de PDF).

U kunt de **onderste balk** of de blokjes rechtsboven gebruiken om door het dashboard te navigeren

Welkom **Testpatiënt test**

Geboortedatum: 02-02-1950

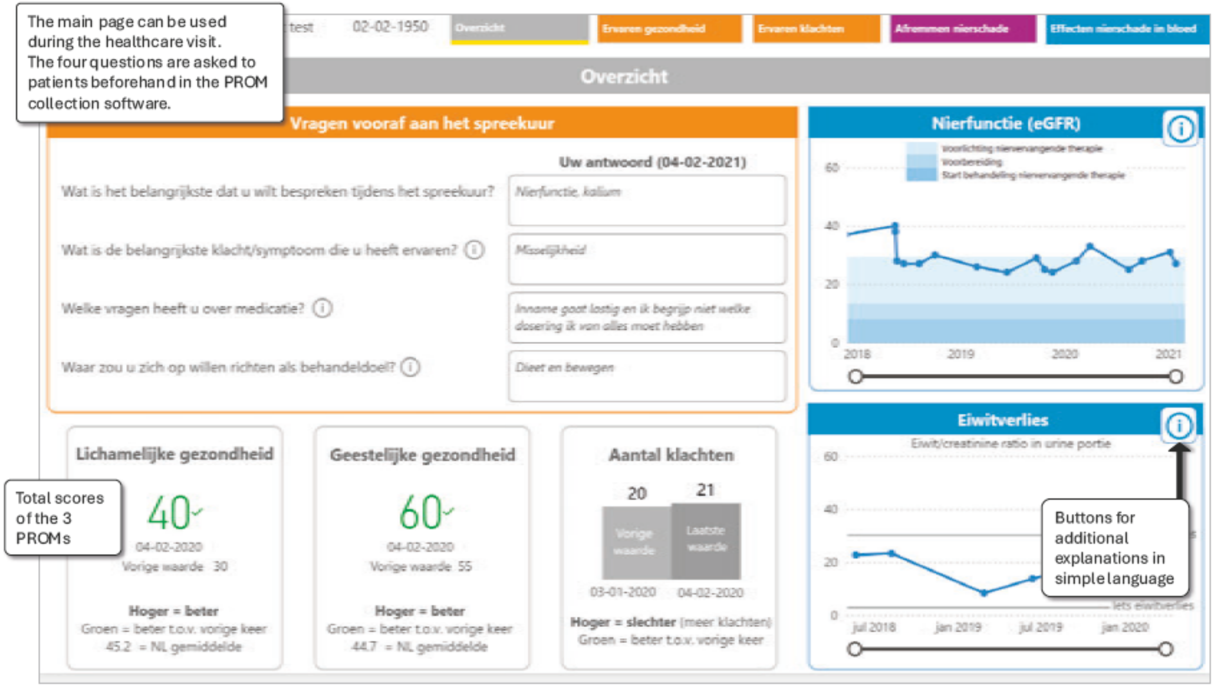
Welkom op "**Mijn nier overzicht**". Dit dashboard is bedoeld voor mensen met een matig tot ernstig afgenomen nierfunctie. Dit dashboard geeft een overzicht van hoe het met uw gezondheid en uw nieren gaat. Samen met uw zorgverleners kunt u met behulp van het dashboard bespreken hoe uw nierfunctie zo stabiel mogelijk blijft.
Dit dashboard kan worden getoond tijdens het gesprek met uw behandelaar.

Het dashboard is opgebouwd uit een voorblad dat u een overzicht geeft en 4 verdiepende bladen waar u meer gegevens kunt inzien.

Klik op de oranje pijl om naar het overzicht te gaan

1 main page and 4 subpages

The dashboard is interactive with the use of buttons.
The 'welcome page' explains usage for patients at home.



The main page can be used during the healthcare visit. The four questions are asked to patients beforehand in the PROM collection software.

