Dorinde E.M. van der Horst

A VISIT TO THE DOCTOR

Shared decision making supported by outcome information in chronic kidney disease

A visit to the doctor

Shared decision making supported by outcome information in chronic kidney disease

Dorinde van der Horst

PhD thesis
Dorinde Eva Margaretha van der Horst
Leiden, The Netherlands, 2025

Printing: Ridderprint
Cover illustration: Acrylic painting by Dorinde van der Horst
Layout and design: Erwin Timmerman, persoonlijkproefschrift.nl

Financial support for printing of this thesis was kindly provided by Santeon.

The research described in this thesis was financially supported by a grant of St. Antonius Hospital Nieuwegein to prof. W.J.W. Bos, a grant by the Maatschap Internal Medicine of St Antonius Hospital and a grant from the Netherlands Organization for Health Research and development (ZonMW) to the Santeon program ‘Experiment Uitkomstindicatoren’ (registration number 516007001).

ISBN 978-94-6522-915-7

A visit to the doctor

Shared decision making supported by outcome information in chronic kidney disease

Proefschrift

ter verkrijging van

de graad van doctor aan de Universiteit Leiden,

op gezag van (waarnemend) rector magnificus,

volgens besluit van het college voor promoties

te verdedigen op vrijdag 6 februari 2026

klokke 13:00 uur

door

Dorinde Eva Margaretha van der Horst
geboren te Leiden
in 1993

Promotores	
Prof. dr. W.J.W. Bos	
Dr. A.H. Pieterse	

Copromotor	
Dr. C.F. van Uden-Kraan	*Santeon*

Leden promotiecommissie	
Prof. dr. J.I. Rotmans	
Prof. dr. A.M. Stiggelbout	
Prof. dr. A.E.A.M. Weel	*Erasmus Medisch Centrum*
Assoc. prof. dr. O.C. Damman	*Amsterdam UMC*

Table of contents

Part one: Shared Decision Making in Chronic Kidney Disease (CKD) - broadening the scope

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

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

1

General introduction and thesis outline

1.1 General introduction and thesis outline

Meet Mrs. Smiths, a 67 year old woman. She is about to go to her appointment with her nephrologist, which as she knows now is the name of 'a doctor specialized in kidneys'. For five years, she has been visiting her nephrologist every half year for a check-up. Although familiar with her doctor, she is always a bit nervous. Will my results still be good? Is my kidney function declining? The visit starts as usual. First, they have some small talk regarding the traffic followed by the infamous question: 'How are you doing?'. 'Good' she replies thinking 'Shouldn't you know? You have my lab results!'. But before the lab results are discussed the nephrologist addresses a longlist of topics including her diet, salt intake, exercise and blood pressure, measured 15 minutes before her visit by a nurse. She mostly nods while regretting the salty pizza she had the previous evening and hoping the doctor does not notice her nervousness. Then, finally, the lab results! The nephrologist reads from a screen that her kidney function is stable, 28 instead of 30 last time. That is two points less! she blurts out. Yes, but over time it barely makes a difference and it's more or less a straight line, replies the nephrologist calmly. Unconvinced she nods. The nephrologist continues: cholesterol is a bit high, but your electrolytes are fine. My what?! she thinks. But she nods again, not wanting to be a burden. The nephrologist suggests dosing up her blood pressure medication and prescribing a new pill. Sitatine or something. She is not entirely thrilled since she already can hardly keep track of all her different medications. She walks out the consultation room, SHOOT, now I forgot to mention my dizziness and low blood pressures when I measure at home.. oh well.. It probably doesn't matter that much anyway...

1.1.1 A patient with chronic kidney disease encounters many decisions

Mrs. Smits suffers from chronic kidney disease (CKD), a chronic condition characterized by progressively reduced kidney function. The incidence of CKD is rising due to factors such as population growth, aging, and increasing rates of diabetes, obesity and hypertension. CKD typically involves gradual decline in kidney function, which may eventually result in the need for kidney replacement therapy (KRT), including different types of dialysis or kidney transplantation [1,2] . In Dutch clinical practice, patients with advanced CKD are treated by a nephrologist. These patients have a remaining kidney function of an eGFR (glomerular filtration rate) below 30 mL/min/1.73m^2 or proteinuria (protein leakage into urine because of damaged kidneys) exceeding 300 mg/g [3]. The primary treatment goal in CKD management is to slow down kidney function decline and delay or prevent the need for KRT [3].

Patients with CKD regularly visit their nephrologist for check-ups or ‘healthcare visits’. During these visits information is exchanged between patient and clinician. This information exchange is important to inform patients about their condition, which enhances ‘patient activation’ - ‘having the knowledge, skills, and confidence for managing your own health’ [4]. Many treatment decisions are made during these visits. Most decisions relate to the overall treatment goal of CKD: slowing down kidney function decline. These decisions often involve lifestyle changes (e.g., limit salt intake, limit protein intake, lose weight, stop smoking) and long-term medications (e.g., hypertension medication, cardiovascular prevention including cholesterol-lowering medication), which require patient commitment [3,5]. However, these decisions may not always feel like active choices to patients, including Mrs. Smits. Still, it is the patient who must implement these decisions to reach effective treatment.

Involving patients in decision-making can improve patients’ willingness and ability to implement decisions made, thus enhancing CKD management. A widely accepted strategy in today’s healthcare to involve patients in medical decisions is Shared Decision Making (SDM). SDM entails a collaborative decision-making process between patient and clinician. A commonly used description of the SDM process outlines four steps (**Box 1**): 1) informing the patient that there is a decision to be made and that the opinion of the patient is important, 2) explaining the options including their pros and cons, 3) discussing patients’ preferences while the clinician supports the patient’s deliberation, 4) jointly discussing patient’s wish to make the decision, decide together or defer the decision and discuss follow-up [6].

Studies show that patient involvement by means of SDM improves treatment adherence and clinical outcomes [7–11]. Besides these benefits, it can be considered an ethical imperative to involve patients in decision making as it directly impacts patients’ daily life and helps ensure care is tailored to their needs [12,13]. In the Netherlands, SDM is an important theme included in the Dutch National Health Agreement (*Integraal Zorg Akkoord, IZA)* which includes the aim to provide care that best fits the patients’ circumstances [14]. Studies have also reported the desire for patients to engage in SDM in their medical care [15,16].

In Nephrology, SDM is already recognized as crucial for the KRT decision; the decision between available kidney replacement therapies such as hemodialysis, peritoneal dialysis, kidney transplantation or conservative therapy [17,18]. The KRT decision is a major preference-sensitive decision with multiple options which all significantly affect patients' lives, yet in different ways. Recently, a decision tool was developed to facilitate SDM in this context [19].

However, the role of SDM in more common, less complex CKD decisions is not well understood. Furthermore, it is not known how these common CKD decisions are currently made and to what extent patients are involved in these decisions. Additionally, a research gap exists in determining when SDM is considered appropriate for different types of decisions in all medical fields. This leads to our first objective:

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

1.1.2 The information exchange during CKD healthcare visits - discussing outcome information.

Outcome information can support treatment decision-making during healthcare visits. "Outcome information" (or 'outcomes') is an umbrella term for information that describes the results of provided care. The concept is grounded in the economic and strategic framework of value-based healthcare (VBHC), introduced globally in 2006. VBHC is a strategic framework that can be used to structure and improve healthcare in such a way that the value of care is increased. Value is defined as the outcomes of care relative to the costs [20]. Thus, to determine value in healthcare, information about outcomes, particularly outcomes that matter to patients, is essential. In the context of VBHC, outcomes are measured and utilized at two distinct levels [21]. First, at the level of patient-clinician interactions, outcomes help for disease monitoring and to facilitate SDM [22,23]. Second, at an aggregated level, outcomes are used to drive quality improvement efforts [24–26].

The Santeon collaborative provides an example of both individual and aggregated use of outcomes in healthcare. This collaborative is also the context of this thesis. Santeon is a collaboration of seven Dutch teaching hospitals, including: Canisius Wilhelmina Hospital in Nijmegen, Catharina Hospital in Eindhoven, Maasstad Hospital in Rotterdam, Martini Hospital in Groningen, Medisch Spectrum Twente in Enschede, Onze Lieve Vrouwen Gasthuis in Amsterdam, and Sint Antonius Hospital in Utrecht and Nieuwegein. These hospitals collectively measure patient outcomes per medical condition and compare results to improve care [27]. As part of the '*Outcome-oriented Care*'- program ("Programma Uitkomstgerichte zorg)", a research and implementation program funded by the Dutch Ministry of Health, Welfare and Sports, Santeon hospitals have worked together to incorporate outcome information into daily clinical practice, supporting SDM, in three patient groups: patients with breast cancer, stroke or chronic kidney disease [28,29] .

In this thesis we focus on the use of outcome information at the patient-clinician level, specifically on how outcome information can improve decision making and patient involvement in disease management. We distinguish four different types of outcome information that can be used in patient-clinician interactions.

First, as illustrated by the case of Mrs. Smits, outcome information can consist of results from clinical tests or measurements administered to the patient of which the clinician reports the results (e.g., blood pressure measurements or lab results). Second, patients can provide outcome information themselves. This information, for example regarding physical symptoms, functioning or overall well-being, can be measured using standardized questionnaires known as Patient Reported Outcome Measures (PROMs). PROMs can be disease-specific, e.g., the Dialysis Symptom Index [30] assessing physical and mental symptoms, or generic (PROMIS-10), assessing overall mental and physical health [31]. Third, outcome information can include aggregated data such as risks based on predictive models (e.g., predicting survival rate per treatment or disease progression), or "patients like me" models, which compare an individual patient to a broader population [32]. **Figure 1** shows how different types of outcome information can support SDM [29].

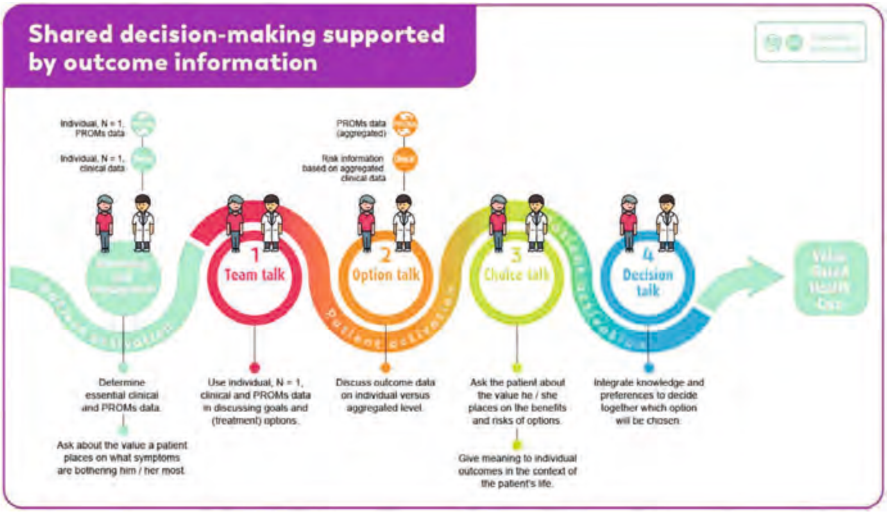


Figure 1. How outcome information can be used to engage in SDM. PROM=patient reported outcome measures.

While the benefits of PROMs in healthcare visits are increasingly described in studies [33–36], research remains limited in exploring the full range of types of outcome information and their preferred use during healthcare visits. Given the rapid advancements in collecting and processing outcome data, it is crucial to better understand how discussing different types of outcomes affects treatment decision making. This will help prioritize which outcomes should be discussed during healthcare visits. Exploring the perspectives of both patients and clinicians on different existing and emerging types of outcome information is a valuable contribution to the literature, which typically focuses on only one outcome type or perspective [33–36]. This leads to our second objective:

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

1.1.3 Stimulating patient involvement through discussing outcomes.

Outcome information plays a crucial role in information exchange during healthcare visits, contributing to both informing patients and SDM. In both ways (informing and SDM) patient activation is stimulated as it equips patients with the information needed to manage their health and patients are more involved in their own care when SDM is implemented [37,38]. Research has demonstrated that higher levels of patient activation are associated with improved clinical outcomes because of better self-management [39–41], and are instrumental in engaging in SDM. Conversely, SDM itself can foster greater patient activation [38,42]. However, in the early stages of CKD, when patients have a residual function between 45-15 mL/min/1.73m^2, studies reveal that patient activation levels are low [43,44]. These patients often lack sufficient awareness of their condition [45], struggle to understand treatment goals [45,46], and exhibit poor medication adherence [47]. Qualitative research highlighted that patients frequently report unmet information needs, indicating gaps in the communication process [48].

To improve patient activation levels and support SDM, it is crucial to enhance the information exchange during healthcare visits. Currently, the use of outcome information is limited, often confined to clinical outcomes such as laboratory results or basic measurements such as blood pressure or weight. PROMs or other types of outcomes, such as prognostic models or "patients like me" models are rarely, if ever, utilized [28,49]. Furthermore, as illustrated by Mrs Smith's healthcare visit, much of the information is conveyed verbally, despite evidence that new verbal information is difficult to retain [50]. Data visualization has been shown to improve information comprehension [51–53] yet is only minimally employed, often limited to basic graphs displayed in electronic health records.

To address this gap, our goal is to improve the exchange of outcome information during healthcare visits to foster patient activation and facilitate SDM. Specifically, our third objective is to develop an innovative tool for presenting outcome information during healthcare visits: a CKD dashboard. We aim to develop this dashboard through a co-creation process with both patients and clinicians and evaluate the impact of usage of the dashboard on patient activation and SDM.

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.

1.2 Aims and thesis outline

This thesis aims to address the three objectives introduced above:

1) Determine the extent to which SDM is appropriate in routine medical decisions and assess current practice in decision making in CKD.
2) Explore patients' and clinicians' preferences in discussing different types of outcome information during healthcare visits.
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.

In three different parts these objectives will be addressed.

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

The focus of the first part of this thesis is on SDM: when it should be applied, and how it is currently applied. Before we dive into the role of SDM in CKD, we will explore in **chapter 2** whether SDM literature offers guidance for which decisions in any medical field SDM should be applied. Is it mainly for decisions characterized as being major and preference-sensitive or is it relevant to other kinds of decisions as well?

In **chapter 3** we zoom in on CKD healthcare visits: what decisions frequently occur in that setting and how do patients experience these decisions. Who made the decision according to them? We also study what patients' preferences are in decision making: who should make those decisions? In addition to the patient perspective, we analyze real-life CKD healthcare visits: who makes the decisions according to independent observers?

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

In the second part we aim to get a better general understanding about patients' and clinicians' perspectives on different types of outcome information and how to discuss them during healthcare visits. We broaden our scope in **chapter 4** to breast cancer in addition to CKD. In this chapter we share the findings of simultaneous interviews with patients and their treating clinician (dyadic interviews) to study their (shared or opposing) perspectives regarding different types of outcomes: clinical outcomes, patient-reported outcomes, comparisons with aggregated data, and prediction models. In **chapter 5** we zoom in on one type of outcome information specifically: risk prediction models. We assess the current use and preferences of both patients and clinicians regarding the use of risk prediction models in CKD practice and provide clinical recommendations for their use.

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

In part three we describe the process of co-development (**chapter 6**) and evaluation (**chapter 7**) of an innovation attempting to optimize the use of outcome information during CKD healthcare visits. The innovation is the CKD dashboard, a digital interactive dashboard visualizing patients' outcomes. The dashboard can be opened on a screen and discussed during healthcare visits. It consists of clinical outcomes (e.g., blood pressure or laboratory results) visualized per treatment goal, and patient-reported outcomes (symptoms and generic outcomes, including overall mental and physical health). Data visualization strategies are applied to maximize ease of comprehension of the information included in the dashboard. In **chapter 7** we provide results of a multicenter study in which we evaluate the impact of the dashboard on patient activation and SDM.

Finally, in **chapter 8,** we provide a summary of the main results of our different studies. Additionally, the results will be discussed including implications of the findings for practice and future perspectives.

References

[1] V. Jha *et al.*, “Chronic kidney disease: Global dimension and perspectives,” *Lancet*, vol. 382, no. 9888, pp. 260–272, 2013, doi: 10.1016/S0140-6736(13)60687-X.

[2] GBD Chronic Kidney Disease Collaboration, “Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017,” *Lancet*, vol. 395, no. 10225, pp. 709–733, 2020, doi: 10.1016/S0140-6736(20)30045-3.

[3] Kidneydisease, “KDIGO 2013 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease,” *Off. J. Int. Soc. Nephrol.*, vol. 3, no. 1, 2013, [Online]. Available: https://kdigo.org/wp-content/uploads/2017/02/KDIGO_2012_CKD_GL.pdf.

[4] J. H. Hibbard, J. Stockard, E. R. Mahoney, and M. Tusler, “Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers,” *Health Serv. Res.*, vol. 39, no. 4 I, pp. 1005–1026, 2004, doi: 10.1111/j.1475-6773.2004.00269.x.

[5] W. G. Couser, G. Remuzzi, S. Mendis, and M. Tonelli, “The contribution of chronic kidney disease to the global burden of major noncommunicable diseases,” *Kidney Int.*, vol. 80, no. 12, pp. 1258–1270, 2011, doi: 10.1038/ki.2011.368.

[6] A. M. Stiggelbout, A. H. Pieterse, and J. C. J. M. De Haes, “Shared decision making: Concepts, evidence, and practice,” *Patient Educ. Couns.*, vol. 98, no. 10, pp. 1172–1179, 2015, doi: 10.1016/j.pec.2015.06.022.

[7] E. A. Joosten, L. DeFuentes-Merillas, G. H. de Weert, T. Sensky, C. P. van der Staak, and C. A. de Jong, “Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status,” *Psychother. Psychosom.*, vol. 77, no. 4, pp. 219–226, 2008, [Online]. Available: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med7&AN=18418028.

