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

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Summary and General Discussion

8.1 Study aims

During chronic kidney disease (CKD) health care visits, CKD patients and their nephrologist exchange information and discuss many treatment decisions. These decisions mostly relate to the overall goal of slowing down kidney function decline and thus preventing or delaying the need for kidney replacement therapy (KRT). These decisions may feel 'small', but often impact patients' daily lives substantially (e.g., lifelong anti-hypertension medication or salt-restricted diet)[1,2]. Sharing these decisions with patients may increase patient activation levels, potentially leading to more effective CKD management. Until now, research on decision processes around more common decisions has been limited compared to highly impactful preference-sensitive decisions. In Nephrology, the role of shared decision making (SDM) is primarily described concerning KRT and not regarding the many more commonly made decisions. This led to our first objective:
Determine the extent to which SDM is appropriate in routine medical decisions and assess current practice in decision making in CKD.

Various types of outcome information can be utilized in patient-clinician interactions, including clinical outcomes, patient-reported outcomes (PROMs), and model-based outcomes that use aggregated data, such as prediction models or "Patients Like Me" models, which compare individual patient outcomes to a broader population. In modern healthcare, the increasing amount of outcome information available during clinical encounters highlights the need to specify which outcomes should be prioritized for discussion and how different outcome information affects treatment decision making. However, research integrating different types of outcomes and perspectives—both from patients and clinicians—remains limited.
This gap in knowledge led to our second objective:
Explore patients' and clinicians' preferences in discussing different types of outcome information during healthcare visits.

In CKD management, effective information exchange during healthcare visits is essential for both SDM and achieving adequate levels of patient activation, both of which are critical for optimal disease management. This exchange consists of clinical outcomes as well as patient-reported information. However, current information exchange practices appear suboptimal, as patients' informational needs are often unmet[3], and activation levels among CKD patients remain low[4,5]. Additionally, data visualization is rarely utilized, despite evidence that patients struggle to retain information when conveyed verbally alone[6–8].

To enhance information exchange and the use of outcome data during healthcare visits we developed and tested a CKD dashboard. This led to our third objective:
Develop and evaluate a CKD dashboard, a novel way to visualize outcome information during healthcare visits, and assess its impact on SDM and patient activation.

8.2 Summary of main results

Below a brief summary is provided of the results of the six studies included in this thesis.

Part one: Shared Decision Making in Chronic Kidney Disease – broadening the scope.

In **chapter 2** we performed an extensive literature review to identify decision characteristics for which Shared Decision Making (SDM) is deemed appropriate and for which it is not. From the 92 included papers, we identified 18 different decision characteristics that make SDM appropriate for decisions according to the authors. Most frequently mentioned decision characteristics included 'preference-sensitive', 'multiple options', 'equipoise', 'high impact of the decision', and 'patient commitment is needed to carry out the decision'. Four decision characteristics identified held ambiguity; 'one best option', 'weight of the decision is light', 'trade-off between individual impact and public benefit', and 'short time frame to make the decision'. Some authors argued that SDM was appropriate for decision with those characteristics, while other authors disagreed. Lastly, authors described decision characteristics where SDM was not deemed appropriate, including: 'no equipoise', 'patient request for therapy in conflict with clinician's judgment', 'immediate life-saving measures needed', and 'potential threat for public safety'.

In **Chapter 3** we studied how SDM is practiced during healthcare visits between patients with CKD and their clinician. This study incorporated multiple perspectives, including the patient perspective and observations of actual healthcare visits. From the patient surveys (N=122) we identified commonly-made CKD decisions. Patients reported a total of 357 decisions. Patients most frequently reported decisions regarding: planning (e.g. of the next visit); medication changes; lifestyle adjustments; treatment goals; and diagnostic tests. Patients' preferred role in making these decisions varied. For many decisions, patients preferred to share the decision (116/357, 32%) or leave the decision mostly (125/357, 35%) or fully (101/357, 28%) up to the clinician. For 151 of 357 decisions, the patients' preferences did not match their experiences. These decisions were either experienced as too much or too little 'shared/patient-directed' in similar quantities. The level of SDM we observed in the 118 decisions coded was low (median score, 4; range, 0 – 22). When comparing observations with patients’ experiences of decision-making, discrepancies emerged. Some decisions rated as “high SDM” based on observation were perceived by patients as being made entirely by the clinician, while in other cases, patients felt involved despite lower observer SDM scores.

Part two: Discussing outcome information in healthcare visits - current practice and preferences

The results from dyadic interviews (total N=22) with both CKD (n=11) and breast cancer (BC) (n=11) patients and their treating clinicians were reported in **chapter 4**. In these interviews, various types of outcomes, including examples specific to either CKD or BC, were discussed: clinical outcomes, patient-reported outcomes (PROs), calculated predictions, and comparisons of individual patient data with aggregated data. The interviews revealed that all types of outcomes were perceived as having both potential benefits and drawbacks when discussed during healthcare visits. Clinicians and patients consistently regarded clinical outcomes as important. However, the emphasis placed on clinical versus patient-reported outcomes varied between individuals. In some cases, the priorities of patients and clinicians did not align, with one placing more importance on clinical outcomes while the other prioritized patient-reported outcomes. These mismatches occurred in both directions. Misconceptions between patients and clinicians also emerged during the interviews. Patients were not always aware that their non-clinical information was valuable to share and did not fully recognize the potential benefits of using PROMs, such as helping them prepare for healthcare visits and facilitating discussion of important topics. Clinicians, on the other hand, did not always accurately anticipate the type of information patients wanted to receive, particularly regarding predictive outcomes.