Total scores of the 3 PROMs

Buttons for additional explanations in simple language

test 02-02-1950

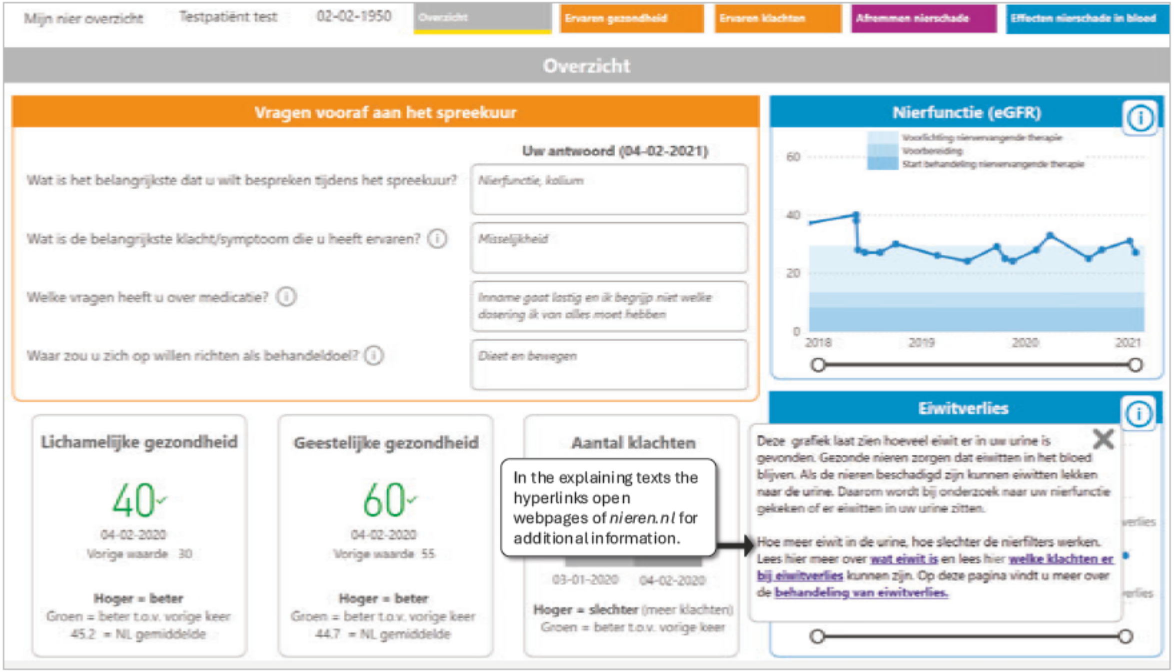
Vragen vooraf aan het spreekuur

	Uw antwoord (04-02-2021)
Wat is het belangrijkste dat u wilt bespreken tijdens het spreekuur?	*Nierfunctie, kalium*
Wat is de belangrijkste klacht/symptoom die u heeft ervaren? ⓘ	*Misselijkheid*
Welke vragen heeft u over medicatie? ⓘ	*Inname gaat lastig en ik begrijp niet welke dosering ik van alles moet hebben*
Waar zou u zich op willen richten als behandeldoel? ⓘ	*Dieet en bewegen*

Lichamelijke gezondheid
40
04-02-2020
Vorige waarde 30
Hoger = beter
Groen = beter t.o.v. vorige keer
45.2 = NL gemiddelde

Geestelijke gezondheid
60
04-02-2020
Vorige waarde 55
Hoger = beter
Groen = beter t.o.v. vorige keer
44.7 = NL gemiddelde

Aantal klachten
20 Vorige waarde 03-01-2020
21 Laatste waarde 04-02-2020
Hoger = slechter (meer klachten)
Groen = beter t.o.v. vorige keer



Vragen vooraf aan het spreekuur

	Uw antwoord (04-02-2021)
Wat is het belangrijkste dat u wilt bespreken tijdens het spreekuur?	*Nierfunctie, kalium*
Wat is de belangrijkste klacht/symptoom die u heeft ervaren? ⓘ	*Misselijkheid*
Welke vragen heeft u over medicatie? ⓘ	*Inname gaat lastig en ik begrijp niet welke dosering ik van alles moet hebben*
Waar zou u zich op willen richten als behandeldoel? ⓘ	*Dieet en bewegen*