[8] S. R. Wilson *et al.*, “Shared treatment decision making improves adherence and outcomes in poorly controlled asthma,” *Am. J. Respir. Crit. Care Med.*, vol. 181, no. 6, pp. 566–577, 2010, doi: 10.1164/rccm.200906-0907OC.

[9] A. T. Langford, S. K. Williams, M. Applegate, O. Ogedegbe, and R. S. Braithwaite, “Partnerships to Improve Shared Decision Making for Patients with Hypertension: Health Equity Implications,” *Ethn. Dis.*, vol. 29, no. Suppl 1, pp. 97–102, Feb. 2019, doi: 10.18865/ed.29.S1.97.

[10] V. M. Montori, A. Gafni, and C. Charles, “A shared treatment decision-making approach between patients with chronic conditions and their clinicians: The case of diabetes,” *Heal. Expect.*, vol. 9, no. 1, pp. 25–36, 2006, doi: 10.1111/j.1369-7625.2006.00359.x.

[11] T. F. Hack, L. F. Degner, P. Watson, and L. Sinha, “Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer,” *Psychooncology.*, vol. 15, no. 1, pp. 9–19, 2006, doi: 10.1002/pon.907.

[12] G. Elwyn, J. Tilburt, and V. Montori, “The ethical imperative for shared decision-making,” *Eur. J. Pers. Centered Healthc.*, vol. 1, no. 1, p. 129, 2013, doi: 10.5750/ejpch.v1i1.645.

[13] A. M. Stiggelbout *et al.*, “Shared decision making: Really putting patients at the centre of healthcare,” *BMJ (Online)*, vol. 344, no. 7842. Feb. 04, 2012, doi: 10.1136/bmj.e256.

[14] Ministry of Health Welfare and Sports, “Integraal Zorgakkoord (IZA),” 2022. [Online]. Available: https://www.lhv.nl/opkomen-voor-belangen/integraal-zorgakkoord/%0Ahttps://www.rijksoverheid.nl/documenten/rapporten/2022/09/16/integraal-zorgakkoord-samen-werken-aan-gezonde-zorg.

[15] A. L. Shay and J. E. Lafata, “Where is the evidence? a systematic review of shared decision making and patient outcomes,” *Med. Decis. Mak.*, vol. 35, no. 1, pp. 114–131, 2015, doi: 10.1177/0272989X14551638.

[16] B. Chewning, C. L. Bylund, B. Shah, N. K. Arora, J. A. Gueguen, and G. Makoul, “Patient preferences for shared decisions: A systematic review,” *Patient Educ. Couns.*, vol. 86, no. 1, pp. 9–18, 2012, doi: 10.1016/j.pec.2011.02.004.

[17] W. R. Verberne *et al.*, “Value-based evaluation of dialysis versus conservative care in older patients with advanced chronic kidney disease: A cohort study,” *BMC Nephrol.*, vol. 19, no. 1, Aug. 2018, doi: 10.1186/s12882-018-1004-4.

[18] W. R. Verberne *et al.*, “Older patients’ experiences with a shared decision-making process on choosing dialysis or conservative care for advanced chronic kidney disease: A survey study,” *BMC Nephrology*, vol. 20, no. 1. BioMed Central Ltd., Jul. 16, 2019, doi: 10.1186/s12882-019-1423-x.

[19] N. Engels *et al.*, “Development of an online patient decision aid for kidney failure treatment modality decisions,” *BMC Nephrol.*, vol. 23, no. 1, pp. 1–16, 2022, doi: 10.1186/s12882-022-02853-0.

[20] M. Porter and E. Teisberg, *Redefining Health Care: Creating Value-Based Competition on Results*. Boston: Harvard Business School Press, 2006.

[21] M. E. Porter, S. Larsson, and T. H. Lee, “Standardizing Patient Outcomes Measurement,” *N. Engl. J. Med.*, vol. 374, no. 6, pp. 651–653, 2016, doi: 10.1111/hae.13072.

[22] O. C. Damman *et al.*, “The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients,” *J. Eval. Clin. Pract.*, vol. 26, no. 2, pp. 524–540, 2020, doi: 10.1111/jep.13321.

[23] P. B. van der Nat, “The new strategic agenda for value transformation,” *Heal. Serv. Manag. Res.*, no. April, 2021, doi: 10.1177/09514848211011739.

[24] N. A. Kampstra, N. Zipfel, P. B. Van Der Nat, G. P. Westert, P. J. Van Der Wees, and A. S. Groenewoud, “Health outcomes measurement and organizational readiness support quality improvement: A systematic review,” *BMC Health Serv. Res.*, vol. 18, no. 1, pp. 1–14, 2018, doi: 10.1186/s12913-018-3828-9.

[25] W. J. W. Bos, M. ten Dam, T. Hoekstra, H. Prinsen, N. van Uden, and C. Voorend, “Showcase nefrologie - samen voor betere nierzorg. Ontwikkeling en toepassing van kwaliteitsinstrumenten bij chronische nierschade.,” 2024. [Online]. Available: https://projecten.zonmw.nl/nl/project/showcase-nefrologie.

[26] G. Steinmann, D. Delnoij, H. Van De Bovenkamp, R. Groote, and K. Ahaus, “Expert consensus on moving towards a value-based healthcare system in the Netherlands: A Delphi study,” *BMJ Open*, vol. 11, no. 4, 2021, doi: 10.1136/bmjopen-2020-043367.

[27] N. Engels *et al.*, “Santeon’s Lessons from a Decade of Implementing Value-Based Health Care,” *NEJM Catal.*, vol. 5, no. 1, 2023, doi: 10.1056/cat.23.0232.

[28] Partners Hoofdlijnenakkoord medisch-specialistische zorg, “Voortgangsrapportage IV - Uitkomstgerichte zorg,” 2022. Accessed: Dec. 11, 2023. [Online]. Available: https://www.uitkomstgerichtezorg.nl/over-ons.

[29] M. Q. Hackert *et al.*, “Effectiveness and implementation of making supported by SHared decision-OUTcome information among patients with breast cancer , stroke and advanced kidney disease : SHOUT study protocol of multiple interrupted time series,” *BMJ Open*, vol. 12, pp. 1–12, 2022, doi: 10.1136/bmjopen-2021-055324.

[30] S. D. Weisbord *et al.*, “Development of a symptom assessment instrument for chronic hemodialysis patients: The dialysis symptom index,” *J. Pain Symptom Manage.*, vol. 27, no. 3, pp. 226–240, 2004, doi: 10.1016/j.jpainsymman.2003.07.004.

[31] C. B. Terwee *et al.*, “Dutch-Flemish translation of 17 item banks from the Patient-Reported Outcomes Measurement Information System (PROMIS),” *Qual. Life Res.*, vol. 23, no. 6, pp. 1733–1741, 2014, doi: 10.1007/s11136-013-0611-6.

[32] M. C. Dorr *et al.*, “Quality improvements of healthcare trajectories by learning from aggregated patient-reported outcomes: a mixed-methods systematic literature review,” *Heal. Res. Policy Syst.*, vol. 20, no. 1, pp. 1–13, 2022, doi: 10.1186/s12961-022-00893-4.

[33] J. Greenhalgh *et al.*, “How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis,” *J. Patient-Reported Outcomes*, vol. 2, no. 1, 2018, doi: 10.1186/s41687-018-0061-6.

[34] J. Field, M. M. Holmes, and D. Newell, “<p>PROMs data: can it be used to make decisions for individual patients? A narrative review</p>,” *Patient Relat. Outcome Meas.*, vol. Volume 10, pp. 233–241, 2019, doi: 10.2147/prom.s156291.

[35] D. Feldman-Stewart and M. D. Brundage, “A conceptual framework for patient – provider communication : a tool in the PRO research tool box,” *Qual Life Res*, vol. 18, pp. 109–114, 2009, doi: 10.1007/s11136-008-9417-3.

[36] L. Y. Yang, D. S. Manhas, A. F. Howard, and R. A. Olson, “Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication,” *Support. Care Cancer*, vol. 26, no. 1, pp. 41–60, 2018, doi: 10.1007/s00520-017-3865-7.

[37] S. G. Smith, A. Pandit, S. R. Rush, M. S. Wolf, and C. J. Simon, “The Role of Patient Activation in Preferences for Shared Decision Making: Results From a National Survey of U.S. Adults,” *J. Health Commun.*, vol. 21, no. 1, pp. 67–75, 2016, [Online]. Available: http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=med13&AN=26313690.

[38] B. Y. Poon, S. M. Shortell, and H. P. Rodriguez, “Patient Activation as a Pathway to Shared Decision-making for Adults with Diabetes or Cardiovascular Disease,” *J. Gen. Intern. Med.*, vol. 35, no. 3, pp. 732–742, 2020, doi: 10.1007/s11606-019-05351-6.

[39] J. H. Hibbard and J. Greene, “What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs,” *Health Aff.*, vol. 32, no. 2, pp. 207–214, 2013, doi: 10.1377/hlthaff.2012.1061.

[40] D. M. Mosen, J. Schmittdiel, J. Hibbard, D. Sobel, C. Remmers, and J. Bellows, “Is patient activation associated with outcomes of care for adults with chronic conditions?,” *J. Ambul. Care Manage.*, vol. 30, no. 1, pp. 21–29, 2007, doi: 10.1097/00004479-200701000-00005.

[41] J. Greene, J. H. Hibbard, R. Sacks, V. Overton, and C. D. Parrotta, “When patient activation levels change, health outcomes and costs change, too,” *Health Aff.*, vol. 34, no. 3, pp. 431–437, 2015, doi: 10.1377/hlthaff.2014.0452.

[42] S. G. Smith, A. Pandit, S. R. Rush, M. S. Wolf, and C. J. Simon, “The role of patient activation in preferences for shared decision making: Results from a national survey of U.S. Adults,” *J. Health Commun.*, vol. 21, no. 1, pp. 67–75, 2016, doi: 10.1080/10810730.2015.1033115.

[43] D. Nair and K. L. Cavanaugh, “Measuring patient activation as part of kidney disease policy: Are we there yet?,” *J. Am. Soc. Nephrol.*, vol. 31, no. 7, pp. 1435–1443, 2020, doi: 10.1681/ASN.2019121331.

[44] T. J. Wilkinson, K. Memory, C. J. Lightfoot, J. Palmer, and A. C. Smith, “Determinants of patient activation and its association with cardiovascular disease risk in chronic kidney disease: A cross-sectional study,” *Heal. Expect.*, no. January, pp. 843–852, 2021, doi: 10.1111/hex.13225.

[45] J. A. Wright Nunes, K. A. Wallston, S. K. Eden, A. K. Shintani, T. A. Ikizler, and K. L. Cavanaugh, “Associations among perceived and objective disease knowledge and satisfaction with physician communication in patients with chronic kidney disease,” *Kidney Int.*, vol. 80, no. 12, pp. 1344–1351, 2011, doi: 10.1038/ki.2011.240.

[46] L. C. Plantinga, D. S. Tuot, and N. R. Powe, “Awareness of Chronic Kidney Disease Among Patients and Providers,” *Adv. Chronic Kidney Dis.*, vol. 17, no. 3, pp. 225–236, 2010, doi: 10.1053/j.ackd.2010.03.002.

[47] E. A. Cedillo-Couvert *et al.*, "Self-reported Medication Adherence and CKD Progression," *Kidney Int. Reports*, vol. 3, no. 3, pp. 645–651, 2018, doi: 10.1016/j.ekir.2018.01.007.

[48] Y. de Jong *et al.*, "Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies," *BMC Nephrol.*, vol. 22, no. 1, pp. 1–16, 2021, doi: 10.1186/s12882-021-02489-6.

[49] H. J. Westerink *et al.*, "The use of outcome data in patient consultations from the healthcare professionals' and patients' perspectives: A mixed methods study," *Patient Educ. Couns.*, vol. 118, no. March 2023, 2024, doi: 10.1016/j.pec.2023.108043.

[50] R. P. C. Kessels, "Patients' memory for medical information," *J. R. Soc. Med.*, vol. 96, pp. 219–222, 2003.

[51] M. R. Turchioe, L. V. Grossman, A. C. Myers, D. Baik, P. Goyal, and R. M. Masterson Creber, "Visual analogies, not graphs, increase patients' comprehension of changes in their health status," *J. Am. Med. Informatics Assoc.*, vol. 27, no. 5, pp. 677–689, 2020, doi: 10.1093/jamia/ocz217.

[52] L. V. Grossman, S. K. Feiner, E. G. Mitchell, and R. M. Masterson Creber, "Leveraging Patient-Reported Outcomes Using Data Visualization," *Appl. Clin. Inform.*, vol. 9, no. 3, pp. 565–575, 2018, doi: 10.1055/s-0038-1667041.

[53] E. T. Bantug, T. Coles, K. C. Smith, C. F. Snyder, J. Rouette, and M. D. Brundage, "Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words?," *Patient Educ. Couns.*, vol. 99, no. 4, pp. 483–490, 2016, doi: 10.1016/j.pec.2015.10.027.

PART ONE

Shared Decision Making in Chronic Kidney Disease – broadening the scope

2

For which decisions is Shared Decision Making considered appropriate? – a systematic review

Dorinde E.M. van der Horst
Mirjam M. Garvelink
Willem Jan W. Bos
Anne M. Stiggelbout
Arwen H. Pieterse

Published in Patient Education and Counseling, 2022

Abstract

Objective

To identify decision characteristics for which SDM authors deem SDM appropriate or not, and what arguments are used.

Methods

We applied two search strategies: we included SDM models from an earlier review (strategy 1) and conducted a new search in eight databases to include papers other than describing an SDM model, such as original research, opinion papers and reviews (strategy 2).

Results

From the 92 included papers, we identified 18 decision characteristics for which authors deemed SDM appropriate, including preference-sensitive, equipoise and decisions where patient commitment is needed in implementing the decision. SDM authors indicated limits to SDM, especially when there are immediate life-saving measures needed. We identified four decision characteristics on which authors of different papers disagreed on whether or not SDM is appropriate.

Conclusion

The findings of this review show the broad range of decision characteristics for which authors deem SDM appropriate, the ambiguity of some, and potential limits of SDM. Practice implications: The findings can stimulate clinicians to (re)consider pursuing SDM in situations in which they did not before. Additionally, it can inform SDM campaigns and educational programs as it shows for which decision situations SDM might be more or less challenging to practice.

1. Introduction

Shared Decision Making (SDM) is increasingly being advocated in clinical practice and efforts are made to implement it throughout healthcare. SDM does not currently have a unified definition, yet attempts have been made to capture its core elements. SDM entails a collaborative decision making process, including clarifying a decision is needed, discussing the options, exploring patient preferences, and ultimately making a decision (or deferring it) [1–3]. These core elements have been translated into workable steps to help incorporate them into practice [4,5].

Several national quality institutes linked to clinical practice guidelines recommend SDM, such as The Institute for Quality and Efficiency in Healthcare in Germany and The National Institute for Health and Care Excellence (NICE) in the UK. In addition, strong political advocacy for SDM is visible in different countries in the form of national campaigns, among which The Netherlands, USA, Germany, Canada, UK and Taiwan [6]. However, SDM is often advocated broadly without specifying *when* to apply SDM. In transitioning from advocating towards implementing SDM in daily clinical practice, questions may arise regarding the limits to SDM's applicability. For effective implementation, guidance for clinicians on when SDM is considered to be appropriate is required.

The large body of literature on patient decision aids, tools to support SDM, shows that SDM is deemed relevant or appropriate for many different decisions in many different settings [7]. Specification in what exactly makes these decisions particularly appropriate for SDM is often lacking. For some decisions, engaging in SDM is deemed so important that it has been made mandatory, for example for lung cancer screening decisions or decisions regarding implanting cardioverter-defibrillators (ICD's) in the US. These decisions are described as *not having one superior option* and *preference-sensitive* [8].

Some SDM authors mention characteristics of decisions for which SDM is particularly appropriate. For example, Whitney et al. propose that the level of *uncertainty* (evidence) around decisions, their *importance* [9], and the *amount of risk* involved in decision options [10], all play a role in determining the relevance of SDM. In their ground-laying work, Charles et al. described SDM in the context of early-stage breast cancer treatment decisions as their main example. They characterized this decision as having *several treatment options* and comprising *uncertainty around possible outcomes* [11] and considered these two decision characteristics to make SDM appropriate.

However, the SDM literature is less extensive on when SDM might *not* be appropriate. Hypothetically, SDM could lead to a burden of choice for patients, particularly in decisions which may have *high impact*. Additionally, for *urgent* decisions with *large (life-saving) consequences*, SDM can potentially be harmful [12,13]. Thus, it seems some decision characteristics clearly make SDM suitable, while others indicate the limits of SDM. Identifying these decision characteristics and how they relate to SDM can help clinicians in implementing SDM effectively in practice. Therefore, in this review, we aim to systematically assess what decision characteristics SDM authors report for which they deem SDM appropriate. Additionally, we wish to explore the limits of SDM and identify which decision characteristics SDM authors mention that make SDM inappropriate or even potentially harmful. We will provide an overview of the different decision characteristics and decision examples reported by SDM authors (including the setting in which they were mentioned), and what arguments authors provide on why SDM is (in) appropriate in those situations.

2. Methods

The focus of this review is on decision characteristics, i.e., features that characterize decisions (e.g., impact of a decision) regardless of the content of the decision or its setting. Decision characteristics are different from characteristics regarding decision makers (e.g., cognitive functioning), decision setting (e.g., primary care), or decision type (e.g., treatment). (**Fig. 1**). For example, decisions to be made within a short time frame (a decision characteristic) may occur in different settings (primary care, emergency department etc.) and may entail different types of decisions (diagnostics, treatment etc).