In **chapter 5** we presented the results of a national survey among CKD patients and nephrologists regarding the use of, and preferences regarding, predictive outcomes based on calculations (clinical prediction models, CPMs) in CKD outpatient care. A total of 126 patients and 50 nephrologists responded to the surveys. Most patients (89%) reported to discuss predictions with their nephrologists, in particular how fast their kidney function would decline and when they were expected to need kidney replacement therapy (KRT). Although almost all nephrologists (98%) reported to indeed discuss this with patients, only half of them reported to use a CPM for this end. Even though well-validated CPMs are freely available, these are underused due to lack of knowledge where to find them and how to use them effectively. Many nephrologists agreed that caution should be taken with CPMs, since it can give patients false expectations or a false sense of security. CPMs do not always correspond to the course of disease of individual patients, and they may be too-time consuming. A small portion of patients (10–15%) indicated they did not want to be informed on predictions regarding CKD progression at all. Patients reported that the results from CPMs regarding CKD progression can be confronting or that they do not trust that the calculation applies to them. The findings of this study underline the importance of exploring individual patient needs regarding predictive outcomes. Furthermore, it shows a need for improving the accessibility of CPMs regarding CKD progression and guidance on how to communicate their results during healthcare visits effectively.

Part three: A novel way to discuss outcomes during care visits - the CKD dashboard

Chapter 6 describes the process of co-developing the CKD dashboard and testing its usability. First, we presented our conceptual model, which theorizes that effectively reporting individual patient outcomes, including both clinical outcomes and PROs, through data visualization (dashboarding) can facilitate SDM and patient activation. Ultimately, this process is expected to enhance self-management behaviors and improve clinical outcomes. We then described the findings from working groups and focus groups with healthcare professionals and patients. In these groups, content and design requirements for effectively transferring information during CKD healthcare visits were identified. Based on these insights, a prototype of the dashboard was developed, followed by usability testing with patients. The findings from these usability tests informed refinements to the final design. A final focus group with healthcare professionals was conducted to inform the implementation and training process. A key finding from this group was the importance of aligning patient and clinician perspectives on which dashboard information should be discussed. Additionally, participants emphasized that the dashboard should support, rather than overshadow the conversational process, ensuring that the patient-clinician dialogue remains central.

Chapter 7 evaluates the implementation of the CKD dashboard in a clinical setting. The evaluation was conducted in two hospitals: one intervention hospital (Hospital A), where the dashboard was implemented, and one control hospital (Hospital B), where the dashboard was not introduced during the study period. Pre- and post-implementation assessments were conducted, including patient surveys and audio recordings of the healthcare visits. The primary outcome, patient activation, was measured using patient surveys, along with secondary outcomes, including patient-centeredness, experienced decisional role, medication adherence, and perceived efficacy during clinical encounters. At both assessment time points (the first visit post-implementation and one year later) no significant changes were observed in patient activation levels or secondary outcomes.

Patient activation levels (range 0-100) were moderately low with levels between 56.6-58.8 at all timepoints. From the audio-recordings of 193 CKD healthcare visits, 247 decisions were coded, with median SDM scores of 4.5 and 6.0 pre- and post-implementation (range 0-24). Thus, overall SDM scores were low. Behavioral change discussions occurred infrequently with low scores on motivational interview components (partnership, empathy, cultivating change talk, and softening change talk). Based on the audio recordings, we observed that the use of the dashboard facilitated discussions on a wider range of topics, including sensitive issues such as mental health concerns and sexual dysfunction. These discussions proved valuable for individual patients, as addressing these topics led to adjustments in treatment plans to better align with their needs.

8.3 General discussion of the main objectives

Objective 1: Determine the extent to which SDM is appropriate in routine medical decisions and assess current practice in decision making in CKD.

Broadening the scope of SDM

Our systematic review fills a research gap regarding SDM and the types of decisions for which SDM is considered appropriate. In accordance with common beliefs regarding SDM, SDM was reported by authors of the included studies to be appropriate in preference-sensitive decisions, decisions with multiple options, decisions with equipoise and decisions with 'high impact'. However, SDM authors also deemed SDM appropriate in other (more commonly occurring) decisions, including decisions for which patients are needed to carry out the decision, decisions with one best option, and decisions with minor impact. The most important exception as to when SDM is not considered appropriate are urgent medical decisions involving life-saving treatments. However, even in such cases SDM may be appropriate, particularly when proposed treatment options might conflict with a patient's goals or values.

Keij et al. identified several characteristics of decisions that may hinder patient involvement in SDM, including: decisions in a life-threatening situation; decisions regarding severe or progressive illnesses; decisions regarding mental illness; decisions with many or complex options and treatment uncertainty[9]. It is important to note that Keij et al. did not specify whether SDM should or should not be pursued in these circumstances, only that these factors can make SDM more challenging for patients. Our review, however, identified examples where SDM was successfully applied even in complex situations, including cases where clinician and patient perspectives on the best course of action conflicted. In such cases, SDM can serve as a valuable strategy to structure discussions, manage conflicts, and ensure that patients are well-informed about their options so that they can participate as best as possible in the decisional process. Hargraves et al. propose an adapted approach to SDM in these challenging situations by shifting the focus from 'exploring preferences' into 'clarifying positions' and from 'deliberation regarding options' to 'negotiating conflict'[10]. This perspective acknowledges that SDM can remain a useful framework even when full deliberation is difficult.