Lichamelijke gezondheid

40✓
04-02-2020
Vorige waarde 30

Hoger = beter
Groen = beter t.o.v. vorige keer
45.2 = NL gemiddelde

Geestelijke gezondheid

60✓
04-02-2020
Vorige waarde 55

Hoger = beter
Groen = beter t.o.v. vorige keer
44.7 = NL gemiddelde

Aantal klachten

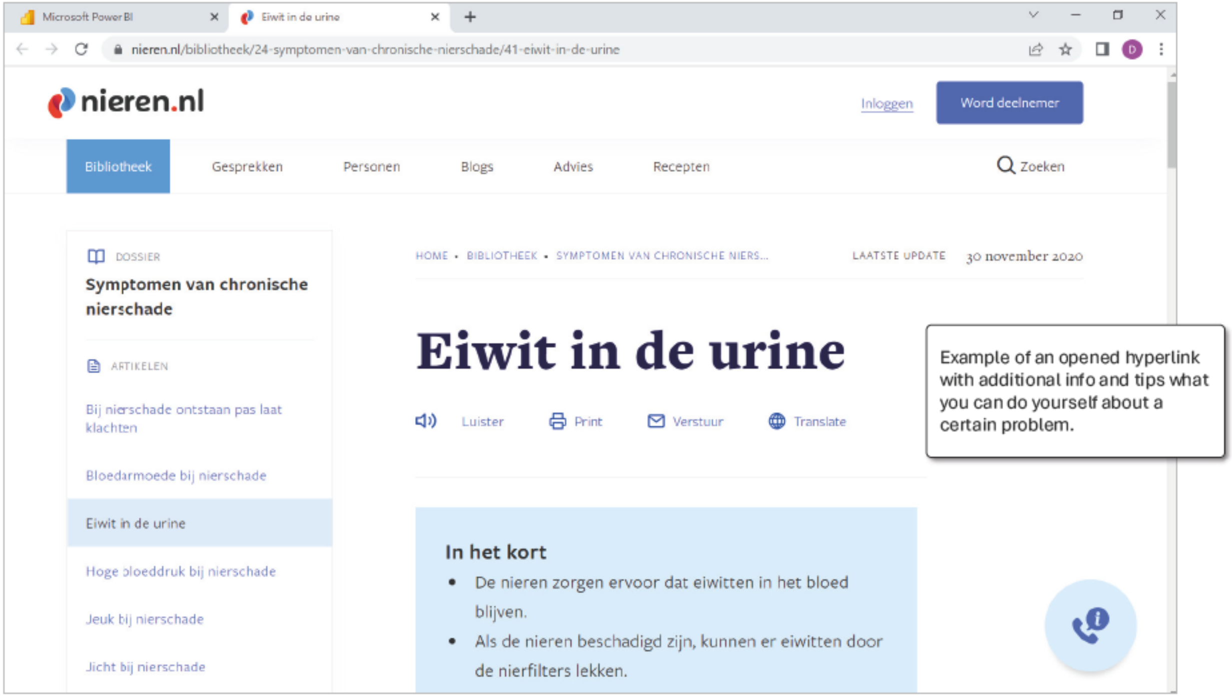
03-01-2020 04-02-2020

Hoger = slechter (meer klachten)
Groen = beter t.o.v. vorige keer

Deze grafiek laat zien hoeveel eiwit er in uw urine is gevonden. Gezonde nieren zorgen dat eiwitten in het bloed blijven. Als de nieren beschadigd zijn kunnen eiwitten lekken naar de urine. Daarom wordt bij onderzoek naar uw nierfunctie gekeken of er eiwitten in uw urine zitten.

Hoe meer eiwit in de urine, hoe slechter de nierfilters werken. Lees hier meer over wat eiwit is en lees hier welke klachten er bij eiwitverlies kunnen zijn. Op deze pagina vindt u meer over de behandeling van eiwitverlies.

In the explaining texts the hyperlinks open webpages of *nieren.nl* for additional information.