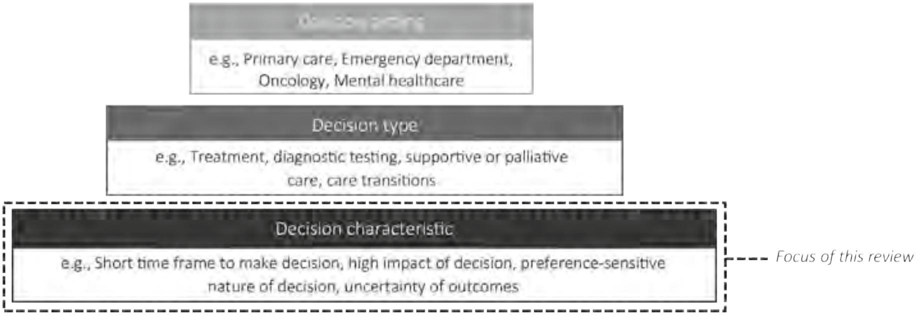


Figure 1. Three levels to describe decisions

2.1. Data collection

In order to identify a broad variety of papers, we applied two strategies to collect data. In strategy 1, we focused on how authors of SDM models implicitly and/or explicitly consider SDM to be appropriate. The papers describing SDM models were derived from a 2019 review of SDM models [1].

Strategy 2 included a systematic search of papers that describe decision characteristics. The second strategy focused on opinion papers, original research and reviews, and not on SDM models. The search consisted of keywords and synonyms for 'SDM', 'decision situation', 'decision type', and decision characteristics that had been identified in the papers included in the first strategy. We searched the following eight databases: Academic Search Premier, Cochrane, Pubmed, Emcare, Embase, Medline, PsychINFO and Web of Science. See **Supplement 1** for the full search strategy. To be eligible, the papers had to be published in a peer-reviewed journal and explicitly describe the authors' view on the appropriateness of SDM as a function of decision characteristics. Papers on SDM models that were published after the search of Bomhof- Roordink et al. [1] and that came up in this search, were also included. We excluded papers that did not present the *authors'* views on when SDM is appropriate as a function of particular decision characteristics and, for example, described the opinions of study participants such as clinicians and/or patients; papers in other languages than English, Dutch or French; and papers on SDM interventions such as decision aids that did not explain why SDM is important for that particular decision. Title-abstract screening and full-text screening were performed independently and in duplicate (DH-AP and DH-MG). In case of disagreement, consensus was reached by discussion and if needed, a third researcher was consulted (AP or MG).

2.2. Data extraction

One researcher (DH) extracted the data from all the papers included based on strategy 1 and 2 using a standardized extraction form, and another researcher (AP or MG) verified the extractions. Consensus, if needed, was reached through discussion. For all papers (both strategy 1 and 2), we extracted the following general characteristics: author(s), year of publication, journal, country of study, and study design. We extracted fragments describing the decisions (including their setting), decision characteristics, and arguments used to determine whether SDM was considered appropriate or not.

2.3. Data analysis

We used the extracted data, based on all papers, including strategy 1 and 2, to build an overview of the decision characteristics and examples of decisions. One researcher

(DH) categorized the decision characteristics based on their similarity, and two other researchers checked the categorization (AH and MG). Inconsistencies were discussed until consensus was reached. In the results, we provide decision characteristics, decision examples and arguments of all papers (both strategy 1 and 2) in a descriptive way. We tried to describe the decision characteristics and decision examples as concretely as possible, while staying close to the original authors' wording.

We counted how often decision characteristics were mentioned in the papers included in strategy 1. We excluded the papers from strategy 2 in this calculation, because we had purposely included decision characteristics in building the search for strategy 2. Quality and risk of bias of all included studies were not assessed, because we aimed to be inclusive of the different views of authors, which is not in line with excluding views based on formal bias/quality assessments. Ethical approval was not required for this study. This review was registered at PROSPERO: CRD42021236297.

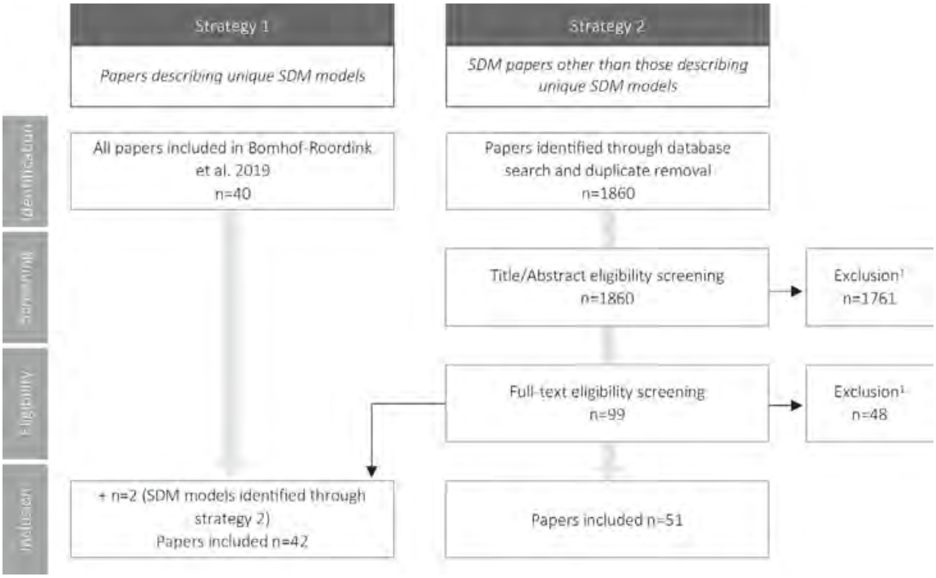


Figure 2. Flow diagram of the inclusion process of relevant papers

[1] Reasons for exclusion: Paper not written in English, French or Dutch or paper does not contain explicit statements describing the authors' view on decision characteristics making SDM appropriate or not. Papers that had already been identified based on strategy 1 were excluded in strategy 2.

3. Results

3.1. Included papers

We included the 40 papers describing an SDM model from the review of Bomhof-Roordink et al. [1]. Two papers, each describing a unique SDM model, were added from the search of strategy 2 [14,15] (**Fig. 2**). The authors of half of the papers on SDM models (n = 21) explicitly stated for what kind of decisions they considered their SDM model to be appropriate [5,11,14–32]. In 19 papers they only implicitly mentioned when they considered SDM appropriate [2,4,33–49]. For example, these authors implied that their SDM model was appropriate for certain decisions by providing decision examples containing specific decision characteristics. Two papers did not mention when their SDM model is appropriate [50,51].

Strategy 2 yielded 1860 papers, of which 51 were included (**Fig. 2**). Eight original studies were included, mostly qualitative [52–59] (**Table 1**). Other papers were reviews (n = 17) [60–75] or other non-empirical papers [9,10,76–100].

Table 1. Overview of included papers

Author, publication year [ref]	Country	Study design/type of paper	Setting Paper
	Papers describing SDM models (strategy 1)		
Bomhof-Roordink et al. 2019 [48]	The Netherlands	Qualitative: interviews	Oncology
Caverly et al. 2020 [14]	USA	Non-empirical paper	Primary care
Charles et al. 1997 [11]	Canada	Non-empirical paper	Early stage breast cancer treatment
Charles et al. 1999 [30]	Canada	Non-empirical paper	Early stage breast cancer treatment
Chor et al. 2019 [22]	USA	Non-empirical paper	Gynaecology: asymptomatic non pregnant women
Dobler et al. 2017 [27]	USA	Non-empirical paper	Lung cancer screening
Eliacin et al. 2015 [41]	USA	Qualitative: interviews	Mental healthcare
Elwyn et al. 2000 [43]	UK	Qualitative: focus groups	Primary care
Elwyn et al. 2012 [4]	UK	Non-empirical paper	Not specified
Elwyn et al. 2013 [44]	UK, USA, Canada	Non-empirical paper	Not specified
Elwyn et al. 2017 [51]	USA, UK	Qualitative and quantitative: commentary, review, survey	Not specified
Gillick et al. 2015 [20]	USA	Non-empirical paper	Not specified
Grim et al. 2016 [35]	Sweden	Qualitative study: focus groups	Mental healthcare
Jansen et al. 2016 [26]	Australia	Non-empirical paper	Elderly care (polypharmacy)
Joseph- Williams et al. 2019 [39]	UK	Qualitative: observation of consultations	Chronic kidney disease and early stage breast cancer
Kane et al. 2014 [24]	USA	Review	Oncology
Karkazis et al. 2010 [25]	USA	Non-empirical paper	Decisions about genital surgery for disorders of sex development
Langer et al. 2018 [31]	USA	Non-empirical paper	Psychotherapy youth and families
Légaré et al. 2011 [40]	Canada	Non-empirical paper	Primary care
Légaré et al. 2011 [46]	Canada	Qualitative design: interviews	Primary care
Lenzen et al. 2018 [29]	The Netherlands	Non-empirical paper	Primary care
Lown et al. 2009 [47]	USA	Qualitative design: working groups	Chronic conditions and primary care
Makoul et al. 2006 [2]	USA	Review	Not specified
Montori et al. 2006 [17]	Canada	Non-empirical paper	Chronic care
Moore et al. 2018 [18]	USA	Non-empirical paper	Physiotherapy
Murray et al. 2006 [16]	UK, Canada	Non-empirical paper	Primary care
Navar et al. 2016 [15]	USA	Review	Cardiovascular disease prevention

Table 1. *(Continued)*

Author, publication year [ref]	Country	Study design/type of paper	Setting Paper
Ng et al. 2019 [23]	Malaysia	Non-empirical paper	Primary care (complex multimorbidity)
Park et al. 2018 [19]	South Korea	Review	Paediatric care
Peek et al. 2008 [101]	USA	Qualitative: interviews	Diabetes
Probst et al. 2017 [32]	USA	Non-empirical paper	Emergency department
Probst et al. 2018 [21]	USA	Non-empirical paper	Emergency cardiovascular care
Rennke et al. 2017 [42]	USA	Non-empirical paper	Inpatient hospital setting
Rusiecki et al. 2018 [36]	USA	Quantitative: pre-post surveys	Not specified
Saidinejad et al. 2018 [34]	USA	Non-empirical paper	Paediatric emergency department
Shay et al. 2014 [37]	USA	Qualitative: interviews	Primary care
Simon et al. 2006 [49]	Germany	Qualitative and Quantitative: Delphi method and survey	Depression, gynaecology, primary care, urology, anaesthesia
Stiggelbout et al. 2015 [5]	The Netherlands	Non-empirical paper	Not specified
Towle et al. 1999 [33]	Canada	Qualitative: interviews	Not specified
Truglio-Londrigan et al. 2018 [28]	USA	Review	Not specified
Van de Pol et al. 2016 [45]	The Netherlands	Qualitative: Delphi method	Elderly care
Volk et al. 2014 [50]	USA	Quantitative: pre- post surveys	Primary care
SDM papers not describing SDM models (strategy 2)			
Anagnostou et al. 2020 [60]	USA	Review	Paediatric allergy care
Armstrong et al. 2019 [96]	USA	Non-empirical paper	Disorders of consciousness
Bailo et al. 2019 [77]	Italy	Non-empirical paper	Not specified
Barry 2012 [78]	USA	Non-empirical paper	Not specified
Blaiss et al. 2019 [61]	USA	Review	Allergology
Clarke et al. 2004 [52]	USA	Qualitative: interviews	Congestive Heart Failure
Colligan et al. 2017 [62]	USA	Review	Multiple sclerosis
De Ligt et al. 2019 [63]	The Netherlands	Review	Breast cancer
Deegan et al. 2014 [79]	USA	Non-empirical paper	Mental healthcare
Drake et al. 2009 [80]	USA	Non-empirical paper	Mental healthcare
Elwyn et al. 1999 [58]	UK/The Netherlands	Qualitative: discourse analysis	Primary care
Elwyn et al. 2009 [81]	USA/UK	Non-empirical paper	Not specified
Elwyn et al. 2014 [83]	UK	Non-empirical paper	Not specified
Engelhardt et al. 2016 [55]	The Netherlands	Qualitative/quantitative: coding of consultations	Breast cancer

Table 1. *(Continued)*

Author, publication year [ref]	Country	Study design/type of paper	Setting Paper
Forner et al. 2020 [64]	Canada	Review	Head and neck oncology (surgery)
Greenhawt et al. 2020 [75]	USA	Review	Food allergy care
Gwyn et al. 1999 [59]	UK	Qualitative: discourse analysis	Primary care
Hamann and Heres. 2014 [82]	Germany	Non-empirical paper	Mental healthcare
Herlitz et al. 2016 [65]	Sweden	Review	Chronic care in general
Jansen et al. 2019 [53]	Australia	Qualitative: interviews	Elderly care
Kahlert et al. 2018 [66]	Switzerland	Review	Breastfeeding HIV infected mothers
Kon et al. 2016 [98]	USA	Non-empirical paper	Intensive Care Unit
Kraus et al. 2016 [67]	USA	Review	Emergency department
Langford et al. 2019 [74]	USA	Review	Hypertension management
Martínez-González et al. 2018 [68]	Switzerland	Review	Prostate cancer
Matthias et al. 2020 [54]	USA	Qualitative: interviews	Primary care
Mercuri et al. 2020 [84]	Canada	Non-empirical paper	Not specified
Mistler et al. 2008 [85]	USA	Non-empirical paper	Mental healthcare
Moulton et al. 2020 [86]	USA	Non-empirical paper	Enrolment in research
Narayan et al. 2015 [69]	USA	Review	Elderly care
Nelson et al. 2014 [87]	Canada	Non-empirical paper	Children with severe neurologic impairment
Niburski et al. 2020 [70]	Canada	Review	Surgery
Opel et al. 2018 [76]	USA	Non-empirical paper	Paediatric care
Palace et al. 2013 [88]	UK	Non-empirical paper	Multiple sclerosis
Pickrell et al. 2015 [89]	UK	Non-empirical paper	Epilepsy
Politi et al. 2013 [71]	USA	Review	Not specified
Politi et al. 2012 [90]	USA	Non-empirical paper	Oncology
Politi et al. 2013 [72]	USA	Review	Not specified
Pynnonen et al. 2014 [91]	USA	Non-empirical paper	Head and neck surgery
Shaw et al. 2020 [100]	UK	Protocol paper qualitative study	Major surgery
Turnbull et al. 2016 [56]	USA	Qualitative: Delphi method	Intensive Care Unit (non-emergent care)
Ubbink et al. 2015 [92]	The Netherlands	Non-empirical paper	Surgery
Van Beek- Peeters et al. 2020 [73]	The Netherlands	Review	Elderly patients with symptomatic severe aortic stenosis
Waldron et al. 2020 [97]	Canada	Review: realist synthesis	Not specified

Table 1. *(Continued)*

Author, publication year [ref]	Country	Study design/type of paper	Setting Paper
Weiss et al. 2019 [93]	USA	Non-empirical paper	Paediatric care
Whitney 2003 [9]	USA	Non-empirical paper	Not specified
Whitney et al. 2003 [10]	USA	Non-empirical paper	Not specified
Whitney et al. 2006 [94]	USA	Non-empirical paper	Paediatric oncology
Whitney et al. 2008 [95]	USA	Non-empirical paper	Not specified
Woolf et al. 2001 [99]	USA	Non-empirical paper: editorial	Not specified
Zhuang et al. 2020 [57]	USA	Qualitative: Delphi method	Carpal tunnel syndrome surgery

3.2. Decision characteristics

In total, 18 decision characteristics were identified for which authors considered SDM appropriate and seven decision characteristics for which it was not. Authors disagreed on four decision characteristics, namely decisions with *one best option*, *weight of the decision being light* (decisions that are considered 'minor' or 'not important'), decisions with *a trade-off between individual impact and public benefit* and decisions to be made *in a short time frame*. Some authors described these as decision characteristics for which SDM is appropriate while others described them as inappropriate for SDM. See **Supplement 2** for a full list of the decision characteristics, decision examples, and the settings in which the decisions were mentioned. In the next paragraphs we will elaborate on the decision characteristics identified.

3.3. Decision characteristics for which SDM is deemed appropriate

3.3.1. Preference-sensitive

Preference-sensitive was frequently mentioned as a decision characteristic that makes SDM appropriate. The definition that the authors provided for this term differed. Therefore, we extracted the features that authors mentioned (**Table 2**). **Supplement 2** contains the complete descriptions that authors gave of preference-sensitive. Preference-sensitive decisions were most often described as bearing *multiple options* or *multiple reasonable options*. In some papers, this was the only feature mentioned [20,23,82,85,95,100]. Other authors further specified that the options entail a *trade-off of risks and benefits* [32,62,68,72,79] and/or that the *decision depends on patient preferences* [22,24,25,53,55,60,63,64, 72,76,81,90,98]. The options in preference-sensitive decisions were stated to be *valued differently between patients* [19,53,64,74,88] or to *differ between patients and healthcare professionals* [77]. Other features mentioned were *limited evidence* [5,53,69,88], *uncertainty around outcomes* [14,55,64], and *equipoise* [5,64,71,88]. Some authors referred to the *impact on patients' lifestyle* and the *need for patient cooperation for implementing the decision*, as features of preference-sensitive decisions [56,63]. Others described preference-sensitive as a *trade-off in which length and quality of life, preservation of bodily integrity, prevention of future problems, costs, and convenience* should be considered [9]. Lastly, authors indicated that in case of 'a clearly better option', the decision can still be preference-sensitive because of the *ensuing risks or burden* [69], or when *preferences around decisions vary per patient* [64]. Examples of preference-sensitive decisions included treatment decisions in breast cancer [9,24,55,63,81,95], decisions regarding prostate cancer screening [68,72,90,95], hypertension treatment decisions [74], and drug choice in mental healthcare [79,82,85]. **Supplement 2** contains more examples. Some authors used the term *value-sensitive*. In this decision characteristic the emphasis lies on patients' religious, moral and other values, as well as philosophical beliefs, that lead to varying preferences among patients and thus making SDM appropriate, for example the decision for genetic prenatal screening [9].