Based on our findings and the broad range of decision characteristics for which SDM is considered appropriate, an attempt to involve patients in decisions through SDM should always be made, except in urgent, life-threatening situations where immediate action is required and aligns with patients goals. Importantly, SDM does not mean that the patient must always make the final decision; the clinician and the patient may conclude that it is preferable for the clinician to take the lead in decision-making. Even in such cases, SDM remains valuable as it involves ensuring that the options are clearly communicated and patient preferences are explored[11]. The view that SDM can still occur when the clinician ultimately decides, prevents decision-making responsibility from being shifted entirely onto the patient, which can be burdensome. Furthermore, contrary to common concerns, studies have shown that SDM does not significantly extend consultation times[12].

Clinical recommendations:

- In addition to following the four established steps of SDM, we argue that common awareness is needed as to when to apply those steps. We argue that SDM is appropriate in every decision apart from the exceptions mentioned (most importantly, a life-threatening medical emergency).
- Every decision should be approached with an effort to apply SDM and begin with step 1 'the clinician makes explicit that there is a choice is to be made and that this choice will depend on what is important to the patient'.

SDM in common CKD decisions

During routine CKD visits, clinicians and patients discuss a wide range of decisions that align with the decision characteristics identified in our review as appropriate for SDM. In our study in **chapter 3** we uniquely combined multiple perspectives regarding SDM in these common CKD decisions: patient preferences regarding their decisional role, patient experiences in their decisional role, and researcher observations of how decisions were made based on audio-recordings of healthcare visits. Our findings indicate that patients' experiences of how shared a decision was, did not always align with their preferred level of involvement. This is similar to findings in other fields, such as oncology. In a large multicenter cross-sectional study in Germany in which 4020 patients were surveyed, both their preferred decisional role (CPS) and experienced level of SDM (using the SDMQ-9 measure) were assessed [13]. Similar to our findings, preferred decisional roles were about equally divided over patient-led, shared, and clinician-led. The researchers also found a discordance between preferred level of involvement and experienced SDM: only 50% of patients who preferred active involvement perceived high levels of SDM in their healthcare visits[13].

In our study, we found that observed level of decision making did not always match patients' experiences. Some decisions that observers coded as high SDM were perceived by patients as clinician-directed, while some decisions coded as low SDM were perceived as shared. This mismatch between patients' preferences, patients' perceived decisional role, and SDM levels as perceived by independent observers can partly be explained by the use of the CPS. The CPS captures who ultimately made the decision (patient, clinician or together) and not on the SDM process as a whole that led to that ultimate decision. For instance, according to the CPS a decision is 'made by the clinician'. This does not say anything regarding which steps of the SDM process actually took place. This decision may still involve key SDM steps, such as eliciting patient preferences and discussing options, yet the CPS does not capture this. Patients may also not perceive these process steps as SDM. This highlights a fundamental gap on understanding of what SDM constitutes: many still believe SDM only occurs when the final decision is made jointly, rather than recognizing it as a structured process of shared deliberation.

We identified low levels of SDM in common CKD decisions. The overall low levels of SDM are similar to findings of Driever et al, who coded 727 healthcare visits of various medical specialties in a Dutch hospital [14]. Notably, Step 1 of SDM 'informing the patient that a decision needs to be made and that their involvement is important' was frequently omitted. This step is particularly crucial, as many patients are not yet accustomed to actively participating in decision-making. In Damman et al., their observations (N=23) of clinical encounters between patients with multiple sclerosis (MS) and their clinicians yielded similar results. Like we did in our study in CKD, they focused on 'smaller' decisions in routine care management of a chronic disease, instead of a major decision (in the case of MS: starting disease-modifying treatment). These 'smaller' decisions in MS often related to symptoms and treatment side effects (e.g. decisions regarding pain medication), referral decisions (e.g. whether or not to refer to a physiotherapist) or frequency of MRI scans to evaluate MS progression. Similar to our findings on common CKD decisions, these decisions were often not mentioned explicitly as a decision to be made during the clinical encounters. Although patients' experiences and priorities were discussed, SDM was also not fully enacted in the MS encounters [15].

It is important to consider certain limitations in how SDM was assessed in our studies. First, we made use of the 4SDM coding tool, which is developed to be used in preference-sensitive decisions. As we argue in our review in chapter 2, SDM is not necessarily limited to these kinds of decisions. However, the coding tool has not been developed to also be used for other, more minor decisions such as logistical decisions (scheduling the next appointment or whether an appointment is in person or by telephone) or dosage adjustments of medications. The way the 4SDM was used in our studies, is that the same criteria applied to all types of decisions even though they ranged in 'how major or minor' the decision was. Therefore, these type of decisions may have been rated quite strict. The perceived importance of the decision may imply what steps of SDM are minimally required and which may be less important. This nuance is not translated in the coding model. However, caution should be taken in trying to estimate which decisions are 'minor' and assuming that fewer steps of SDM are required. Lupu et al. discuss our findings of **chapter 3** in their editorial and underscore the need to avoid clinician-driven assumptions about the perceived weight of a decision[16]. This is in line with the results of our dyadic interview study (**chapter 4**), in which we found that clinicians may hold inaccurate assumptions regarding how a decision weighs for a patient. Therefore, we recommend that exploring patients preferences in decision making and navigating towards a fitting conversational strategy together with the patient is an integrated part of the SDM process.