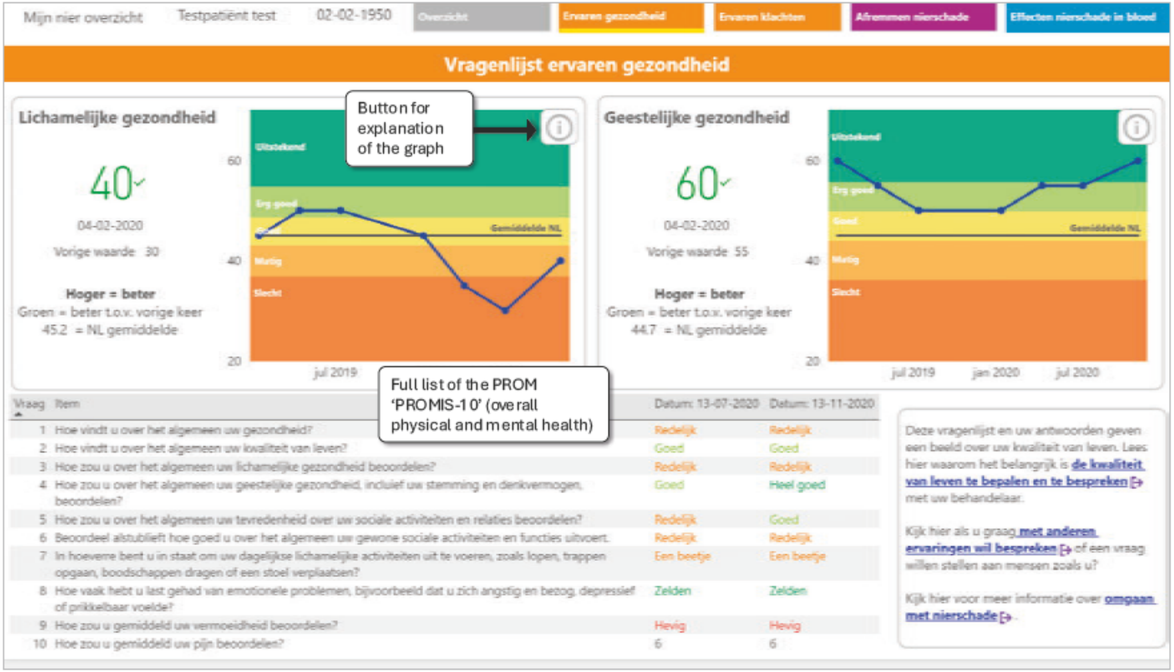
Symptomen van chronische nierschade

Eiwit in de urine

In het kort

- De nieren zorgen ervoor dat eiwitten in het bloed blijven.
- Als de nieren beschadigd zijn, kunnen er eiwitten door de nierfilters lekken.

Example of an opened hyperlink with additional info and tips what you can do yourself about a certain problem.



Button for explanation of the graph

Full list of the PROM 'PROMIS-10' (overall physical and mental health)