The arguments for SDM being applicable in preference-sensitive decisions were often related to the ethical imperative to include patients in these decisions [22,28,80,85], or as a means to achieve patient-centred care [53,85]. Additionally, SDM was mentioned as a conversation process that can help in exploring patients' values and preferences [96], and aligning them with the best available clinical evidence [57]. Another argument was that clarifying preferences through SDM is needed because clinicians cannot, and should not, presume patient preferences as they may misperceive them [62,99]. If not prompted as in SDM, patients may not express their preferences because clinicians do not make explicit that their preferences are relevant, or patients (wrongfully) assume clinicians know their preferences [53].

Table 2. Features of the term 'preference-sensitive'

References	Core features of authors' descriptions of 'preference-sensitive'
[20,23,82,85,95,100]	Multiple reasonable options
[24,25,75,98]	Choice depends on personal preferences and values of patient
[22,72,76,90]	Multiple reasonable options, decision depends on patient preferences
[74]	Multiple reasonable options, decision depends on patient preferences, which vary per patient
[88]	Multiple reasonable options each with benefits and disadvantages and may vary in scientific certainty (i.e. where equipoise exist); this is valued differently per patient
[77]	Multiple reasonable options (evidence uncertain), patient views on benefits and risks vary per patient or differ from those of healthcare professionals

Table 2. *(Continued)*

References	Core features of authors' descriptions of 'preference-sensitive'
[19]	Multiple reasonable options, benefit and risks valued differently by patients
[32,62,68,79]	Multiple reasonable options with trade-off risks and benefits
[55]	Multiple reasonable options with trade-off risks and benefits where patients preferences should adjudicate, uncertainty which patients might benefit
[60,81]	Multiple options with trade off harms and benefits, decision dependent on values and personal preferences patient
[63]	Multiple options with trade-off risks and benefits, options comparable in outcomes, insufficient evidence what's the best option, outcomes highly dependent on patient cooperation/high impact patient's lifestyle
[5]	Multiple options, evidence lacking or equipoise, only patient preferences can adjudicate
[69]	Multiple options (no clear evidence) or clear evidence but benefit in tandem with risks or burdens
[56]	Criteria: multiple options with trade-off risks and benefits, options comparable in outcomes, insufficient evidence what is the best option, outcomes highly dependent on patient cooperation/ high impact patient's lifestyle
[9]	Trade-off including considerations related to length- and quality of life or preservation of bodily integrity, prevention of future problems, cost, and convenience
[14]	Uncertainty outcomes and individual preferences
[71]	Equipoise between treatment options with equal or similar outcomes from a medical standpoint
[64]	Equipoise or substantial uncertainty effect of treatment or: clear option, but values vary per patient
[53]	Evidence benefit and harms limited, decision depend on weighing many factors, option depends on how outcomes are valued, for which preferences vary widely

3.3.2. Equipoise

Another frequently mentioned decision characteristic that makes SDM appropriate was *equipoise*. Again, authors' definitions differed and we extracted the features (**Table 3**). Supplement 2 shows the complete authors' descriptions of the term equipoise. The most often mentioned feature of equipoise was that it entails decisions with *multiple options* or *multiple reasonable options* [18,28,59,70,89], similar to preference-sensitive decisions. Other authors added that these options are *dependent on patient preferences* [31,32] and/or have to be *in balance* [31,66,81,88]. The existence of a reasonable balance between options in a situation with equipoise was described in one paper as: "*when a majority of people would agree that it is reasonable to consider making a choice between competing options*" [81]. Others described equipoise as multiple options from which *potential benefits and disadvantages need to be weighed* [40,46] or more simply as decisions with *not one best option* [18,28,59, 70] due to limited evidence [18]. Examples of equipoise decisions included decisions regarding anticoagulation for patients with new-onset atrial fibrillation [21] and decisions regarding breastfeeding by HIV-infected mothers with low viral load [66]. Some authors who used the term '*clinical equipoise*' included the *uncertainty on the potential benefits and disadvantages of the options* in their description [89], for example in the choice of medication in epilepsy treatment [89]. '*Professional equipoise*' was described as decisions where 1) *clinicians deem there is no best choice* [43], 2) *"where there is consensus among clinicians that there is no superior option"* [81], *3) patients have 'freedom' to choose* between options [58,59], or 4) as a precondition for '*dual equipoise*': a situation in which both clinicians and patients agree that all options are in balance and patient preferences are paramount to decide [58].

Table 3. Features of the term 'equipoise'

References	Core features of authors' descriptions of 'equipoise'	Used term
[40,46]	Multiple options (including maintaining status quo) for which potential benefits and disadvantages need to be weighed	**Equipoise**
[28]	Alternative options (based on evidence)	**Equipoise**
[31]	Multiple options with equal effectiveness, dependent on patient preferences	**Equipoise**
[70]	Multiple options, not one best option	**Equipoise**
[18]	Multiple options, not one best option (because of conflicting or inadequate evidence)	**Equipoise**
[59]	Multiple reasonable options	**Equipoise**
[32]	Multiple reasonable options dependent on patients values and preferences	**Equipoise**
[88]	Multiple reasonable options with trade off benefits and disadvantages, may vary in scientific uncertainty	**Equipoise**
[58]	Reasonable balance in benefits and disadvantages of options: when a majority of people would agree that it is reasonable to consider making a choice between competing options	**Equipoise**
[66]	Balance in benefits and disadvantages of options	**Clinical Equipoise**
[89]	Multiple reasonable options in clinical situations	**Clinical Equipoise**
[86]	Uncertainty potential benefits and disadvantages	**Clinical Equipoise**
[81]	Both healthcare professionals and patients agree that all options are in balance and patient preferences are paramount	**Dual Equipoise**
[43]	In clinicians point of view there is no best choice	**Professional Equipoise**
[58,59]	Multiple options, patient 'free' to choose	**Professional Equipoise**
[81]	Consensus among clinicians that there is no superior option, as a pre-condition for dual equipoise	**Professional Equipoise**

In summary, both the terms preference-sensitive and equipoise share an important key element: the decision has multiple (reasonable) options. The multitude of options are a result of having comparable options in terms of risks and benefits, or existing uncertainty about which option may be best. With the term 'equipoise' the emphasis is on having multiple options and those options being somewhat in balance. A preference-sensitive decision may also contain these elements, but is further portrayed as depending on patient preferences, and the possibility that patients may value the options differently. A preference-sensitive decision may contain equipoise, but this is not a requirement. A decision with equipoise on the other hand, could be considered a preference-sensitive decision, in most or all cases.

3.3.3. Multiple options

In addition to being mentioned as a feature of 'equipoise' and 'preference-sensitive', the availability of multiple options was also mentioned independently as a decision characteristic for which SDM is considered appropriate, and described as a decision with: *multiple options* [25,31,44,70,83,97], *multiple options with different possible outcomes* [11,19,30,54] or *multiple reasonable options* [4,5,24,33,61,76,78,92,94]. Foregoing active treatment may also count as a reasonable option [4, 30]. Authors described decisions with *no best option* as a specific form of decisions with multiple options for which SDM was deemed applicable [11,25,61,87,91,94]. These decision situations entail no superior option, for example whether or not to perform a tonsillectomy on a child with recurrent throat infection [91].

3.3.4. Uncertainty

Uncertainty around the decision was another decision characteristic that was frequently mentioned [9,10,28,48,90,96]. A further distinction can be made between *uncertainty about evidence* and *uncertainty about outcomes* of decision options. The authors described *uncertainty about evidence* as situations in which evidence about options was limited, conflicting or lacking [19,24,25,27,71,87,90,92]. Examples are introduction of new technologies in surgery [92] and children with severe neurologic impairment [87]. Uncertainty can also originate from the difficulty to apply evidence, often deriving from well-controlled trials among highly-selected patient populations, to individual patients [72, 90]. *Uncertainty about outcomes* relates to uncertainty about what the outcome of the decision will be and how outcomes might impact physical and physiological wellbeing [11,30,72]. Some authors proposed that regardless of the severity of decisions, SDM is appropriate when there is uncertainty [10]. For example, both high-risk decisions, e.g. mastectomy versus lumpectomy in treating breast cancer, and low-risk decisions, e.g. lifestyle changes versus hyperlipidaemia medication, contain uncertainty and therefore SDM was deemed appropriate [10].

3.3.5. Trade-off

Authors proposed that SDM is appropriate in decisions characterized by containing trade-offs. Examples included trade-offs in the advantages and disadvantages of genital surgery for children with disorders of sex development [25] and of cancer screening [14].

3.3.6. High impact of decision

High impact decisions may have serious implications for health outcomes or quality of life [24]; hold effects that emerge over time and contain multiple life domains [35]; entail potentially major harmful effects [27,48,90,100]; have consequences that are immediate and important [17]; impact family members/loved ones [75,87]; or heavily influence daily routines [70,79,87]. Some authors described SDM to be applicable in 'major' [14] or 'high stake' decisions [33,94,97]. Authors of one paper proposed 'detailed SDM' versus 'everyday SDM' to be appropriate for, respectively, major decisions and substantive everyday decisions. 'Everyday SDM' focuses on eliciting individual patient preferences but in a less detailed process than 'detailed SDM' [14]. Examples of substantive everyday decisions include: at what age to initiate breast cancer screening or prescribing cardiovascular preventive medicine [14]. Related to decision impact is a decision's *irreversibility*, which was mentioned as a decision characteristic where SDM is deemed appropriate [70,81]. The irreversible impact of decisions in surgery for example, can potentially result in a radical life and health status change, making SDM especially important [70].

3.3.7. Patient commitment needed

Multiple authors identified decisions that require patient commitment for carrying out the treatment as decisions for which SDM is appropriate. Requiring such patient commitment particularly applies in (lifestyle) decisions in chronic care. Authors argued that an increase in patients' involvement in decision making can stimulate patients to implement the decision [16,17,31]. In addition, SDM can help to align treatment options with individual patients needs and circumstances, and in turn positively affect treatment adherence [17,31,61,66,76]. With similar reasoning, authors advised practicing SDM in decisions requiring significant time commitment of patients, such as physiotherapy for chronic pain [54] or decisions regarding food allergy [60]. In addition, patient-clinician relationship, creating a situation in which patients feel safe to express their worries and beliefs. This enables to jointly identify the best fitting treatment, to which the patient is likely to adhere [66].

It was further argued that the involvement of patients in decision processes is essential when patients need to implement decisions in their own space and with their own resources. Patients know best how to evaluate options in terms of how realistic and feasible they are for the patient to carry them out [17]. Exploring patients' potential barriers for implementing the decision is especially important when decisions are *reversible*. Therapy adherence may be more difficult for patients if they have the possibility to revisit decisions over an extended period of time without immediate harm, for example decisions on hypertension treatment [17].

3.3.8. Decisions known to often entail misalignment in views

Different authors considered SDM appropriate for decisions for which it is known *beforehand* that clinicians' and patients' views are likely to be misaligned and each perspective needs to be considered. Examples included planning psychotherapy in youth mental health [31] and non-emergent decisions in the intensive care unit which are possibly incompatible with common patient goals, such as offering a permanent feeding tube or placing a suprapubic urinary catheter [56]. Enrolment in clinical research intrinsically contains misalignment between the researchers' and patients' views because of competing interests. An alternative form for SDM was proposed here, focusing mainly on properly informing the patient and explicating the alignment of different options with patients' personal contexts and overall goals [86].

3.3.9. Every decision

Some authors considered SDM to be appropriate in every decision [28,62,79,86,92]. To illustrate, it was proposed that in surgery: "*all delivered care decisions independent of the level of evidence regarding treatment options or presence of equipoise SDM should be practiced"* [92]. Other authors nuanced this position by stating that in every decision reasonable attempts for SDM should be made [67] or that SDM is most commonly applied in decisions with clinical uncertainty, but can also be applied in decisions with certainty [62].

Tables 4 and 5 offers an overview of all the decision characteristics identified. In green, it shows the variety of decision characteristics for which SDM was deemed appropriate and how often these were mentioned in papers describing SDM models (strategy 1). The most frequently mentioned decision characteristics (*preference-sensitive*, *multiple options* and *equipoise*) for which SDM was deemed appropriate had overlap; they all portrayed the presence of multiple (reasonable) options'. Other frequently-mentioned decision characteristics also related to the availability of multiple options: *trade-off* and *uncertainty*. Regardless of how decisions with multiple options are described or phrased, it clearly is deemed an important indicator for the appropriateness of SDM. Other decision characteristics did not relate to the number of options of the decision, such as: *decision impact*, *who is implementing the decision*, or the *reversibility/time frame* in which a decision can be made.

SDM deemed appropriate

- Preference-sensitive (11)[1]
- Multiple options (11)
- Equipoise (10)
- Impact of decision is high (7)
- Patient commitment is needed to carry out the decision (5)
- Uncertainty of evidence (4)
- Uncertainty of outcomes (4)
- Trade-off involved in decision (2)
- Uncertainty (2)
- No best option (2)
- One best option but likely to disagree (1)
- Known to often entail misalignment in views (1)
- Every decision (1)
- Reversibility of decision (1)
- Weight of the decision (heavy)
- Long time frame to make decision
- Irreversibility of decision
- Value-sensitive

SDM deemed appropriate vs NOT appropriate in different papers[2]

- One best option (3)
- Weight of the decision (light) (1)
- Trade-off between individual impact and public benefit
- Short time frame to make decision

SDM deemed NOT appropriate

- No equipoise (1)
- Patient request for therapy in conflict with clinician's judgment
- Immediate life-saving measures needed
- Potential threat for public safety
- Options restricted by legal/institutional policies
- Clinician implements decision (based on clinical expertise)
- Behaviour change needed to carry out decision

Table 4. Overview of decision characteristics identified

[1] (number) = in how many papers the decision characteristic was mentioned, only counted in papers describing SDM models (strategy 1). Decision characteristics without a number are only mentioned in papers included through strategy 2.

[2] Decision characteristics both identified as a decision characteristic for which SDM is appropriate and for which it is not appropriate according to different authors

3.4. Decision characteristics on which authors differed regarding whether they deem SDM appropriate or not

3.4.1. Weight of the decision

Decisions described as ‘major’ [78,96,98], ‘complex’ [73], or ‘important’ [57] were all considered as decisions for which SDM is appropriate. Examples of such decisions included: hip replacement to manage pain, treatment for newly-diagnosed breast or prostate cancer [78], starting immunomodulatory therapies for multiple sclerosis [88], or surgery for carpal tunnel syndrome [57]. However, some authors argued that SDM is also applicable in case of other decisions that might be less ‘major’, as long as they entail multiple reasonable options with different side-effects and benefits. This was illustrated with the choice of cholesterol-lowering therapy for patients with no known coronary heart disease [78]. Other authors referred to the need for both patients and clinicians to become proficient in SDM, starting with minor decisions: “*We are not surprised that patients shun making decisions about treatment for breast cancer if their prior experience gave little opportunity or encouragement in relatively minor medical situations*” [33].

Yet other authors argued that some decisions can be so unimportant from a clinical perspective, that even when it may be appropriate to apply SDM because of the available multiple options with similar effects, it can be unfeasible to apply SDM for these decisions. An example included the decision between a cotton elastic compression wrap or a soft padding bandage in case of orthosis [57].

3.4.2. Time frame to make decisions

Some authors considered a *long time frame* to make decisions as a decision characteristic making SDM appropriate [56]. Having a *short time frame* to make decisions was mentioned both as a decision characteristic making SDM appropriate [67,81,97] and inappropriate [21, 32]. Examples of decisions for which authors considered SDM appropriate even though there is a short time frame to make the decision, are do-not-resuscitate decisions and cyanoacrylate versus sutures in treating wounds [67]. These authors further indicated that SDM is ‘*an ethical imperative, especially in the emergency department’* [67].

Other authors deemed SDM not appropriate when decisions must be made quickly and in an emergency setting [21,32]. They mentioned that SDM was only appropriate when all of the following criteria were met: 1) clinical equipoise, 2) adequate/sufficient patient decision-making ability and 3) sufficient time. If one criteria is not met, other decision-making approaches apply, such as persuasion, informed consent, or physician-directed decision-making. An exception includes treatment that is incongruent with patients' goals, such as performing intubation to a terminally-ill patient in respiratory distress [32].

3.4.3. Decisions with one best option

Several authors argued that SDM can still be appropriate when only one best option exists. This may be the case when the decision encompasses other decisions that may be malleable and suitable for SDM, e.g. decisions about specifying treatment goals and deciding who to include as treatment participants in youth psychotherapy [31]. SDM was also deemed applicable for decisions with one best option when illness severity is low, for example the decision about starting an antihistamine for mild seasonal allergies [76]. Moreover, decision situations with one best option in which it *is known beforehand that patients and clinicians are likely to disagree*, may benefit from SDM [31,82]. SDM was considered to improve the decision process by integrating evidence whilst informing the patient and elucidating the patients' perspective, which might differ from clinicians' [18,31,34]. For example, a mother demanding antibiotics for her child with a viral upper respiratory infection might come to understand the options better through an SDM process, and therefore more easily accept discharge without antibiotics [34]. However, other authors, using the same example of prescribing antibiotics for a viral respiratory infection, argued that it is not yet known whether SDM is effective or practical in such a decision entailing disagreement. At the same time, they also emphasize that the underlying communicative elements of SDM might benefit these decision situations and possibly prevent unnecessary antibiotic prescribing [58]. Following the same reasoning, some authors suggested that the steps of SDM should be followed in decisions with one best option, particularly the exploration of preferences. However, eventually clinicians may nudge patients according to their view [76]. Such a process was described by others as*: 'an informed decision engineered according to doctor preference*' in which the SDM process is not fully neglected, but ultimate decisional authority lies with the clinician in case of a possible 'incorrect' decision [59]. Authors of one paper identified a common set of communication skills from both SDM (in particular how to assist patients in identifying or developing their preferences), motivational interviewing and negotiation for decisional situations with one best option, which they named 'SDM-PLUS' [82].