Second, the 4SDM coding model does not capture SDM-supporting behaviors such as using a moment of silence to leave room for patients to chime in. We noticed these communicative strategies had a major impact on what patients shared during the conversations. Pieterse and colleagues described the following underlying clinician qualities required for successful SDM in clinical practice: humility, flexibility, honesty, fairness, self-regulation, curiosity, compassion, judgment, creativity, and courage (to step away from usual treatment plans) [17]. Such qualities or humanistic aspects of patient-clinician communication are rarely assessed by SDM evaluation tools, including the 4SDM [18]. We argue that SDM involves more than merely implementing the behavioral skills to implement the four SDM steps, highlighting the need for *flexibility* towards patients regarding their information needs as well as exploring preferences from a point of *curiosity*. A focus on these qualities requires a culture-change with the end result of clinicians fostering more meaningful patient engagement and ensuring that treatment decisions align more closely with individual values and priorities.

Clinical recommendations:

- Clinicians should be aware of their role of encouraging patient involvement as patients may not (yet) be used to active involvement in decision making.
- An SDM process does not require the patient to make the final decision, it can result in the clinician doing so. Thus, patient preferences regarding the decision options can (and should) be explored also with patients who want the clinician to decide.
- SDM should be initiated, even in common 'minor' CKD decisions. Assumptions about patients' preferences in decision making or the perceived weight of the decision should be checked.
- SDM-supporting behaviors are essential alongside the theoretical steps of SDM, particularly in terms of creating space for patients to express themselves, such as the strategic use of silence, as well as curiosity in exploring patients' preferences and flexibility to adapt to patients' information needs.

Objective 2: Explore patients' and clinicians' preferences in discussing different types of outcome information during healthcare visits.

Chapter 4 and 5 both demonstrate the individual variation of both patients and clinicians in preferences regarding if and which outcome information should be discussed during healthcare visits. In **chapter 4** we did not observe variation between patients and clinicians, but rather individual variation. For example, the preference for using patient reported outcomes (PROs) in addition to medical information varied per person regardless of being a clinician or a patient. This finding resonates with the results of the interview study by Westerink et al. on preferences regarding discussing outcomes [19]. Additionally, both studies in **chapter 4 and 5** indicate that simply because outcome information is available does not mean all patients wish to receive it, as such information can have unforeseen negative effects. Moreover, these information preferences may change over time. This aligns with previous research which suggests that patients' information needs vary depending on disease stage and physical or mental wellbeing at a given time[20].

In **chapter 5,** we contribute to existing literature by specifying how predictive outcome information on CKD progression can be used during healthcare visits. In addition to the Kidney Failure Risk Equation (KFRE), which provides percentages of the probability of needing kidney replacement therapy (KRT) in 2 or 5 years, calculating the estimated time to KRT is also possible[21]. Our study confirms that both patients and clinicians prefer discussing the latter. However, regardless of the format, not all patients want to receive predictive information about possible disease progression. This finding is in line with results from Engels et al., who developed a decision aid for the decision regarding kidney failure treatment and also noticed differences between patients' and clinicians' preferences regarding predictive outcome information [22]. In another study, a similar discrepancy between clinicians' and patients' preferences regarding predictive outcomes was identified: only half of the patients reported to want to hear their personalized risk on the recurrence of breast cancer, as opposed to clinicians who considered it a useful outcome to discuss [23]. **Chapter 4**'s dyadic interviews provided deeper insights into why some patients preferred not to receive predictive information. Patients who were reluctant to receive predictive information often did so from an individualistic and present-oriented perspective. They argued that individual disease course may differ from statistical predictions. Moreover, patients mentioned to be focused on the present and felt that (negative) forecasts may impact their daily lives too much. The dyadic interviews offered a richer understanding complementing the findings of the surveys in **chapter 5**, as they allowed for a deeper exploration of why patients and clinicians held certain preferences. Both the studies emphasize that patient preferences for outcome information vary, making tailored communication essential. Again, a clinician's genuine curiosity about the patient in front of them remains key, regardless of which types of outcome information are available.

Both **chapter 4 and 5** highlight a preference for visual representation of predictive outcome information, underscoring the potential role of prognostic models in patient dashboards. However, the optimal visual format may vary depending on the particular outcomes and patients' graph literacy and numeracy[24,25]. Incorporating multiple visualization options and allowing patients to hide certain predictions may enhance usability and alignment with individual preferences. The latter was also mentioned as a favorable option of presenting sensitive outcomes by patients in the study by Engels et al [22].

Our findings regarding discussing PROs in **chapter 5** mirror previous studies in identifying both benefits –such as initiating discussion on sensitive topics, facilitating healthcare visit preparation, and enhancing understanding of symptoms– and downsides, such as potential information overload and time constraints [19,26,27]. In the dyadic interviews the importance of a trusting patient-clinician relationship was emphasized, consistent with findings by Willik et al. in their interview study regarding the use of PROs in routine dialysis care [28]. As mentioned in both studies by Damman et al. and Westerink et al., clinicians are not inherently opposed to using PROs; however, they often refrain from incorporating them due to factors such as inattentiveness, the perception that PROs offer little added value beyond routine patient conversations, and IT-related barriers.

These clinician views on PROs resonate with our findings in the dyadic interviews. Additionally, the study by Westerink et al. describe that clinicians find it challenging to translate PROs into (treatment) decisions [19]. Interestingly, the dyadic interviews in our study revealed that patients rejected the assumption that they expect immediate solutions to the concerns they report in PROs questionnaires.