Vragenlijst ervaren gezondheid

Lichamelijke gezondheid

40✓

04-02-2020

Vorige waarde 30

Hoger = beter

Groen = beter t.o.v. vorige keer

45.2 = NL gemiddelde

Geestelijke gezondheid

60✓

04-02-2020

Vorige waarde 55

Hoger = beter

Groen = beter t.o.v. vorige keer

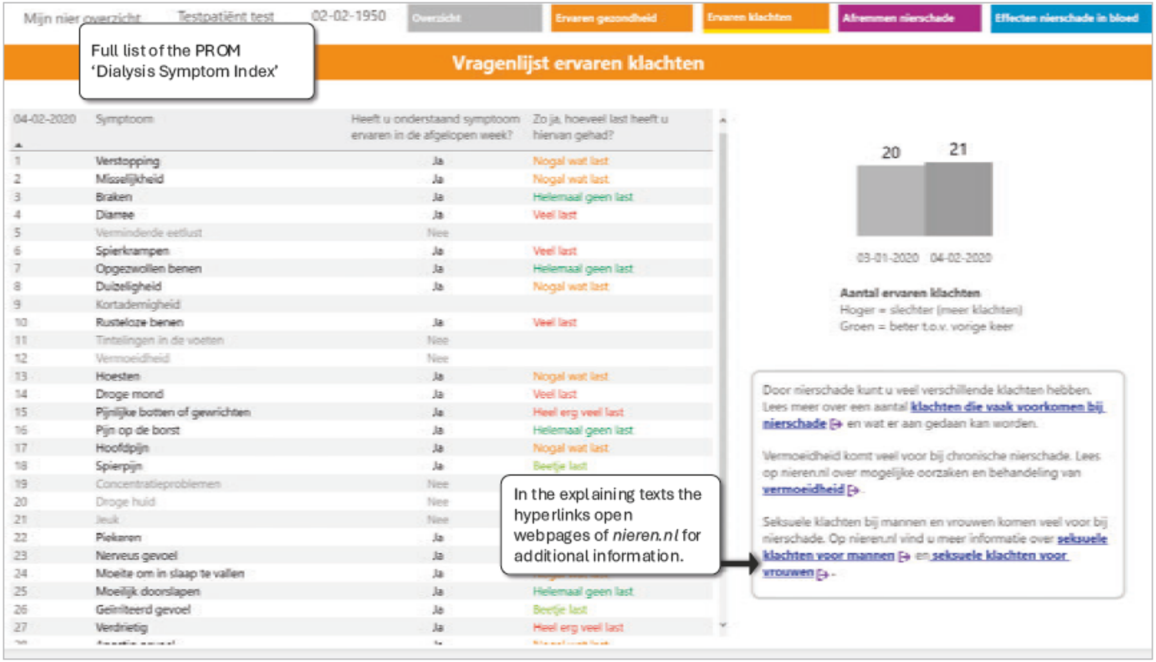
44.7 = NL gemiddelde

Vraag	Item	Datum: 13-07-2020	Datum: 13-11-2020
1	Hoe vindt u over het algemeen uw gezondheid?	Redelijk	Redelijk
2	Hoe vindt u over het algemeen uw kwaliteit van leven?	Goed	Goed
3	Hoe zou u over het algemeen uw lichamelijke gezondheid beoordelen?	Redelijk	Redelijk
4	Hoe zou u over het algemeen uw geestelijke gezondheid, inclusief uw stemming en denkvermogen, beoordelen?	Goed	Heel goed
5	Hoe zou u over het algemeen uw tevredenheid over uw sociale activiteiten en relaties beoordelen?	Redelijk	Goed
6	Beoordeel alstublieft hoe goed u over het algemeen uw gewone sociale activiteiten en functies uitvoert.	Redelijk	Redelijk
7	In hoeverre bent u in staat om uw dagelijkse lichamelijke activiteiten uit te voeren, zoals lopen, trappen opgaan, boodschappen dragen of een stoel verplaatsen?	Een beetje	Een beetje
8	Hoe vaak hebt u last gehad van emotionele problemen, bijvoorbeeld dat u zich angstig en bezorgd, depressief of prikkelbaar voelde?	Zelden	Zelden
9	Hoe zou u gemiddeld uw vermoeidheid beoordelen?	Hevig	Hevig
10	Hoe zou u gemiddeld uw pijn beoordelen?	6	6

Deze vragenlijst en uw antwoorden geven een beeld over uw kwaliteit van leven. Lees hier waarom het belangrijk is **de kwaliteit van leven te bepalen en te bespreken** met uw behandelaar.

Kijk hier als u graag **met anderen ervaringen wil bespreken** of een vraag willen stellen aan mensen zoals u?

Kijk hier voor meer informatie over **omgaan met nierschade**.



Full list of the PROM ‘Dialysis Symptom Index’

Vragenlijst ervaren klachten

04-02-2020	Symptoom	Heeft u onderstaand symptoom ervaren in de afgelopen week?	Zo ja, hoeveel last heeft u hiervan gehad?
1	Verstopping	Ja	Nogal wat last
2	Misselijkheid	Ja	Nogal wat last
3	Braken	Ja	Helemaal geen last
4	Diarree	Ja	Veel last
5	Verminderde eetlust	Nee	
6	Spierkrampen	Ja	Veel last
7	Opgezwollen benen	Ja	Helemaal geen last
8	Duizeligheid	Ja	Nogal wat last
9	Kortademigheid		
10	Rusteloze benen	Ja	Veel last
11	Tintelingen in de voeten	Nee	
12	Vermoeidheid	Nee	
13	Hoesten	Ja	Nogal wat last
14	Droge mond	Ja	Veel last
15	Pijnlijke botten of gewrichten	Ja	Heel erg veel last
16	Pijn op de borst	Ja	Helemaal geen last
17	Hoofdpijn	Ja	Nogal wat last
18	Spierpijn	Ja	Beetje last
19	Concentratieproblemen	Nee	
20	Droge huid	Nee	
21	Jeuk	Nee	
22	Piekeren	Ja	
23	Nerveus gevoel	Ja	
24	Moeite om in slaap te vallen	Ja	
25	Moeilijk doorslapen	Ja	Helemaal geen last
26	Geïrriteerd gevoel	Ja	Beetje last
27	Verdrietig	Ja	Heel erg veel last

Aantal ervaren klachten
Hoger = slechter (meer klachten)
Groen = beter t.o.v. vorige keer

Door nierschade kunt u veel verschillende klachten hebben. Lees meer over een aantal **klachten die vaak voorkomen bij nierschade** en wat er aan gedaan kan worden.