Other authors considered decision situations with one best option as decisions in which SDM is inappropriate [9,10,32,62,78,81,91,94,95, 99]. Examples included decisions in medically threatening situations, such as antibiotics for sepsis, hospital admission for acute myocardial infarction, and melanoma resection [10,32,62,95,99]. Authors explained that SDM does not apply/is not required in these situations entailing high risk, because there is no 'real' choice [9,10,99]. Instead, an informed consent process is required [10], and negotiation and persuasion might be needed [32,95]. Especially when there is a high change of cure (with the best option), a clinician recommendation instead of SDM is considered 'ethically justifiable' [94]. Authors emphasize the importance of adequately informing patients in these processes [32,91,95]. The authors' choice of decision examples implied that refraining from doing the 'best treatment option' can cause harm to the patient, but this was not explicitly stated. An exception where SDM might still apply was mentioned in one paper: when religious beliefs go against the dominant choice, for example, an adult Jehovah's witness refusing blood transfusion because he believes this may jeopardize his chance on eternal life [95].

Decision examples with one best option and entailing low risk were also mentioned, such as lowering a diuretic because of high potassium levels [10]. Here, 'simple consent', a less extensive version of informed consent, was deemed sufficient [10]. Lastly, for decisions in managing chronic condition, which may often entail one best option, authors proposed that other strategies, such as motivational interviewing [78, 81], or even persuasion [78], might be a better fitting approach than SDM, and SDM '*might not be worth the investment*' [81].

3.4.4. Trade-off between individual impact and public benefit

A special form of trade-off in decisions that authors mentioned was a *trade-off between individual impact and public benefit*, for example in decisions regarding vaccinations [72]. An argument for practicing SDM in these situations was that SDM can help make sense of available data and communicate the difference between population- and individual-based estimates of risks and benefits [72]. Other authors argued that it may be justifiable not to apply SDM to these decisions when potential public health benefits outweigh individual burden, particularly in case of emergency [93]. They noted however that assessing this balance is difficult. This was illustrated by the decision whether or not to perform diagnostics on a child with bloody stool when there is suspicion for an E. coli outbreak; the minimal benefit and potential hassle in collecting stool for the patient and parent should be balanced against the potential public health benefit [93].

In summary, most ambiguity occurred regarding the decision characteristic '*decisions with one best option*'. SDM might be beneficial in these decisions when SDM elements such as sharing information and exploring preferences are effectively incorporated in the conversation. However, when there is a possibility of choosing a 'wrong' option, it is questioned whether the ultimate decisional responsibility truly lies with both the patient and the clinician, or rather with the clinician alone. Clinician-directed decision making strategies may be justified whilst still incorporating important (communicative) elements of SDM. Although major decisions were more frequently associated with SDM, minor decisions were also considered appropriate for SDM; as long as multiple reasonable options exist. Again, this was only considered so to some degree: decisions that are too unimportant were considered unfeasible to share. Authors did not state criteria for determining the weight/ importance of decisions. Lastly, in decisions to be made in a short time frame, SDM might still be appropriate or even needed, unless medical urgency limits the time available for SDM. In the latter situation, SDM is potentially harmful and not appropriate, unless the treatment is incongruent with patients' goals.

3.5. Decision characteristics for which SDM is deemed NOT appropriate

3.5.1. Patient request for therapy in conflict with clinician's judgment

Authors deem SDM inappropriate when patients and clinicians hold conflicting views *at the time* of decision making. Reasons for such conflicts may be inappropriate patient requests, or inappropriate patient responses to medical situations. Examples include medically futile aggressive treatments in the face of inevitable death [67], excessive opioid prescriptions [54,67], and antipsychotic medication management [85]. In these situations, different authors believed SDM not to be possible [67], to be inappropriate [98], or challenging [54]. Clinical judgment may overrule inappropriate patient requests [54,98] or requests incompatible with best patients' interest [67,85]. Authors proposed conflict resolution strategies instead of SDM [98], or informing patients on the clinician's' decision and offering alternatives if appropriate, such as a care transfer [67].

3.5.2. Immediate life-saving measures needed

Multiple authors considered SDM not appropriate when the decision is made under circumstances in which immediate life-saving measures are needed, such as: acute surgery decisions [70]; starting antibiotics for bacterial meningitis [62]; or cardiopulmonary resuscitation for an acutely instable patient [56]. In these examples, delaying treatment initiation is potentially harmful. SDM is also considered 'logistically impractical' when a patient is acutely unstable [56]. Authors suggested to weigh per situation, whether time is crucial for life-saving measures or there is time to discuss options [70]. Others suggested that in making these decisions, patients should rather be informed than invited to participate [62]. Furthermore, authors recommend to discuss potential future (emergent) treatments prospectively as part of advance care planning [56].

3.5.3. Potential threat for public safety

SDM was not considered applicable and even potentially harmful in case decisions may impact public safety, or patients' own safety [82,85]. Examples included discharging suicidal patients [82] or starting antipsychotic treatment in psychotic patients [85]. A paternalistic or directive approach was deemed needed in these cases [82,85].

3.5.4. Options restricted by legal and/or institutional policies

SDM could be constrained when legal or institutional policies restrict choice, as is the case in opioid prescribing [54], and whether or not to use extracorporeal life support (ECLS) in children with submersion injury [93]. Practice variation in the use of ECLS across paediatric centres indicates that there is not one best option, but since it is a scarce resource, its availability overrules the ability to employ SDM [93].

3.5.5. Clinician implements the decision (based on clinical expertise)

Multiple authors considered SDM logistically impractical [98] or even 'absurd' [93] in routine care decisions based on clinical expertise, such as the choice of vasoactive drip rates in the intensive care unit [98] or the frequency of checking vital signs [93]. In decisions that the clinician implements and for which the clinician is primarily responsible, the success of the implemented therapy can be a function of the clinician's expertise. A clinician may hold particular experience and comfort with the different options, which may possibly affect the success of implementing the decision. For these decisions, such as the choice of ketamine versus propofol to sedate patients for fracture reduction [76], more 'provider-oriented' rather than 'shared' - decision making was considered justified [76].

3.5.6. Patient behaviour change necessary

When patient behaviour change is needed, motivational interviewing may be more appropriate than SDM [83]. The authors provided the example of whether or not to perform gastric bypass surgery for weight reduction. They considered SDM not applicable if the patient was not yet willing to lose weight, and first deemed a behaviour change process necessary [83].

To summarize, the original authors clearly agreed that in urgent situations in which life-saving measures are needed, and/or there is a potential threat for the patient's or public safety, SDM is not appropriate and can even be harmful. A clinician directive approach is then needed. SDM might not be harmful, but rather impractical or unnecessary in decisions based on clinical expertise and implemented by the clinician (technical decisions) or when decisions ask for other conversation strategies because behaviour change is needed. Lastly, SDM can be restricted when a patient's request is in conflict with clinicians' judgment or when the decision is constrained by legal or institutional policies.

3.6. The settings of the decision characteristics

The decisions and decision characteristics identified in this review were collected from a broad range of clinical settings. **Table 5** shows how often authors mentioned a particular decision characteristic per setting. Equipoise, preference-sensitive decisions and decisions with high impact were mentioned in the highest number of different settings. Notably, decisions with one best option for which SDM was deemed *appropriate* were mentioned in mental healthcare and paediatric care, whilst decisions with one best option for which SDM was deemed *inappropriate* were most often mentioned in the emergency department, and also in gynaecology, neurology, oncology, primary care and surgery. This might relate to how urgent the decision is, which was mentioned as a limit to the applicability of SDM. Overall, decision characteristics for which SDM was deemed appropriate were most often mentioned in oncology, primary care/chronic care and paediatric care, and those or which SDM was deemed inappropriate were most often mentioned in primary/chronic care, surgery, and emergency care.

Table 5. List of decision characteristics and how often they were mentioned per clinical setting

SDM deemed appropriate	Allergy care	Childbearing mother with disease	Elderly care	Emergency Department	Enrolment research	Gynaecology	Intensive Care Unit	Mental healthcare	Neurology	Oncology	Paediatric care	Physiotherapy	Primary care / chronic care	Surgery / invasive treatment	Urology	Vaccination
Total number of decision characteristics per setting	**8**	**1**	**2**	**7**	**2**	**4**	**6**	**15**	**6**	**46**	**19**	**1**	**29**	**16**	**1**	**1**
Preference-sensitive	2		1	1		1	2	3	2	11	4		6	1		
Multiple options	1							1		8	4		4	3		
Equipoise		1		3	1	2		2	1	4		1	2	1	1	
Impact of decision is high	1			1			1	3		6	2		3	2		
Patient commitment is needed to carry out the decision	3		1					1			1		5			
Uncertainty of evidence										4	3		2	1		
Uncertainty of outcomes										5	1		2			
Trade-off involved in decision								1			1		2	1		
Uncertainty									1	3				1		
No best option										2	2			1		
One best option but likely to disagree								2		1						
Decision known to often entail misalignment in views	1				1		1	1								
Every decision				1												
Reversibility of the decision													1			
Long time frame to make decision							1									
Weight of the decision (heavy)							1		2	1				3		
Irreversibility of the decision														2		
Value-sensitive						1										
One best option								1			1					
Short time frame to make decision				1						1			1			
Weight of the decision (light)													1			
Trade-off individual impact and public benefit																1

Table 5. *(Continued)*

SDM deemed NOT appropriate	Allergy care	Childbearing mother with disease	Elderly care	Emergency Department	Enrolment research	Gynaecology	Intensive Care Unit	Mental healthcare	Neurology	Oncology	Paediatric care	Physiotherapy	Primary care / chronic care	Surgery / invasive treatment	Urology	Vaccination
Total number of decision characteristics per setting				**6**		**1**	**2**	**4**	**2**	**3**	**3**		**7**	**6**		
No equipoise													1			
Patient request for therapy in conflict with clinician's judgment				1				1			1		1			
Immediate life saving measures needed							1		1					1		
Clinician implements decision (based on clinical expertise)							1				1			1		
Decision entails potential threat for public safety								2								
Options restricted by legal/institutional policies								1					1			
Behaviour change needed to carry out decision													1			
One best option				4		1			1	3			3	3		
Short time frame to make decision				1												
Weight of the decision (light)														1		
Trade-off individual impact and public benefit											1					

- *The more saturated the colour, the more frequently a decision characteristic was mentioned in that particular setting.*
- *[Grey shading] = decision characteristic both identified as a decision characteristic for which SDM is appropriate and for which it is not appropriate according to different authors*
- *Mental healthcare includes: mental health in general and specifically in youth*
- *Neurology includes: Multiple sclerosis, epilepsy, disorders of unconsciousness, meningitis*
- *Oncology includes: breast, prostate and head and neck cancer, unspecified, unspecified in paediatric patients*
- *Paediatric care includes: paediatrics in general, emergency, children with severe neurologic impairment, genital surgery children with disorders of sex development*
- *Primary care and chronic care includes: hypertension, pain management, cardiovascular disease management, lifestyle, chronic kidney disease, end-of-life decisions, lung cancer screening*
- *Allergy care includes: paediatric allergy care and food allergy care*
- *Emergency Department includes: cardiovascular diagnoses and care delivered at the emergency department in general*

4. Discussion and conclusion

4.1. Discussion

We explored how authors describe the applicability of SDM depending on how decisions are characterized. Decision characteristics for which SDM was deemed appropriate were often related to a decision having multiple (reasonable options), including 'preference-sensitive decisions' and decisions with 'equipoise'. However, SDM was also deemed appropriate for less 'typical' decision characteristics, such as the effect of the decision in terms of impact and/or the level of patient engagement necessary to implement the decision. Some decision characteristics made SDM seem less appropriate or inappropriate. First, legal or institutional requirements may constrain whether SDM can take place. Second, in technical routine decisions carried out solely by the clinician and/or decisions that are clinically too unimportant, it may be unfeasible to engage in SDM. The challenge therein lies in deciding what those 'technical' and 'unimportant' decisions are, as such qualification may vary across patients. It is yet unknown whether patients would want to be included in technical decisions, which may lead to information overload. This could potentially impede their capacity to engage in decisions for which their input is more important. Overall, caution should be taken in assuming the importance of decisions for patients, and the ideal approach would be to 'just ask them'. However, in the turmoil of daily practice this may be impossible for all decisions. Third, in some decisions, SDM may potentially be harmful. This can be the case when 'wrong' decisions can be made, leading to a potential threat to the patient or to others, and/or when decisions need to be made quickly due to medical urgency. However, even under these extreme conditions, when (life-saving) treatment is incongruent with a patient's goal, SDM may still be needed. This shows the difficulty of determining 'clear-cut' guidelines as to when SDM is (in)appropriate.

This difficulty is further underlined by the ambiguity reflected in decision characteristics that different authors used to describe either as decisions for which SDM is appropriate versus inappropriate. In some cases, even exactly the same decision examples were used to argue for or against the appropriateness of SDM. Differences in definitions of SDM to which the original authors adhered could explain the different viewpoints. To illustrate, some authors reasoned that SDM is appropriate in decisions with one best option entailing (the possibility of) conflict, because elements of SDM can (still) benefit the decision process. Others considered SDM not to be appropriate in this case because even though steps of SDM should largely be followed, eventually the clinician is justified to steer towards the 'better' option, when a 'wrong' decision could be made. The different authors may vary in what they believe should be considered as SDM: following a large part of the process or also ultimately deciding together? Thus, not having a universal definition of SDM [1–3] may have caused some of the ambiguity in these study findings. Original authors used different definitions of SDM, or did not provide a definition. Additionally, some authors proposed different forms of SDM to be appropriate in different decision situations [14,65, 76,86].

Regardless of the SDM definition used and whether authors deemed SDM appropriate or not, the importance of applying core elements of SDM, in particular exploring preferences, and the communicative behaviours needed for these core SDM elements (e.g., listening to the patient and leaving room for the patient to express themselves) was recognized. It can be argued that particular core elements of SDM and underlying communicative behaviours are always important, regardless of the decision to be made. SDM then is not something to be turned 'on' or 'off', but rather a decision-making approach entailing particular communication behaviours that become part of adequate communication during any clinical encounter. This brings us back to the lack of a unique definition of SDM, as it leaves open what should still be seen as SDM? Simply put, clinicians should always thrive for 'good communication' to happen. SDM focuses specifically on the actual and full involvement of patients in decisions that are made about their care. In today's healthcare, we should be careful with the fluidity between the concepts of 'SDM' and 'good communication'. The normality and importance of sharing decisions with patients in today's practice is not fully embraced or implemented yet. Agreeing on a more tangible definition of SDM may allow healthcare culture to change more easily into one in which patients get more say in the care that they receive. When we see SDM as an upgrade of 'a good conversation' the message to implement SDM may spread less effectively. Thus, we do think that a clear and shared idea on what an SDM process entails, or at least its core, would foster its successful implementation in clinical practice.

Core elements of SDM processes have already for a large part been identified [1–3]. A first step forward would be to determine which communicative behaviours are then minimally required to achieve SDM, depending on the decisional situation. For example, is there a different emphasis on certain communication behaviours for 'minor' routine care decisions than for major preference-sensitive decisions? Can agreement be reached regarding what communication behaviours would be minimally required when making decisions for which we found ambiguity whether or not SDM is appropriate? Such a framework would assist clinicians in implementing SDM in their daily encounters. Hargraves et al. developed a framework relevant to this proposition, as it describes different kinds of SDM, including their associated communication strategies, depending on the problem that SDM tries to solve in different (decisional) situations [102,103].

In interpreting the results of this study, it should first be noted that we focused on when original authors considered SDM to be appropriate, not when patients or clinicians prefer SDM or believe it to be appropriate. Evidence suggests that, when asked, patients and clinicians identify comparable decision characteristics to determine the applicability of SDM, such as time available for decision making, number of therapeutic options, and/or available evidence on efficacy [104]. We do not intend to make recommendations to clinicians about whether or not they should try and engage in SDM in particular decision situations. As illustrated above, knowing when SDM is appropriate or not is not an exact science and (communicative) elements of SDM should probably not be fully switched 'on' or 'off'. Furthermore, some authors consider SDM as something to always thrive for, because it can be seen as an ethical imperative to foster patient autonomy [22,28,80,85,105]. In addition, not only the decision itself, but also other factors affect the applicability of SDM (or the possibility to apply it), such as patient cognition or patient preferences for SDM [106,107].

A strength of our review is that we combined different search strategies to identify papers describing decision characteristics. Furthermore, to our knowledge, this is the first study to describe how authors explain the frequently-used terms 'preference-sensitive' and 'equipoise', which can serve as input to developing consistent definitions of these terms. This study also has limitations. First, we made choices in grouping the decision characteristics which may not always reflect the original authors' intentions. Second, we based our understanding of the terms 'preference-sensitive' and 'equipoise' on the descriptions from the included papers, without also incorporating information from the literature that the papers referenced, as our aim was to explore how the authors of the included papers had chosen to describe decisions. Third, we could not create mutually exclusive categories when grouping the decision characteristics while staying close to the text in the papers. For example, we extracted 'multiple options' and 'uncertainty' separately if preference-sensitivity was not mentioned, even though other authors described preference-sensitivity in terms of multiple options and/or uncertainty. Fourth, the original authors' descriptions determined the limit to how extensively we could describe the decision characteristics, as we stayed close to their wording. For example, what exactly defines 'major decisions' was not always further explicated.