It should be noted that in both **chapter 4 and 5**, patients participating in the studies had relatively high education levels and high health literacy. This may have affected our findings, because patients with lower health literacy may respond differently to discussing outcomes. Damman et al. found that patients with lower health literacy were often more 'shocked' when receiving clinical outcomes. This led clinicians to provide reassurance and positive interpretations of the presented outcomes. Patients with lower health literacy levels were also less likely to receive detailed explanations regarding clinical outcomes from clinicians, possibly because these patients expressed fewer concerns and less uncertainty regarding the presented outcomes compared to patients with higher health literacy [15]. Additionally, other studies have shown that patients with lower health literacy ask fewer clarifying questions during healthcare visits [29,30]. When discussing outcomes, it is important to acknowledge these differences in coping and in processing outcomes, depending on health literacy levels. Regardless of the type of outcome information, outcomes should be discussed in plain non-medical language, using short sentences as much as possible, applying teach-back techniques, and ideally supported by simple visuals [31].

Clinical recommendations

- Clinicians should recognize that discussing certain types of outcomes, particularly predictive information, may have unintended negative effects.
- A conversation driven by curiosity of the clinician in this patient is key. Assumptions should be checked as they may be incorrect.
- Clinicians should realize that information needs of patients may change over time; their re-assessment is therefore necessary.
- When incorporating prediction models or patients-like-me models into decision aids, dashboards, or educational tools, we recommend to include options for patients to hide certain predictions and to ensure information is presented in adaptable visual formats.
- In particular with patients with low health literacy, outcomes should be discussed in easy-to-understand language, and teach-back techniques should be regularly applied.

Objective 3: Develop and evaluate a CKD dashboard, a novel way to visualize outcome information during healthcare visits, and assess its impact on SDM and patient activation.

Development

We developed a dashboard that visualizes patient outcomes, designed specifically for CKD care. The idea of visualizing outcomes by using a dashboard including its underlying data structure originated from a dashboard developed in rheumatology at Maasstad Hospital [32]. The CKD dashboard was developed in co-creation with patients, clinicians, (specialized) nurses, dieticians and IT-developers. Including patients from the start of the development proved to be very valuable, as their input helped to define the main structure of the dashboard. At first, we aimed to develop a dashboard only to be used in the consultation room, but patients made clear that it would helpful to allow reviewing the information at home. Additionally, patients opted for including four prompt questions to be asked to patients before the healthcare visit **(box 1)** which were later considered a highly valuable tool according to both nephrologists and patients: patients felt better prepared for the healthcare visits and clinicians were able to better prepare their answers to patients' questions and concerns.

Box 1. The four prompt questions asked before the healthcare visit

- What is the most important issue you want to discuss during the health visit?
- What is the most important symptom you have experienced?
- Which questions do you have regarding your medication?
- On what treatment goal do you want to focus on? (Examples include 'a healthier weight' or remaining able to undertake certain activities, such as walking one's dog)

A key challenge was determining which outcome information to include in the dashboard, as excessive data could lead to information overload. The primary objectives 'clarifying information exchange and supporting SDM' guided the selection of content for the main pages. Initially, only clinical outcomes from the electronic patient record (EHR) and patient-reported outcomes (PROMs) were included, while prediction models, at-home measurements, and patients-like-me models (which compare individual PRO data to aggregated data) were deferred for potential future development based on user needs. During the development and usability testing phases, we observed that even relatively straightforward data, such as clinical outcomes and PROMs, posed challenges in terms of clear visualization and information overload.

Another challenge in developing the dashboard was ensuring it worked in two different contexts of use: during healthcare visits (presenting information to support conversations) and at patients' home (access by patients to re-read information or find additional information). These different contexts required different data visualization strategies. Through iterative testing in working groups and refinement following usability tests, we developed a dashboard that suits both contexts. Layering the information proved to be a successful strategy. For example, supplementary content from the Dutch Kidney Foundation's website (nieren.nl) was embedded behind buttons and hyperlinks. This prevented information overload on the main interface while still allowing patients to access more detailed information from home when needed.

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

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

Implementation and evaluation of the dashboard

The dashboard was implemented in one Dutch hospital during the study period, with a nephrologist serving as a clinical ambassador to lead the implementation process. This role was crucial in securing support from other healthcare professionals. This finding is in agreement with previous observations that the most important factor for successful adoption of a new innovation in healthcare is having a supporting clinical ambassador [33,34]. Implementation further required meeting technical requirements, such as effortlessly making the dashboard available on screen during healthcare visits and collecting PROMs, and a structured training program.

Our evaluation study (**chapter 7**) did not demonstrate significant effects of the CKD dashboard on SDM levels or patient activation levels. Several factors may explain these findings. First, measurements were conducted relatively soon after implementation of the dashboard, meaning clinicians had not yet fully adapted to using it. In the audio recordings, we observed that the dashboard was used differently depending on the clinician; some clinicians might adopt the innovation quicker than others. These differences will be most noticeable shortly after implementation. Furthermore the impact on patient activation may require a longer timeframe to manifest. Given that CKD patients typically have only 2–3 healthcare visits per year, the final measurement at one year post-implementation may have been too early to detect meaningful changes. Another important limiting factor in reaching measurable effects of the dashboard using our primary and secondary outcomes was that the interactive version of the dashboard was not yet accessible to patients at home. Due to data privacy restrictions, patients were unable to access the dashboard at home, limiting their ability to review information after visits or explore additional explanations via embedded links in a PDF format of the dashboard.

Short-cyclic evaluation of the dashboard

In addition to the formal evaluation presented in **chapter 7**, we also conducted a short cyclic evaluation. This non-systematic evaluation focused on gathering feedback from clinicians on their experiences with the dashboard, in order to identify usability issues and gain insights to iteratively refine the dashboard. This evaluation included online questionnaires sent to clinicians (N=20) and interviews with clinicians (N=6) from three hospitals where the dashboard had been implemented. The evaluation was held after completing the study's measurements (chapter 7). The questionnaire and interview topic list were constructed based on preliminary findings of the evaluation study described in **chapter 7**. The interviews were conducted by the project manager involved in implementing the dashboard. Subsequently, a plenary feedback session was held with clinicians to discuss the findings of the questionnaires and interviews and to further explore different thoughts and possibilities to improve (the use of) the dashboard during healthcare visits. This session was led by the main researcher. In **Box 2** we summarize the main findings of this evaluation.