Vermoeidheid komt veel voor bij chronische nierschade. Lees op nieren.nl over mogelijke oorzaken en behandeling van **vermoeidheid**.

Seksuele klachten bij mannen en vrouwen komen veel voor bij nierschade. Op nieren.nl vind u meer informatie over **seksuele klachten voor mannen** en **seksuele klachten voor vrouwen**.

In the explaining texts the hyperlinks open webpages of *nieren.nl* for additional information.

Let op:
Het patiëntportaal/EPD blijft de plek voor de exacte laatste medische waarden

De metertjes en getallen op deze pagina zijn **behandeldoelen** die belangrijk zijn voor het **afremmen van verdere nierschade**.

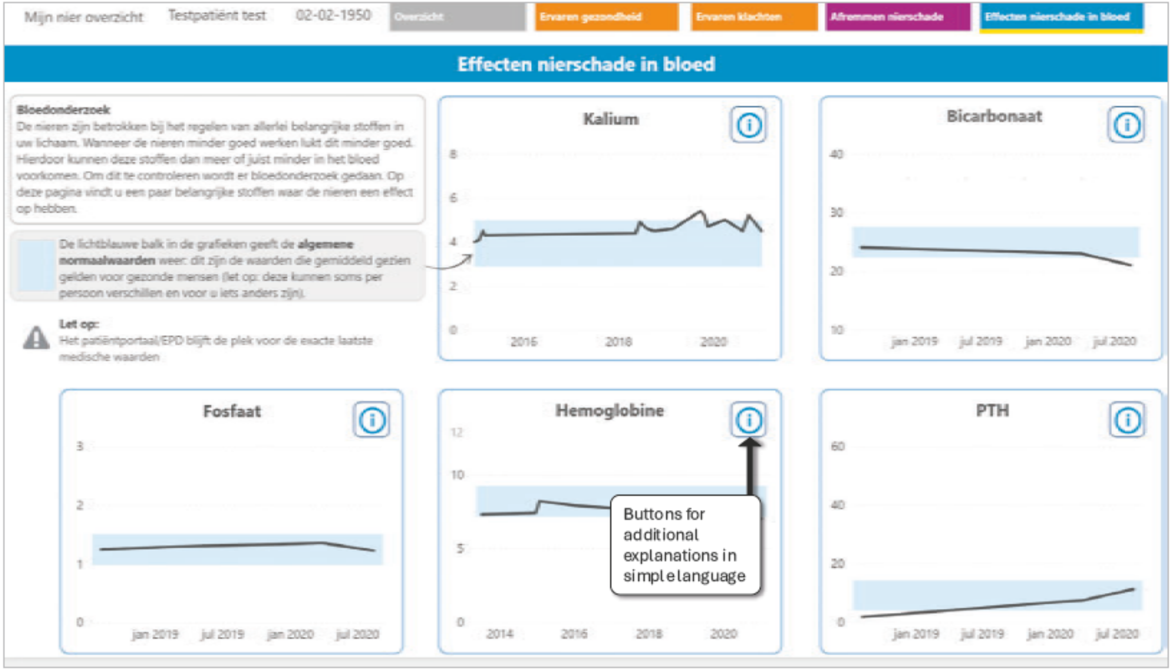
Om verdere nierschade te voorkomen schrijft uw arts soms medicijnen voor. Ook voedingsadviezen en adviezen voor een gezonde leefstijl zijn onderdelen van de behandeling.

Kijk hier voor meer informatie over het **voorkomen van verdere nierschade en de behandeling**

All treatment goals related to slowing down kidney function decline are visualized on this page.

Button to show course over time of the variable (in a graph).

Button to show additional information about the variable.



Bloedonderzoek
De nieren zijn betrokken bij het regelen van allerlei belangrijke stoffen in uw lichaam. Wanneer de nieren minder goed werken lukt dit minder goed. Hierdoor kunnen deze stoffen dan meer of juist minder in het bloed voorkomen. Om dit te controleren wordt er bloedonderzoek gedaan. Op deze pagina vindt u een paar belangrijke stoffen waar de nieren een effect op hebben.

De lichtblauwe balk in de grafieken geeft de **algemene normaalwaarden** weer: dit zijn de waarden die gemiddeld gezien gelden voor gezonde mensen (let op: deze kunnen soms per persoon verschillen en voor u iets anders zijn).

Let op:
Het patiëntportaal/EPD blijft de plek voor de exacte laatste medische waarden