4.2. Practice implications

Most clinicians might already acknowledge the relevance of SDM in preference-sensitive decisions, decisions with multiple (reasonable) options, and situations of equipoise. This review shows that SDM can be relevant to decisions with other characteristics too, such as *when patient commitment is needed to carry out the decision* or decisions with *one* *best option*. Practicing SDM in these ‘less typical’ decisional situations can even come with benefits for clinicians, such as improving their relationship with patients, offer care that fits better with their patients’ preferences and personal circumstances, improve patients’ knowledge, and increasingly activate patients in their own care. This is not to say that SDM should ‘simply’ always be attempted, as this may engender potentially adverse consequences in certain circumstances, especially when there is medical urgency. Neither would it suffice to only apply SDM for a limited amount of decisional situations. In most cases an SDM approach to decision making would not hurt, the process itself might even lead to benefits for both clinicians and patients. This leaves us somewhere in the middle with regard to what recommendations could be made. We do hope that clinicians and patients will soon have fully embraced the idea of sharing decisions, and that they practice SDM in decisions for which its relevance seems undisputed. This overview can help to identify when SDM should be thrived for and when it may be unfitting. The broad range of decisions for which the relevance of SDM is recognized can create awareness in clinicians in particular. It may stimulate them to (re)evaluate when they choose to try and engage in SDM, including decisions for which they did not consider SDM before. After all, it is the clinician who has the largest role in initiating SDM and it is up to them to navigate their ethical compass in trying to tailor their conversational strategy to the patient, the decision problem, and the circumstances as best as possible. Additionally, the current overview can provide input into SDM training programs, in which it is often asked when one should try and engage in SDM. These findings may finally inform campaigns and educational programs advocating for SDM, as it helps to determine in which settings and for which decision characteristics the need for SDM is commonly acknowledged, as well as when SDM is considered challenging or inappropriate.

4.3. Conclusion

Our review summarizes original authors’ statements about decision characteristics for which SDM is considered to be appropriate or not. Our findings show a broad range of decision characteristics for which SDM is deemed appropriate, the ambiguity of some, and the limits of the applicability of SDM for certain decisions. Deciding when to apply SDM is no exact science, and communicative behaviour and core elements underlying the SDM process might be needed in most clinical encounters. Identifying which SDM elements are always required, and which may vary depending on the decisional situation needs to be further investigated. This overview of decisions may stimulate clinicians to (re-) evaluate SDM as the approach of choice in making decisions in clinical practice, and to further develop their ethical compass as when to try and engage in SDM.

References

[1] H. Bomhof-Roordink, F.R. Gärtner, A.M. Stiggelbout, A.H. Pieterse, Key components of shared decision making models: A systematic review, BMJ Open. 9 (2019). https://doi.org/10.1136/bmjopen-2019-031763.

[2] G. Makoul, M.L. Clayman, An integrative model of shared decision making in medical encounters, Patient Educ Couns. 60 (2006) 301–312. https://doi.org/10.1016/j.pec.2005.06.010.

[3] N. Moumjid, A. Gafni, A. Brémond, M.O. Carrère, Shared decision making in the medical encounter: Are we all talking about the same thing?, Medical Decision Making. 27 (2007) 539–546. https://doi.org/10.1177/0272989X07306779.

[4] G. Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, E. Cording, D. Tomson, C. Dodd, S. Rollnick, A. Edwards, M. Barry, Shared decision making: A model for clinical practice, J Gen Intern Med. 27 (2012) 1361–1367. https://doi.org/10.1007/s11606-012-2077-6.

[5] A.M. Stiggelbout, A.H. Pieterse, J.C.J.M. de Haes, Shared decision making: Concepts, evidence, and practice, Patient Educ Couns. 98 (2015) 1172–1179. https://doi.org/10.1016/j.pec.2015.06.022.

[6] A. Coulter, National Strategies for Implementing Shared Decision Making (engl.), Gütersloh, Germany: Bertelsmann Stiftung. (2018) 66.

[7] D. Stacey, F. Légaré, K. Lewis, M.J. Barry, C.L. Bennett, K.B. Eden, M. Holmes-Rovner, H. Llewellyn-Thomas, A. Lyddiatt, R. Thomson, L. Trevena, Decision aids for people facing health treatment or screening decisions, Cochrane Database of Systematic Reviews. 2017 (2017). https://doi.org/10.1002/14651858.CD001431.pub5.

[8] F. Merchant, N. Dickert, D. Horward, Mandatory Shared Decision Making by the Centers for Medicare &Medicaid Services for Cardiovascular Procedures and Other Tests Faisal, JAMA. 320 (2018) 641–642. https://doi.org/10.1001/jama.2018.6617.

[9] S.N. Whitney, A new model of medical decisions: Exploring the limits of shared decision making, Medical Decision Making. 23 (2003) 275–280. https://doi.org/10.1177/0272989X03256006.

[10] S.N. Whitney, A.L. McGuire, L.B. McCullough, A Typology of Shared Decision Making, Informed Consent, and Simple Consent, Ann Intern Med. 140 (2003) 54–59.

[11] C. Charles, A. Gafnv, T. Whelan, SHARED DECISION-MAKING IN THE MEDICAL ENCOUNTER: WHAT DOES IT MEAN? (OR IT TAKES AT LEAST TWO TO TANGO), 1997.

[12] E. v. Grant, J. Summapund, D.D. Matlock, V. Vaughan Dickson, S. Iqbal, S. Patel, S.D. Katz, S.I. Chaudhry, J.A. Dodson, Patient and Cardiologist Perspectives on Shared Decision Making in the Treatment of Older Adults Hospitalized for Acute Myocardial Infarction, Medical Decision Making. 40 (2020) 279–288. https://doi.org/10.1177/0272989X20912293.

[13] E.M. Schoenfeld, S.L. Goff, T.R. Elia, E.R. Khordipour, K.A. Nault, P.K. Lindenauer, K.M. Mazor, Physician-identified barriers to and facilitators of shared decision-making in the Emergency Department: an exploratory analysis, Emerg Med J. 36 (2019) 346–354. https://doi.org/10.1136/emermed-2018-208242.

[14] T.J. Caverly, R.A. Hayward, Dealing with the Lack of Time for Detailed Shared Decision-making in Primary Care: Everyday Shared Decision-making, J Gen Intern Med. 35 (2020) 3045–3049. https://doi.org/10.1007/s11606-020-06043-2.

[15] A.M. Navar, N.J. Stone, S.S. Martin, What to say and how to say it: effective communication for cardiovascular disease prevention, Curr Opin Cardiol. 31 (2016) 537–544.

[16] E. Murray, C. Charles, A. Gafni, Shared decision-making in primary care: Tailoring the Charles et al. model to fit the context of general practice, Patient Educ Couns. 62 (2006) 205–211. https://doi.org/10.1016/j.pec.2005.07.003.

[17] V.M. Montori, A. Gafni, C. Charles, A shared treatment decision-making approach between patients with chronic conditions and their clinicians: The case of diabetes, Health Expectations. 9 (2006) 25–36. https://doi.org/10.1111/j.1369-7625.2006.00359.x.

[18] C.L. Moore, S.L. Kaplan, A framework and resources for shared decision making: Opportunities for improved physical therapy outcomes, Phys Ther. 98 (2018) 1022–1036. https://doi.org/10.1093/PTJ/PZY095.

[19] E.S. Park, I.Y. Cho, Shared decision-making in the paediatric field: a literature review and concept analysis, Scand J Caring Sci. 32 (2018) 478–489.

[20] M.R. Gillick, Re-engineering shared decision-making, J Med Ethics. 41 (2015) 785–788. https://doi.org/10.1136/medethics-2014-102618.

[21] M.A. Probst, P.A. Noseworthy, J.P. Brito, E.P. Hess, Shared Decision/Making as the Future of Emergency Cardiology, Can J Cardiol. 34 (2018) 117–124. https://doi.org/10.1016/j.cjca.2017.09.014.Shared.

[22] J. Chor, D.B. Stulberg, S. Tillman, Shared Decision-Making Framework for Pelvic Examinations in Asymptomatic, Nonpregnant Patients, Obstetrics and Gynecology. 133 (2019) 810–814. https://doi.org/10.1097/AOG.0000000000003166.

[23] C.J. Ng, Y.K. Lee, A. Abdullah, A.I. Abu Bakar, A.M. Tun Firzara, H.W. Tiew, Shared decision making: A dual-layer model to tackling multimorbidity in primary care, J Eval Clin Pract. 25 (2019) 1074–1079. https://doi.org/10.1111/jep.13163.

[24] H.L. Kane, M.T. Halpern, L.B. Squiers, K.A. Treiman, L.A. McCormack, Implementing and evaluating shared decision making in oncology practice, CA Cancer J Clin. 64 (2014) 377–388. https://doi.org/10.3322/caac.21245.

[25] K. Karkazis, A. Tamar-Mattis, A.A. Kon, Genital surgery for disorders of sex development: Implementing a shared decision-making approach, Journal of Pediatric Endocrinology and Metabolism. 23 (2010) 789–805. https://doi.org/10.1515/jpem.2010.129.

[26] J. Jansen, V. Naganathan, S.M. Carter, A.J. McLachlan, B. Nickel, L. Irwig, C. Bonner, J. Doust, J. Colvin, A. Heaney, R. Turner, K. McCaffery, Too much medicine in older people? Deprescribing through shared decision making, BMJ (Online). 353 (2016) 1–6. https://doi.org/10.1136/bmj.i2893.

[27] C.C. Dobler, D.E. Midthun, V.M. Montori, Quality of Shared Decision Making in Lung Cancer Screening: The Right Process, With the Right Partners, at the Right Time and Place, Mayo Clin Proc. 92 (2017) 1612–1616. https://doi.org/10.1016/j.mayocp.2017.08.010.

[28] M. Truglio-Londrigan, J.T. Slyer, Shared Decision-Making for Nursing Practice: An Integrative Review, Open Nurs J. 12 (2018) 1–14. https://doi.org/10.2174/1874434601812010001.

[29] S.A. Lenzen, R. Daniëls, M.A. van Bokhoven, T. van der Weijden, A. Beurskens, Development of a conversation approach for practice nurses aimed at making shared decisions on goals and action plans with primary care patients, BMC Health Serv Res. 18 (2018) 1–11. https://doi.org/10.1186/s12913-018-3734-1.

[30] C. Charles, A. Gafni, T. Whelan, Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model, Soc Sci Med. 49 (1999) 651–661.

[31] D.A. Langer, A. Jensen-Doss, Shared Decision-Making in Youth Mental Health Care: Using the Evidence to Plan Treatments Collaboratively, Journal of Clinical Child and Adolescent Psychology. 47 (2018) 821–831. %3CGo.

[32] M.A. Probst, H.K. Kanzaria, E.M. Schoenfeld, M.D. Menchine, M. Breslin, C. Walsh, E.R. Melnick, E.P. Hess, Shared Decisionmaking in the Emergency Department: A Guiding Framework for Clinicians, Ann Emerg Med. 70 (2017) 688–695.

[33] A. Towle, W. Godolphin, Framework for teaching and learning informed shared decision making, Br Med J. 319 (1999) 766–771. https://doi.org/10.1136/bmj.319.7212.766.

[34] M. Saidinejad, The Patient-Centered Emergency Department, Adv Pediatr. 65 (2018) 105–120. https://doi.org/10.1016/j.yapd.2018.04.008.

[35] K. Grim, D. Rosenberg, P. Svedberg, U.K. Schön, Shared decision-making in mental health care-a user perspective on decisional needs in community-based services, Int J Qual Stud Health Well-Being. 11 (2016) 1–8. https://doi.org/10.3402/qhw.v11.30563.

[36] J. Rusiecki, J. Schell, S. Rothenberger, S. Merriam, M. McNeil, C. Spagnoletti, An Innovative Shared Decision-Making Curriculum for Internal Medicine Residents: Findings from the University of Pittsburgh Medical Center, Academic Medicine. 93 (2018) 937–942. https://doi.org/10.1097/ACM.0000000000001967.

[37] L.A. Shay, J.E. Lafata, Understanding patient perceptions of shared decision making, Patient Educ Couns. 96 (2014) 295–301. https://doi.org/10.1016/j.pec.2014.07.017.

[38] M.E. Peek, M.T. Quinn, R. Gorawara-Bhat, A. Odoms-Young, S.C. Wilson, M.H. Chin, How is shared decision-making defined among African-Americans with diabetes?, Patient Educ Couns. 72 (2008) 450–458. https://doi.org/10.1016/j.pec.2008.05.018.

[39] N. Joseph-Williams, D. Williams, F. Wood, A. Lloyd, K. Brain, N. Thomas, A. Prichard, A. Goodland, H. McGarrigle, H. Sweetland, A. Edwards, A descriptive model of shared decision making derived from routine implementation in clinical practice ('Implement-SDM'): Qualitative study, Patient Educ Couns. 102 (2019) 1774–1785. https://doi.org/10.1016/j.pec.2019.07.016.

[40] F. Légaré, D. Stacey, S. Pouliot, F.P. Gauvin, S. Desroches, J. Kryworuchko, S. Dunn, G. Elwyn, D. Frosch, M.P. Gagnon, M.B. Harrison, P. Pluye, I.D. Graham, Interprofessionalism and shared decision-making in primary care: A stepwise approach towards a new model, J Interprof Care. 25 (2011) 18–25. https://doi.org/10.3109/13561820.2010.490502.

[41] J. Eliacin, M.P. Salyers, M. Kukla, M.S. Matthias, Patients' Understanding of Shared Decision Making in a Mental Health Setting, (2015). https://doi.org/10.1177/1049732314551060.

[42] S. Rennke, P. Yuan, B. Monash, R. Blankenburg, I. Chua, S. Harman, D.S. Sakai, A. Khan, J.F. Hilton, L. Shieh, J. Satterfield, The SDM 3 circle model: A literature synthesis and adaptation for shared decision making in the hospital, J Hosp Med. 12 (2017) 1001–1008. https://doi.org/10.12788/jhm.2865.

[43] G. Elwyn, A. Edwards, P. Kinnersley, R. Grol, Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices, British Journal of General Practice. 50 (2000) 892–897.

[44] G. Elwyn, M. Tsulukidze, A. Edwards, F. Légaré, R. Newcombe, Using a "talk" model of shared decision making to propose an observation-based measure: Observer OPTION5 Item, Patient Educ Couns. 93 (2013) 265–271. https://doi.org/10.1016/j.pec.2013.08.005.

[45] M.H.J. van de Pol, C.R.M.G. Fluit, J. Lagro, Y.H.P. Slaats, M.G.M. Olde Rikkert, A.L.M. Lagro-Janssen, Expert and patient consensus on a dynamic model for shared decision-making in frail older patients, Patient Educ Couns. 99 (2016) 1069–1077. https://doi.org/10.1016/j.pec.2015.12.014.

[46] F. Légaré, D. Stacey, S. Gagnon, S. Dunn, P. Pluye, D. Frosch, J. Kryworuchko, G. Elwyn, M.P. Gagnon, I.D. Graham, Validating a conceptual model for an inter-professional approach to shared decision making: A mixed methods study, J Eval Clin Pract. 17 (2011) 554–564. https://doi.org/10.1111/j.1365-2753.2010.01515.x.

[47] B.A. Lown, J.L. Hanson, W.D. Clark, Mutual influence in shared decision making: A collaborative study of patients and physicians, Health Expectations. 12 (2009) 160–174. https://doi.org/10.1111/j.1369-7625.2008.00525.x.

[48] H. Bomhof-Roordink, M.J. Fischer, N. van Duijn-Bakker, M.C. Baas-Thijssen, T. van der Weijden, A.M. Stiggelbout, A.H. Pieterse, Shared decision making in oncology: A model based on patients', health care professionals', and researchers' views, Psychooncology. 28 (2019) 139–146. https://doi.org/10.1002/pon.4923.

[49] D. Simon, G. Schorr, M. Wirtz, A. Vodermaier, C. Caspari, B. Neuner, C. Spies, T. Krones, H. Keller, A. Edwards, A. Loh, M. Härter, Development and first validation of the shared decision-making questionnaire (SDM-Q), Patient Educ Couns. 63 (2006) 319–327. https://doi.org/10.1016/j.pec.2006.04.012.

[50] R.J. Volk, N.K. Shokar, V.B. Leal, R.J. Bulik, S.K. Linder, P.D. Mullen, R.M. Wexler, G.S. Shokar, Development and pilot testing of an online case-based approach to shared decision making skills training for clinicians, BMC Med Inform Decis Mak. 14 (2014) 1–9. https://doi.org/10.1186/1472-6947-14-95.

[51] G. Elwyn, M.A. Durand, J. Song, J. Aarts, P.J. Barr, Z. Berger, N. Cochran, D. Frosch, D. Galasiski, P. Gulbrandsen, P.K.J. Han, M. Härter, P. Kinnersley, A. Lloyd, M. Mishra, L. Perestelo-Perez, I. Scholl, K. Tomori, L. Trevena, H.O. Witteman, T. van der Weijden, A three-talk model for shared decision making: Multistage consultation process, BMJ (Online). 359 (2017). https://doi.org/10.1136/bmj.j4891.

[52] G. Clarke, G. Rosencrance, R.T. Hall, Physician-patient relations: No more models, American Journal of Bioethics. 4 (2004) W16–W19. https://doi.org/10.1162/152651604323097934.

[53] J. Jansen, S. McKinn, C. Bonner, D.M. Muscat, J. Doust, K. McCaffery, Shared decision-making about cardiovascular disease medication in older people: a qualitative study of patient experiences in general practice, BMJ Open. 9 (2019) e026342.

[54] M.S. Matthias, T.L. Talib, M.A. Huffman, Managing Chronic Pain in an Opioid Crisis: What Is the Role of Shared Decision-Making?, Health Commun. (2020) 1–9.

[55] E.G. Engelhardt, A.H. Pieterse, A. van der Hout, H.J. de Haes, J.R. Kroep, P. van Ufford-Mannesse, J.E. Portielje, E.M. Smets, A.M. Stiggelbout, Use of implicit persuasion in decision making about adjuvant cancer treatment: A potential barrier to shared decision making, Eur J Cancer. 66 (2016) 55–66.

[56] A.E. Turnbull, S.K. Sahetya, D.M. Needham, Aligning critical care interventions with patient goals: A modified Delphi study, Heart Lung. 45 (2016) 517–524.