Box 2. Main findings of the short-cyclic evaluation based on clinicians' experiences with the CKD dashboard – questionnaire (N=20) and interviews (N=6).

Strengths of the CKD dashboard:

- The kidney function graph provides a clear and useful overview.
- The four prompt questions to be asked to patients before the visit help clinicians (and patients) to prepare for consultations.
- The dashboard facilitates discussions on topics often overlooked such as sexual dysfunction, which clinicians realized was rarely addressed, despite being a common issue.
- The information presented in the dashboard is comprehensive, offering a clear overview of disease progression and treatment goals. Most clinicians also agreed that it can help patients to see what they can do themselves.

Limitations of the CKD dashboard:

- Consultations tend to take longer when the dashboard is used. Some clinicians suggested limiting its use to once per year.
- Logistical barriers in PROM collection occurred. PROM collection is not automatically linked to the date of the healthcare visit. Consequently, sometimes no PROMS are filled out before a visit or patients struggled to recall their responses when the timing of completing the PROMs did not align closely with their healthcare visit.
- IT limitations, including slow performance and lack of real-time data updates (e.g., not being able to display the blood pressure measurements done directly before the healthcare visit, because of an hour delay in updating the data).

Opportunities to increase effectiveness of the dashboard:

- Access for patients at home.
- Include at-home measurements, in particular blood pressure measurements.

An important finding in the short cyclic evaluation was the perceived benefits of the prompt questions in the dashboard (**Box 1**). Clinicians reported that these helped them to prepare for the healthcare visit. It allowed them to review the concerns that patients had mentioned beforehand and to coordinate timely with clinicians from other specialties or other healthcare professionals if needed (e.g. physiotherapist, social worker or psychologist). Additionally, clinicians felt patients were better prepared for the healthcare visits. A review on information provision to patients with limited health literacy supports this claim[31]. Clinicians also mentioned that the visual of kidney function over time presented in the dashboard is useful.

Clinicians varied in their preferences regarding the amount of information displayed in the dashboard. Several clinicians opted for including more information. In particular at-home blood pressure measurements were frequently mentioned as a valuable addition. Others wanted less information displayed in the dashboard, making it more comprehensible and preferably fitting on one page.

Important limitations of the dashboard that clinicians mentioned regarded IT challenges. Data were not always included in the dashboard ‘real-time’. Also, due to the lack of an automated system to send PROMs to patients based on specific healthcare visit dates, PROMs were not always successfully collected and presented in the dashboard. Furthermore, many clinicians remarked that it was a missed opportunity that patients did not yet have access to the dashboard at home. They argued that at-home access for patients, allowing them to review the dashboard in advance, would greatly enhance the dashboard’s effectiveness.

Questions regarding patients’ experiences with the dashboard were included in the last survey to patient participants in the intervention group, who had discussed the dashboard during healthcare visits in our study in **chapter 7**. Responding to these open-ended questions was optional. The questions related to their experiences and opinions on the dashboard and their suggestions on how to improve it. Although some patients mentioned the importance of being able to have access to the dashboard at home, they also stressed the importance to discuss it *with* the clinician. They expressed the need to discuss the dashboard with a clinician to better understand the information presented and to discuss topics that they deemed important jointly. One patient remarked: ‘the conversation *about* the dashboard is what stays most important!’ Patients also mentioned, similarly to the clinicians, that they found the kidney function over time visual very insightful. Patients reported they appreciated to see a complete overview of their condition. Points of improvement included a more simplified visual design, access to the dashboard at home, and a more thorough discussion about the dashboard with the clinician.

Clinicians in the feedback session reported that the nature of conversations changed when the dashboard was discussed. This observation was confirmed by the analysis of the recorded CKD healthcare visits. The use of the dashboard led to discussions on a broader range of topics without reducing attention to key clinical outcomes. In particular, thanks to the PROs in the dashboard, mental health and sexual dysfunction were addressed more frequently. Importantly, when these topics were discussed, treatment plans were often adjusted accordingly. For instance, a patient experiencing sexual dysfunction had blood pressure medication modified to avoid exacerbating the issue. In this way, we observed that discussing PROs can positively influence the decisional process in initiating a decision to be made and thereby supporting SDM.

Clinical recommendations

- For effective implementation and use of the CKD dashboard over a longer period of time, the following requirements need to be met:
    - Adoption of a new way of working by clinicians, requiring: sufficient training, short cyclic evaluations, and sufficient time to gain exposure to the dashboard.
    - Adequate IT-support, such as easy access to the dashboard in the consultation room *and* at home for patients.
    - An efficient PROM system to gather PROM data from patients.
- The following steps are important for clinicians in order to meaningfully use the CKD dashboard:
    - View the dashboard before the healthcare visits, i.e. the patient's answers to the four questions asked before the healthcare visit (**Box 1**) and the PROs, contributing to an effective preparation of the healthcare visit.
    - Before discussing the dashboard, clinicians should set an agenda with the patient to determine which elements to address. This approach ensures that important topics from both the clinician's and patient's perspective are discussed. It also allows to prioritize in what to discuss of all the information presented in the dashboard (instead of having to discuss all of it).
    - Clinicians should realize that it is not just a learning process for them, but also for patients to fill out and discuss PROMs and to see a dashboard. It may take time before both parties are used to it. Additionally, it may be useful to point patients to upcoming PROMs, so as to stimulate them to complete the PROMs.
    - The conversation *about* the dashboard during healthcare visits remains key, merely showing the information visualized in the dashboard is insufficient to use it meaningfully and engage in conversations and decision making processes regarding the outcomes presented.