[57] T. Zhuang, L.M. Shapiro, D. Ring, E. Akelman, D.S. Ruch, M.J. Richard, A. Ladd, P. Blazar, J. Yao, S. Kakar, A.H.S. Harris, C. Got, R.N. Kamal, Which Decisions For Management of Carpal Tunnel Syndrome and Distal Radius Fractures Should Be Shared?, J Hand Surg Am. 45 (2020) 690-697.e7.

[58] G. Elwyn, R. Gwyn, A. Edwards, R. Grol, Is “shared decision-making” feasible in consultations for upper respiratory tract infections? Assessing the influence of antibiotic expectations using discourse analysis, Health Expect. 2 (1999) 105–117.

[59] R. Gwyn, G. Elwyn, When is a shared decision not (quite) a shared decision? Negotiating preferences in a general practice encounter, Soc Sci Med. 49 (1999) 437–447.

[60] A. Anagnostou, J.O.B. Hourihane, M. Greenhawt, The Role of Shared Decision Making in Pediatric Food Allergy Management, Journal of Allergy and Clinical Immunology: In Practice. 8 (2020) 46–51. https://doi.org/10.1016/j.jaip.2019.09.004.

[61] M.S. Blaiss, G.C. Steven, B. Bender, D.A. Bukstein, E.O. Meltzer, T. Winders, Shared decision making for the allergist, Ann Allergy Asthma Immunol. 122 (2019) 463–470.

[62] E. Colligan, A. Metzler, E. Tiryaki, Shared decision-making in multiple sclerosis, Mult Scler. 23 (2017) 185–190.

[63] K.M. de Ligt, L.S.E. van Egdom, L.B. Koppert, S. Siesling, J.A. van Til, Opportunities for personalised follow-up care among patients with breast cancer: A scoping review to identify preference-sensitive decisions, Eur J Cancer Care (Engl). 28 (2019) e13092.

[64] D. Forner, C.W. Noel, A.G. Shuman, P. Hong, M. Corsten, V.E. Rac, A.H. Pieterse, D. Goldstein, Shared Decision-making in Head and Neck Surgery: A Review, JAMA Otolaryngol Head Neck Surg. (2020).

[65] A. Herlitz, C. Munthe, M. Törner, G. Forsander, The Counseling, Self-Care, Adherence Approach to Person-Centered Care and Shared Decision Making: Moral Psychology, Executive Autonomy, and Ethics in Multi-Dimensional Care Decisions, Health Commun. 31 (2016) 964–973.

[66] C. Kahlert, K. Aebi-Popp, E. Bernasconi, B. de Tejada, D. Nadal, P. Paioni, C. Rudin, C. Staehelin, N. Wagner, P. Vernazza, Is breastfeeding an equipoise option in effectively treated HIV-infected mothers in a high-income setting?, Swiss Med Wkly. 148 (2018) w14648.

[67] C.K. Kraus, C.A. Marco, Shared decision making in the ED: ethical considerations, Am J Emerg Med. 34 (2016) 1668–1672.

[68] N.A. Martínez-González, A. Plate, O. Senn, S. Markun, T. Rosemann, S. Neuner-Jehle, Shared decision-making for prostate cancer screening and treatment: a systematic review of randomised controlled trials, Swiss Med Wkly. 148 (2018) w14584.

[69] M. Narayan, D. Matlock, Shared Decision-Making in Older Persons with Cardiovascular Disease, Curr Cardiovasc Risk Rep. 9 (2015). http://www.springer.com/medicine/cardiology/journal/12170.

[70] K. Niburski, E. Guadagno, S. Mohtashami, D. Poenaru, Shared decision making in surgery: A scoping review of the literature, Health Expectations. 22 (2020) 22. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medp&AN=32700367.

[71] M.C. Politi, C.L. Lewis, D.L. Frosch, Supporting shared decisions when clinical evidence is low, Med Care Res Rev. 70 (2013) 113s–128s.

[72] M.C. Politi, K.Y. Wolin, F. Légaré, Implementing clinical practice guidelines about health promotion and disease prevention through shared decision making, J Gen Intern Med. 28 (2013) 838–844.

[73] J. van Beek-Peeters, E.H.M. van Noort, M.C. Faes, A. de Vos, M.W.A. van Geldorp, M.M.N. Minkman, N.J.M. van der Meer, Shared decision making in older patients with symptomatic severe aortic stenosis: a systematic review, Heart. 106 (2020) 647–655.

[74] A.T. Langford, S.K. Williams, M. Applegate, O. Ogedegbe, R.S. Braithwaite, Partnerships to Improve Shared Decision Making for Patients with Hypertension - Health Equity Implications, Ethn Dis. 29 (2019) 97–102.

[75] M. Greenhawt, Shared decision-making in the care of a patient with food allergy, Ann Allergy Asthma Immunol. (2020).

[76] D.J. Opel, A 4-Step Framework for Shared Decision-making in Pediatrics, Pediatrics. 142 (2018) S149-s156.

[77] L. Bailo, L. Vergani, G. Pravettoni, Patient Preferences as Guidance for Information Framing in a Medical Shared Decision-Making Approach: The Bridge Between Nudging and Patient Preferences, Patient Prefer Adherence. 13 (2019) 2225–2231.

[78] M.J. Barry, Shared decision making: informing and involving patients to do the right thing in health care, J Ambul Care Manage. 35 (2012) 90–98.

[79] P.E. Deegan, Shared decision making must be adopted, not adapted, Psychiatric Services. 65 (2014) 1487. http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2015-04418-013&site=ehost-live.

[80] R.E. Drake, P.E. Deegan, Shared decision making is an ethical imperative, Psychiatric Services. 60 (2009) 1007. http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2009-11985-002&site=ehost-live.

[81] G. Elwyn, D. Frosch, S. Rollnick, Dual equipoise shared decision making: definitions for decision and behaviour support interventions, Implement Sci. 4 (2009) 75.

[82] J. Hamann, S. Heres, Adapting shared decision making for individuals with severe mental illness, Psychiatr Serv. 65 (2014) 1483–1486.

[83] G. Elwyn, C. Dehlendorf, R.M. Epstein, K. Marrin, J. White, D.L. Frosch, Shared decision making and motivational interviewing: Achieving patient-centered care across the spectrum of health care problems, Ann Fam Med. 12 (2014) 270–275. https://doi.org/10.1370/afm.1615.

[84] M. Mercuri, R.E. Upshur, A. Gafni, Guidelines should not recommend the type of decision-making for the medical encounter, Patient Educ Couns. 15 (2020) 15. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=medp&AN=32473839.

[85] L.A. Mistler, R.E. Drake, Shared decision making in antipsychotic management, J Psychiatr Pract. 14 (2008) 333–344.

[86] H. Moulton, B. Moulton, T. Lahey, G. Elwyn, Can Consent to Participate in Clinical Research Involve Shared Decision Making?, AMA J Ethics. 22 (2020) E365-371.

[87] K.E. Nelson, S. Mahant, Shared decision-making about assistive technology for the child with severe neurologic impairment, Pediatr Clin North Am. 61 (2014) 641–652.

[88] J. Palace, Partnership and consent in MS treatment choice, J Neurol Sci. 335 (2013) 5–8.

[89] W.O. Pickrell, G. Elwyn, P.E. Smith, Shared decision-making in epilepsy management, Epilepsy Behav. 47 (2015) 78–82.

[90] M.C. Politi, J.L. Studts, J.W. Hayslip, Shared decision making in oncology practice: what do oncologists need to know?, Oncologist. 17 (2012) 91–100.

[91] M.A. Pynnonen, S.T. Hawley, A patient-centered approach to clinical practice guidelines in otolaryngology, Otolaryngology - Head and Neck Surgery (United States). 150 (2014) 910–913. http://oto.sagepub.com/content/by/year.

[92] D. Ubbink, M. Hageman, D. Legemate, Shared Decision-making in Surgery, Surg Technol Int. 26 (2015) 31–36.

[93] E.M. Weiss, J.D. Clark, C.L. Heike, A.R. Rosenberg, S.K. Shah, B.S. Wilfond, D.J. Opel, Gaps in the Implementation of Shared Decision-making: Illustrative Cases, Pediatrics. 143 (2019).

[94] S.N. Whitney, A.M. Ethier, E. Frugé, S. Berg, L.B. McCullough, M. Hockenberry, Decision making in pediatric oncology: who should take the lead? The decisional priority in pediatric oncology model, J Clin Oncol. 24 (2006) 160–165.

[95] S.N. Whitney, M. Holmes-Rovner, H. Brody, C. Schneider, L.B. McCullough, R.J. Volk, A.L. McGuire, Beyond shared decision making: an expanded typology of medical decisions, Med Decis Making. 28 (2008) 699–705.

[96] M.J. Armstrong, Developing the Disorders of Consciousness Guideline and Challenges of Integrating Shared Decision-Making Into Clinical Practice, Journal of Head Trauma Rehabilitation. 34 (2019) 199–204. http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=prem&AN=31058760.

[97] T. Waldron, T. Carr, L. Mcmullen, G. Westhorp, V. Duncan, S. Neufeld, L. Bandura, G. Groot, Development of a program theory for shared decision-making : a realist synthesis, 1 (2020) 1–17.

[98] A.A. Kon, J.E. Davidson, W. Morrison, M. Danis, D.B. White, M. of Critical Care, S. American Thoracic, Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement, Crit Care Med. 44 (2016) 188–201.

[99] S.H. Woolf, Editorial: The logic and limits of shared decision making, Journal of Urology. 166 (2001) 244–245. https://doi.org/10.1016/S0022-5347(05)66136-8.

[100] S. Shaw, G. Hughes, T. Stephens, R. Pearse, J. Prowle, R.E. Ashcroft, E. Avagliano, J. Day, M. Edsell, J. Edwards, L. Everest, Understanding decision making about major surgery: protocol for a qualitative study of shared decision making by high-risk patients and their clinical teams, BMJ Open. 10 (2020) e033703.

[101] M.E. Peek, M.T. Quinn, R. Gorawara-Bhat, A. Odoms-Young, S.C. Wilson, M.H. Chin, How is shared decision-making defined among African-Americans with diabetes?, Patient Educ Couns. 72 (2008) 450–458. https://doi.org/10.1016/j.pec.2008.05.018.

[102] I.G. Hargraves, V.M. Montori, J.P. Brito, M. Kunneman, K. Shaw, C. Lavecchia, M. Wilson, L. Walker, Patient Education and Counseling Purposeful SDM : A problem-based approach to caring for patients with shared decision making, Patient Educ Couns. 102 (2019) 1786–1792. https://doi.org/10.1016/j.pec.2019.07.020.

[103] I.G. Hargraves, A.K. Fournier, V.M. Montori, A.S. Bierman, Generalized shared decision making approaches and patient problems. Adapting AHRQ's SHARE Approach for Purposeful SDM, Patient Educ Couns. 103 (2020) 2192–2199. https://doi.org/10.1016/j.pec.2020.06.022.

[104] M. Müller-Engelmann, N. Donner-Banzhoff, H. Keller, L. Rosinger, C. Sauer, K. Rehfeldt, T. Krones, When decisions should be shared: A study of social norms in medical decision making using a factorial survey approach, Medical Decision Making. 33 (2013) 37–47. https://doi.org/10.1177/0272989X12458159.

[105] G. Elwyn, J. Tilburt, V. Montori, The ethical imperative for shared decision-making, Eur J Pers Cent Healthc. 1 (2013) 129. https://doi.org/10.5750/ejpch.v1i1.645.

[106] T. Waldron, T. Carr, L. McMullen, G. Westhorp, V. Duncan, S.M. Neufeld, L.A. Bandura, G. Groot, Development of a program theory for shared decision-making: a realist synthesis, BMC Health Serv Res. 20 (2020) 59.

[107] M. Müller-Engelmann, H. Keller, N. Donner-Banzhoff, T. Krones, Shared decision making in medicine: The influence of situational treatment factors, Patient Educ Couns. 82 (2011) 240–246. https://doi.org/10.1016/j.pec.2010.04.028.

Supplement 1 – Search Strategy

Search summary: Total found on 7-8-2020: 1860 refereces, originating from:

- PubMed: 741
- MEDLINE: 1031 - 294 unique
- Embase: 832 - 287 unique
- Web of Science: 208 - 70 unique
- COCHRANE Library: 98 - 58 unique
- Emcare: 566 - 109 unique
- PsycINFO: 394 - 292 unique
- Academic Search Premier: 109 - 9 unique

Pubmed

Strategy: one of both components at least being in a lead role. - 741 references

(((″Decision Making, Shared″[Mesh] OR″shared decision making″[tw] OR″shared decisionmaking″[tw] OR″shared decision″[tw] OR″shared decisions″[tw] OR″SDM″[tw] OR″shared decis*″[tw] OR ((″shared″[tw] OR″share″[tw] OR ″sharing″[tw]) AND (″Decision Making″[Mesh] OR″decision″[tw] OR″decisions″[tw])) OR ((″Decision Making″[mesh] OR ″decision making″[ti] OR″decision-making″[ti]) AND (″social environment″[mesh] OR″family″[tiab] OR″community″[tiab] OR ″friend″[tiab] OR ″friends″[tiab] OR ″communication″[mesh] OR ″interpersonal relations″[mesh] OR ″patient participation″[mesh] OR″patient participation″[tiab] OR″Physician-Patient Relations″[mesh] OR″Physician-Patient Relations″[tiab] OR ″patient empowerment″[tiab] OR ″Power, Psychological″[Mesh])) OR ″patient decision″[tw] OR ″patient decisions″[tw] OR ″informed decision making″[tw] OR ″evidence-based patient choic*″[tw]) AND (″nonpreference″[ti] OR″non preference″[ti] OR″nonprefer*″[ti] OR″non prefer*″[ti] OR″sensitive decisions″[ti] OR ″sensitive decision″[ti] OR″effective decisions″[ti] OR″effective decision″[ti] OR″effective decision*″[ti] OR″preference-sensitive″[ti] OR″preference sensitiv*″[ti] OR″preference effective″[ti] OR″non equipoise*″[ti] OR″nonequipoise*″[ti] OR ″equipoise″[ti] OR ″counterbalance″[ti] OR ″counterpoise″[ti] OR ″equipoise*″[ti] OR ″counterbalanc*″[ti] OR ″counterpois*″[ti] OR″Decision situation″[ti] OR″choice situation″[ti] OR″decision type″[ti] OR″Decision situations″[ti] OR″choice situations″[ti] OR″decision types″[ti] OR″Decision situation*″[ti] OR″choice situation*″[ti] OR″decision type*″[ti] OR″disagreements″[ti] OR″disagreement″[ti] OR″dis agreement″[ti] OR″dis agreements″[ti] OR″typology″[ti] OR″typolog*″[ti] OR″decisional situation*″[ti] OR″decision characteristic*″[ti] OR″decision making characteristic*″[ti] OR″decision making typ*″[ti] OR″decision making situation*″[ti] OR″decision making preference*″[ti] OR″decision preference*″[ti] OR″decisional preference*″[ti])) **OR** ((″Decision Making, Shared″[majr] OR″shared decision making″[ti] OR″shared decisionmaking″[ti] OR″shared decision″[ti] OR″shared decisions″[ti] OR″SDM″[ti] OR″shared decis*″[ti] OR ((″shared″[ti] OR″share″[ti] OR″sharing″[ti]) AND (″Decision Making″[majr] OR″decision″[ti] OR″decisions″[ti])) OR ((″Decision Making″[majr] OR″decision making″[ti] OR″decision-making″[ti]) AND (″social environment″[majr] OR ″family″[ti] OR ″community″[ti] OR ″friend″[ti] OR ″friends″[ti] OR ″communication″[majr] OR ″interpersonal relations″[majr] OR″patient participation″[majr] OR″patient participation″[ti] OR″Physician-Patient Relations″[majr] OR″Physician-Patient Relations″[ti] OR″patient empowerment″[ti] OR″Power, Psychological″[majr])) OR″patient decision″[ti] OR″patient decisions″[ti] OR″informed decision making″[ti] OR″evidence-based patient choic*″[ti]) AND (″nonpreference″[tw] OR″non preference″[tw] OR″nonprefer*″[tw] OR″non prefer*″[tw] OR″sensitive decisions″[tw]

OR″sensitive decision″[tw] OR″effective decisions″[tw] OR″effective decision″[tw] OR″effective decision*″[tw] OR ″preference-sensitive″[tw] OR″preference sensitiv*″[tw] OR″preference effective″[tw] OR″non equipoise*″[tw] OR ″nonequipoise*″[tw] OR″equipoise″[tw] OR″counterbalance″[tw] OR″counterpoise″[tw] OR″equipoise*″[tw] OR ″counterbalanc*″[tw] OR″counterpois*″[tw] OR″Decision situation″[tw] OR″choice situation″[tw] OR″decision type″[tw] OR″Decision situations″[tw] OR″choice situations″[tw] OR″decision types″[tw] OR″Decision situation*″[tw] OR″choice situation*″[tw] OR″decision type*″[tw] OR″disagreements″[tw] OR″disagreement″[tw] OR″dis agreement″[tw] OR″dis agreements″[tw] OR″typology″[tw] OR″typolog*″[tw] OR″decisional situation*″[tw] OR″decision characteristic*″[tw] OR″decision making characteristic*″[tw] OR″decision making typ*″[tw] OR″decision making situation*″[tw] OR ″decision making preference*″[tw] OR″decision preference*″[tw] OR″decisional preference*″[tw])))**)**

MEDLINE via OVID

http://gateway.ovid.com/ovidweb.cgi?T=JS&MODE=ovid&NEWS=n&PAGE=main&D=medall

(14706973 OR 18556639 OR 11141876 OR 19922647 OR 11281884).ui

Additional search techniques with proximity operators and phrase-searching (**bold**) leads to around 300-600 additional references