8.4 Strengths and limitations

This thesis has multiple strengths. We provided new insights on when SDM is considered appropriate to apply. We revealed the value of outcome information to support information exchange and treatment decision making from patients' and clinicians' perspectives. Additionally, we pioneered by implementing an innovative tool to visualize outcome information during healthcare visits.

A key strength of our research is the use of multiple methods, including both qualitative and quantitative approaches, as well as the inclusion of multiple perspectives from both patients and clinicians. This comprehensive approach was essential for evaluating the current use, preferences, and effectiveness of outcome information and the CKD dashboard specifically. It allowed for both an in-depth exploration of relevant topics, a user-centered design of the CKD dashboard, and a systematic assessment of the dashboard's impact.

Moreover, this research was directly linked to clinical practice. Findings were implemented in CKD outpatient care to improve patient-clinician communication. Beyond the hospitals included in our study, we facilitated broader dissemination of the dashboard by making it available to all Santeon hospitals and adapting it to their local IT structures. To support implementation, we developed an onboarding training program and provided guidance for local integration. Santeon served as a key platform for facilitating this dissemination.

Our study also demonstrated adaptability in response to external factors such as the COVID-19 pandemic. Given the reduced number of in-person visits during this period, we included video and telephone healthcare visits in our study sample to ensure the relevance and applicability of our findings.

A potential limitation is related to patient representation. Those who agreed to participate in the study may not fully represent the general patient population in terms of engagement and willingness to be involved in decision-making. It is possible that more proactive or engaged patients were overrepresented in our studies.

Furthermore, conducting academic research on the implementation of a practical tool presents challenges. The timelines for academic research and real-world implementation often do not align. In practical settings, tools are typically implemented and continuously refined based on real-time feedback. However, academic research involving a pre-post study design is not well-suited to evaluate the more iterative improvement process that tools typically undergo in practice. Our findings indeed suggest that academic evaluations may not always capture the full impact of an innovation as seen in daily clinical practice. Therefore, short-cycle feedback mechanisms, such as brief surveys, interviews and clinician feedback sessions provided valuable insights into improving the dashboard; insights that were not always captured through formal academic data collection.

Successful implementation of an innovation itself is a significant undertaking, requiring considerable efforts and resources. When combined with academic research, implementation efforts may receive fewer dedicated hours, potentially limiting the full realization of an innovation's impact. A stronger focus on practical evaluation and continuous improvement may enhance the ability to implement and disseminate tools effectively. Action-research design may offer a suitable combination of academically evaluating innovations whilst focusing on iterative improvements to enhance uptake in practice [35].

Lastly, in developing the CKD dashboard, we prioritized short-term feasibility, allowing for an initial implementation that could be built upon over time. However, certain important features such as multilingual support, were not included in the initial version. This limitation hindered accessibility for non-Dutch-speaking patients and should be a high priority for future development.

8.5 Future directions

Future directions for research

Future research should further explore conversational behaviors that positively influence the SDM process. Analyzing audio recordings of healthcare visits can help identify specific behaviors that enhance patient involvement. However, rather than developing a rigid, one-size-fits-all conversational strategy, the goal should be to highlight behaviors that clinicians can integrate into their own communication styles to adapt to situational needs and maintain autonomy.

Reflecting on our study results and the academic evaluation of the CKD dashboard, we question the most effective approach to assessing practical innovations like this. As demonstrated in **Chapter 6**, capturing the impact of the dashboard using standardized outcome measures in a pre-post design with limited follow-up time proved challenging. In contrast, our short-cyclic practical evaluation provided valuable insights into barriers to optimal implementation and ways to refine the intervention. Future research on similar innovations should consider whether a full academic evaluation is the best approach. A more action-oriented research approach may be more effective. Action research involves short-cycle feedback loops with end users to iteratively refine the innovation. The focus lies on continuous adjustments with the ultimate goal to realize positive impact [35]. It is more reflexive to the clinical environment thereby enhancing successful embedment.

Additionally, qualitative research methods appear particularly useful for improving innovations and supporting implementation efforts. It provides in-depth explanations as to why certain elements do or do not work well. Applying implementation frameworks such as Normalization Process Theory (NPT) could provide further insights into challenges and facilitators in adoption of an innovation. We also recommend incorporating audio recordings in future evaluations, as they offer rich data, both on how an intervention is used and on broader conversational dynamics. These recordings could serve as valuable resources for training clinicians in SDM techniques and refining the use of tools like the CKD dashboard.

Future directions for clinical practice

Supporting SDM implementation in all medical fields

Our research has informed SDM trainings in hospitals, particularly in defining for which decisions SDM is considered appropriate. These insights extend beyond nephrology and have been incorporated into SDM training initiatives in multiple hospitals for different specialties. For instance, the Santeon *Teach-the-Teacher* training program now integrates our findings, equipping healthcare professionals with the knowledge to train their colleagues in SDM implementation.

Additionally, our findings on SDM in different decisional situations as well as our findings regarding the use of PROMs, have contributed to the development of the Santeon SDM-implementation guide (‘*routekaart samen beslissen*’) [36]. This step-by-step guide helps SDM implementation in hospital healthcare pathways. Currently, this guide is further being developed into a toolbox together within ‘Uitkomstgerichte Zorg II’; a program of the Dutch Minister of Health, Welfare and Sports. These toolbox aids will be available nationally to facilitate healthcare organizations in standardizing, personalizing, and digitalizing care at www.samendezorgvernieuwen.nl/personaliseren.

Accelerating the cultural shift towards SDM

In alignment with the Dutch National Health Agreement (*Integraal Zorg Akkoord , 2024)* [37], our findings reinforce the notion that SDM should not be treated as a stand-alone initiative but as an integral part of daily clinical practice. The question is not whether SDM should be applied, but rather how to implement it in the most effective way, and how outcome information can best support decision-making in different clinical contexts.

Broadening the scope of included decisions and related outcomes in the Dutch standardized outcome set for CKD

The Dutch governmental program 'Uitkomstgerichte zorg' of the Dutch Ministry of Health, Welfare and Sports aims to set national standards for the use of outcome information in healthcare, defining which outcomes are essential to measure and how to integrate them into clinical practice. Outcome information is used to learn and improve care, and in the decision making process. The governmental working group mapped clinical pathways, including relevant decision making moments. CKD care has been one of the national examples within this program for how to define and subsequently implement such an outcome set. Our study findings have directly influenced the content of the Dutch standardized CKD outcome set, shifting the focus beyond kidney replacement therapy (KRT) decisions to include a broader range of common CKD-related decisions. Hereby, the importance of SDM across multiple topics within CKD care was acknowledged. The revised outcome sets serve as national guidelines for measuring relevant outcomes in CKD-related decision-making [38].

Ongoing development of the CKD dashboard

The CKD dashboard had been adjusted based on our findings and been built and implemented in five Santeon hospitals after the study ended. Currently, within the '*Zorg bij jou*' program initiated by Santeon, efforts are being undertaken to continue the development of the CKD dashboard. In this next phase of development, relevant outcome information (as identified in our studies) is collected and visualized by means of an app for patients. In addition to clinical outcomes and PROs similar to the CKD dashboard in our studies, home measurements (e.g. blood pressure and weight) are added. The app is used to monitor patients remotely from a medical service center by monitoring nurses. When abnormal measurement values are detected, the monitoring nurse will contact the responsible healthcare provider. By using the app, situations in which an outpatient appointment is warranted is distinguished from situations in which an outpatient appointment may be redundant. The PROs and clinical data are also visualized in a dashboard linked to the EHR for clinicians to review and discuss with patients during healthcare visits.

CKD dashboard as a template for visualizing outcomes in other medical fields

Additionally, the CKD dashboard has been used as a 'best practice' example within the Linnean initiative. Linnean is a nationwide foundation with 1800+ members working in healthcare and aiming to improve quality of care and accelerating value-based healthcare principles in the Netherlands, by learning from each other and stimulating innovations [39]. The CKD dashboard serves as an example for meaningful exchange between patients and clinicians of PROMs and clinical data. The visual template of the CKD dashboard and its underlying data structure has also been used in other specialties within St. Antonius Hospital to visualize outcome information, including atrial fibrillation, rheumatology and diabetes.

8.6 Conclusion

This thesis showed that shared decision making (SDM) is appropriate for a broader scope of medical decisions than is currently usually assumed. In chronic kidney disease (CKD), the scope of SDM extends beyond major preference-sensitive choices, such as kidney replacement therapy, to more commonly occurring CKD-related decisions. Visualizing patient outcomes during healthcare visits may enhance the information exchange necessary for SDM. The introduction of the dashboard did not lead to significant changes in the primary study outcomes, including SDM levels. However, the healthcare visit observations suggest that the discussion of the dashboard (when used as intended) provided meaningful benefits for individual patients. The dashboard helped to elicit problems of patients and facilitated comprehensive and patient-centered discussions.

Whereas many CKD patients desire greater involvement in decision making than they currently experience, we also observed that many patients preferred the clinician taking on a leading role in making treatment decisions. This emphasizes the importance of aiming for a shared decision *process*, rather than imposing a role on patients in making the final choice. Even when patients prefer a more clinician-directed approach, SDM steps remain crucial to align care with patient values, preferences, and daily lives.

Individual variations exist both between clinicians and between patients regarding which outcomes they consider essential for SDM and which, in particular predictive outcomes, they prefer not to discuss. The variation in patient preferences stresses the importance of assessing individual preferences both in regarding participation in decision making and in selecting which outcome information to share. In addition to supporting SDM by improving the information transfer by visually presenting outcomes, fostering an environment in which patients feel encouraged to express their preferences is essential. Clinicians' genuine interest in patients driven by curiosity should drive this shift. This entails *asking* about patients' preferences regarding their decisional role, the decision itself and information needs, instead of making assumptions without checking them.

For every clinician reading this thesis, we invite you to take a moment to reflect on your own interactions with patients. Do you feel there are elements in your conversations with patients that you could add or adjust to improve the shared decision making *process* when making decisions? Please also reflect on whether you can catch yourself in making assumptions about patients' preferences. What would happen if you actively checked assumptions about patients' information preferences, desired level of involvement in decision making, and preferences regarding the decision at hand? Would your assumptions always be accurate? Reflecting and continuously aiming to improve ourselves, also regarding communication, is an inherent part of being a clinician. As we all, including myself, promised when we took the oath of Hippocrates: *'I will respect patients' beliefs and values; I will listen attentively and inform my patients honestly and compassionately; I will remain open to accountability and critical self-reflection'.*

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