One of both components at least being in a lead role

((″Decision Making, Shared″/ OR″shared decision making″.mp OR″shared decisionmaking″.mp OR″shared decision″.mp OR″shared decisions″.mp OR″SDM″.mp OR″shared decis*″.mp OR ((″shared″.mp OR″share″.mp OR″sharing″.mp) AND (exp″Decision Making″/ OR″decision″.mp OR″decisions″.mp)) OR ((exp″Decision Making″/ OR″decision making″.ti OR″decision-making″.ti) AND (exp″social environment″/ OR″family″.ti,ab OR″community″.ti,ab OR″friend″.ti,ab OR″friends″.ti,ab OR exp″communication″/ OR exp″interpersonal relations″/ OR exp″patient participation″/ OR ″patient participation″.ti,ab OR exp″Physician-Patient Relations″/ OR″Physician-Patient Relations″.ti,ab OR″patient empowerment″.ti,ab OR exp″Power, Psychological″/)) OR″patient decision″.mp OR″patient decisions″.mp OR″informed decision making″.mp OR″evidence-based patient choic*″.mp) AND (″nonpreference″.ti OR″non preference″.ti OR ″nonprefer*″.ti OR″non prefer*″.ti OR″sensitive decisions″.ti OR″sensitive decision″.ti OR″effective decisions″.ti OR ″effective decision″.ti OR″effective decision*″.ti OR″preference-sensitive″.ti OR″preference sensitiv*″.ti OR″preference effective″.ti OR″non equipoise*″.ti OR″nonequipoise*″.ti OR″equipoise″.ti OR″counterbalance″.ti OR″counterpoise″.ti OR″equipoise*″.ti OR″counterbalanc*″.ti OR″counterpois*″.ti OR″Decision situation″.ti OR″choice situation″.ti OR ″decision type″.ti OR″Decision situations″.ti OR″choice situations″.ti OR″decision types″.ti OR″Decision situation*″.ti OR″choice situation*″.ti OR″decision type*″.ti OR″disagreements″.ti OR″disagreement″.ti OR″dis agreement″.ti OR″dis agreements″.ti OR″typology″.ti OR″typolog*″.ti OR″decisional situation*″.ti OR″decision characteristic*″.ti OR″decision making characteristic*″.ti OR″decision making typ*″.ti OR″decision making situation*″.ti OR″decision making preference*″.ti OR″decision preference*″.ti OR″decisional preference*″.ti **OR″type of decision*″.ti OR″types of decision*″.ti OR ((″sensitive″.ti OR″effective″.ti OR″situation″.ti OR″situations″.ti OR″type″.ti OR″types″.ti OR ″characteristic*″.ti OR″preference*″.ti) ADJ2″decision*″.ti) OR ((″boundaries″.ti OR″boundary″.ti OR″limits″.ti OR″limit″.ti) ADJ3″decision*″.ti))**) **OR** ((*″Decision Making, Shared″/ OR″shared decision making″.ti OR″shared decisionmaking″.ti OR″shared decision″.ti OR″shared decisions″.ti OR″SDM″.ti OR″shared decis*″.ti OR ((″shared″.ti OR ″share″.ti OR″sharing″.ti) AND (exp *″Decision Making″/ OR″decision″.ti OR″decisions″.ti)) OR ((exp *″Decision Making″/ OR″decision making″.ti OR″decision-making″.ti) AND (exp *″social environment″/ OR″family″.ti OR″community″.ti OR ″friend″.ti OR″friends″.ti OR exp *″communication″/ OR exp *″interpersonal relations″/ OR exp *″patient participation″/ OR″patient participation″.ti OR exp *″Physician-Patient Relations″/ OR″Physician-Patient Relations″.ti OR″patient empowerment″.ti OR exp *″Power, Psychological″/)) OR″patient decision″.ti OR″patient decisions″.ti OR″informed decision making″.ti OR″evidence-based patient choic*″.ti) AND (″nonpreference″.mp OR″non preference″.mp OR ″nonprefer*″.mp OR″non prefer*″.mp OR″sensitive decisions″.mp OR″sensitive decision″.mp OR″effective decisions″.mp OR″effective decision″.mp OR″effective decision*″.mp OR″preference-sensitive″.mp OR″preference sensitiv*″.mp OR″preference effective″.mp OR″non equipoise*″.mp OR″nonequipoise*″.mp OR″equipoise″.mp OR″counterbalance″.mp OR″counterpoise″.mp OR″equipoise*″.mp OR″counterbalanc*″.mp OR″counterpois*″.mp OR″Decision situation″.mp OR″choice situation″.mp OR″decision type″.mp OR″Decision situations″.mp OR″choice situations″.mp OR″decision types″.mp OR″Decision situation*″.mp OR″choice situation*″.mp OR″decision type*″.mp OR″disagreements″.mp OR ″disagreement″.mp OR″dis agreement″.mp OR″dis agreements″.mp OR″typology″.mp OR″typolog*″.mp OR″decisional situation*″.mp OR″decision characteristic*″.mp OR″decision making characteristic*″.mp OR″decision making typ*″.mp OR″decision making situation*″.mp OR″decision making preference*″.mp OR″decision preference*″.mp OR″decisional preference*″.mp **OR″type of decision*″.mp OR″types of decision*″.mp OR ((″sensitive″.ti,ab OR″effective″.ti,ab OR ″situation″.ti,ab OR″situations″.ti,ab OR″type″.ti,ab OR″types″.ti,ab OR″characteristic*″.ti,ab OR″preference*″.ti,ab) ADJ2″decision*″.ti,ab) OR ((″boundaries″.ti,ab OR″boundary″.ti,ab OR″limits″.ti,ab OR″limit″.ti,ab) ADJ3 ″decision*″.ti,ab))**)

Embase

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=main&MODE=ovid&D=oemezd

((*″Shared Decision Making″/ OR″shared decision making″.ti,ab OR″shared decisionmaking″.ti,ab OR″shared decision″.ti,ab OR″shared decisions″.ti,ab OR″SDM″.ti,ab OR″shared decis*″.ti,ab OR ((″shared″.ti,ab OR″share″.ti,ab OR″sharing″.ti,ab) AND (exp″Decision Making″/ OR″decision″.ti,ab OR″decisions″.ti,ab)) OR ((exp *″Decision Making″/ OR″decision making″.ti OR″decision-making″.ti) AND (exp *″social environment″/ OR″family″.ti,ab OR″community″.ti,ab OR″friend″.ti,ab OR″friends″.ti,ab OR exp *″communication″/ OR exp *″human relation″/ OR exp *″patient participation″/ OR ″patient participation″.ti,ab OR *″Doctor Patient Relationship″/ OR″Physician-Patient Relations″.ti,ab OR″patient empowerment″.ti,ab OR *″Empowerment″/)) OR″patient decision″.ti,ab OR″patient decisions″.ti,ab OR″informed decision making″.ti,ab OR″evidence-based patient choic*″.ti,ab) AND (″nonpreference″.ti OR″non preference″.ti OR ″nonprefer*″.ti OR″non prefer*″.ti OR″sensitive decisions″.ti OR″sensitive decision″.ti OR″effective decisions″.ti OR ″effective decision″.ti OR″effective decision*″.ti OR″preference-sensitive″.ti OR″preference sensitiv*″.ti OR″preference effective″.ti OR″non equipoise*″.ti OR″nonequipoise*″.ti OR″equipoise″.ti OR″counterbalance″.ti OR″counterpoise″.ti OR″equipoise*″.ti OR″counterbalanc*″.ti OR″counterpois*″.ti OR″Decision situation″.ti OR″choice situation″.ti OR ″decision type″.ti OR″Decision situations″.ti OR″choice situations″.ti OR″decision types″.ti OR″Decision situation*″.ti OR″choice situation*″.ti OR″decision type*″.ti OR″disagreements″.ti OR″disagreement″.ti OR″dis agreement″.ti OR″dis agreements″.ti OR″typology″.ti OR″typolog*″.ti OR″decisional situation*″.ti OR″decision characteristic*″.ti OR″decision making characteristic*″.ti OR″decision making typ*″.ti OR″decision making situation*″.ti OR″decision making preference*″.ti OR″decision preference*″.ti OR″decisional preference*″.ti **OR″type of decision*″.ti OR″types of decision*″.ti OR ((″sensitive″.ti OR″effective″.ti OR″situation″.ti OR″situations″.ti OR″type″.ti OR″types″.ti OR ″characteristic*″.ti OR″preference*″.ti) ADJ2″decision*″.ti) OR ((″boundaries″.ti OR″boundary″.ti OR″limits″.ti OR″limit″.ti) ADJ3″decision*″.ti))**) **OR** ((*″Shared Decision Making″/ OR″shared decision making″.ti OR″shared decisionmaking″.ti OR″shared decision″.ti OR″shared decisions″.ti OR″SDM″.ti OR″shared decis*″.ti OR ((″shared″.ti OR ″share″.ti OR″sharing″.ti) AND (exp″Decision Making″/ OR″decision″.ti OR″decisions″.ti)) OR ((exp *″Decision Making″/ OR″decision making″.ti OR″decision-making″.ti) AND (exp *″social environment″/ OR″family″.ti OR″community″.ti OR″friend″.ti OR″friends″.ti OR exp *″communication″/ OR exp *″human relation″/ OR exp *″patient participation″/ OR″patient participation″.ti OR *″Doctor Patient Relationship″/ OR″Physician-Patient Relations″.ti OR″patient empowerment″.ti OR *″Empowerment″/)) OR″patient decision″.ti OR″patient decisions″.ti OR″informed decision making″.ti OR″evidence-based patient choic*″.ti) AND (″nonpreference″.ti,ab OR″non preference″.ti,ab OR″nonprefer*″.ti,ab OR″non prefer*″.ti,ab OR″sensitive decisions″.ti,ab OR″sensitive decision″.ti,ab OR″effective decisions″.ti,ab OR ″effective decision″.ti,ab OR″effective decision*″.ti,ab OR″preference-sensitive″.ti,ab OR″preference sensitiv*″.ti,ab OR ″preference effective″.ti,ab OR″non equipoise*″.ti,ab OR″nonequipoise*″.ti,ab OR″equipoise″.ti,ab OR″counterbalance″.ti,ab OR ″counterpoise″.ti,ab OR ″equipoise*″.ti,ab OR ″counterbalanc*″.ti,ab OR ″counterpois*″.ti,ab OR ″Decision situation″.ti,ab OR″choice situation″.ti,ab OR″decision type″.ti,ab OR″Decision situations″.ti,ab OR″choice situations″.ti,ab OR″decision types″.ti,ab OR″Decision situation*″.ti,ab OR″choice situation*″.ti,ab OR″decision type*″.ti,ab OR ″disagreements″.ti,ab OR″disagreement″.ti,ab OR″dis agreement″.ti,ab OR″dis agreements″.ti,ab OR″typology″.ti,ab OR ″typolog*″.ti,ab OR″decisional situation*″.ti,ab OR″decision characteristic*″.ti,ab OR″decision making characteristic*″.ti,ab OR″decision making typ*″.ti,ab OR″decision making situation*″.ti,ab OR″decision making preference*″.ti,ab OR ″decision preference*″.ti,ab OR″decisional preference*″.ti,ab **OR″type of decision*″.ti,ab OR″types of decision*″.ti,ab OR ((″sensitive″.ti,ab OR″effective″.ti,ab OR″situation″.ti,ab OR″situations″.ti,ab OR″type″.ti,ab OR″types″.ti,ab OR″characteristic*″.ti,ab OR″preference*″.ti,ab) ADJ2″decision*″.ti,ab) OR ((″boundaries″.ti,ab OR″boundary″.ti,ab OR″limits″.ti,ab OR″limit″.ti,ab) ADJ3″decision*″.ti,ab))**)) NOT (conference review or conference abstract).pt

Web of Science

http://isiknowledge.com/wos

((TI=(″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* NEAR/5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR ″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR ″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND TS=(″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR ″nonequipoise*″ OR ″equipoise″ OR ″counterbalance″ OR ″counterpoise″ OR ″equipoise*″ OR ″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR″choice situation″ OR″decision type″ OR″Decision situations″ OR ″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR ″disagreements″ OR″disagreement″ OR″dis agreement″ OR″dis agreements″)) **OR** (TS=(″shared decision making″ OR ″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR ″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* NEAR/5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR″friends″ OR″communication″ OR ″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR″Physician-Patient Relations″ OR ″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND TI=(″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR ″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR″nonequipoise*″ OR″equipoise″ OR ″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR ″choice situation″ OR″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR″disagreement″ OR″dis agreement″ OR ″dis agreements″))**)** NOT dt=(meeting abstract)

Cochrane

https://www.cochranelibrary.com/advanced-search/search-manager

((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR ″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* NEAR/5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR ″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR ″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR ″counterpois*″ OR″Decision situation″ OR″choice situation″ OR″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR″disagreement″ OR″dis agreement″ OR″dis agreements″)):ti,ab,kw NOT (conference abstract):pt

Emcare

http://ovidsp.ovid.com/ovidweb.cgi?T=JS&NEWS=n&CSC=Y&PAGE=main&D=emcr

((*″Shared Decision Making″/ OR″shared decision making″.ti,ab OR″shared decisionmaking″.ti,ab OR″shared decision″.ti,ab OR″shared decisions″.ti,ab OR″SDM″.ti,ab OR″shared decis*″.ti,ab OR ((″shared″.ti,ab OR″share″.ti,ab OR″sharing″.ti,ab) AND (exp″Decision Making″/ OR″decision″.ti,ab OR″decisions″.ti,ab)) OR ((exp *″Decision Making″/ OR″decision making″.ti OR″decision-making″.ti) AND (exp *″social environment″/ OR″family″.ti,ab OR″community″.ti,ab OR″friend″.ti,ab OR″friends″.ti,ab OR exp *″communication″/ OR exp *″human relation″/ OR exp *″patient participation″/ OR ″patient participation″.ti,ab OR *″Doctor Patient Relationship″/ OR″Physician-Patient Relations″.ti,ab OR″patient empowerment″.ti,ab OR *″Empowerment″/)) OR″patient decision″.ti,ab OR″patient decisions″.ti,ab OR″informed decision making″.ti,ab OR″evidence-based patient choic*″.ti,ab) AND (″nonpreference″.ti OR″non preference″.ti OR ″nonprefer*″.ti OR″non prefer*″.ti OR″sensitive decisions″.ti OR″sensitive decision″.ti OR″effective decisions″.ti OR ″effective decision″.ti OR″effective decision*″.ti OR″preference-sensitive″.ti OR″preference sensitiv*″.ti OR″preference effective″.ti OR″non equipoise*″.ti OR″nonequipoise*″.ti OR″equipoise″.ti OR″counterbalance″.ti OR″counterpoise″.ti OR″equipoise*″.ti OR″counterbalanc*″.ti OR″counterpois*″.ti OR″Decision situation″.ti OR″choice situation″.ti OR ″decision type″.ti OR″Decision situations″.ti OR″choice situations″.ti OR″decision types″.ti OR″Decision situation*″.ti OR″choice situation*″.ti OR″decision type*″.ti OR″disagreements″.ti OR″disagreement″.ti OR″dis agreement″.ti OR″dis agreements″.ti OR″typology″.ti OR″typolog*″.ti OR″decisional situation*″.ti OR″decision characteristic*″.ti OR″decision making characteristic*″.ti OR″decision making typ*″.ti OR″decision making situation*″.ti OR″decision making preference*″.ti OR″decision preference*″.ti OR″decisional preference*″.ti **OR″type of decision*″.ti OR″types of decision*″.ti OR ((″sensitive″.ti OR″effective″.ti OR″situation″.ti OR″situations″.ti OR″type″.ti OR″types″.ti OR ″characteristic*″.ti OR″preference*″.ti) ADJ2″decision*″.ti) OR ((″boundaries″.ti OR″boundary″.ti OR″limits″.ti OR″limit″.ti) ADJ3″decision*″.ti))**) **OR** ((*″Shared Decision Making″/ OR″shared decision making″.ti OR″shared decisionmaking″.ti OR″shared decision″.ti OR″shared decisions″.ti OR″SDM″.ti OR″shared decis*″.ti OR ((″shared″.ti OR ″share″.ti OR″sharing″.ti) AND (exp″Decision Making″/ OR″decision″.ti OR″decisions″.ti)) OR ((exp *″Decision Making″/ OR″decision making″.ti OR″decision-making″.ti) AND (exp *″social environment″/ OR″family″.ti OR″community″.ti OR″friend″.ti OR″friends″.ti OR exp *″communication″/ OR exp *″human relation″/ OR exp *″patient participation″/ OR″patient participation″.ti OR *″Doctor Patient Relationship″/ OR″Physician-Patient Relations″.ti OR″patient empowerment″.ti OR *″Empowerment″/)) OR ″patient decision″.ti OR ″patient decisions″.ti OR ″informed decision making″.ti OR″evidence-based patient choic*″.ti) AND (″nonpreference″.ti,ab OR″non preference″.ti,ab OR″nonprefer*″.ti,ab OR″non prefer*″.ti,ab OR″sensitive decisions″.ti,ab OR″sensitive decision″.ti,ab OR″effective decisions″.ti,ab OR ″effective decision″.ti,ab OR″effective decision*″.ti,ab OR″preference-sensitive″.ti,ab OR″preference sensitiv*″.ti,ab OR ″preference effective″.ti,ab OR″non equipoise*″.ti,ab OR″nonequipoise*″.ti,ab OR″equipoise″.ti,ab OR″counterbalance″.ti,ab OR ″counterpoise″.ti,ab OR ″equipoise*″.ti,ab OR ″counterbalanc*″.ti,ab OR ″counterpois*″.ti,ab OR ″Decision situation″.ti,ab OR″choice situation″.ti,ab OR″decision type″.ti,ab OR″Decision situations″.ti,ab OR″choice situations″.ti,ab OR″decision types″.ti,ab OR″Decision situation*″.ti,ab OR″choice situation*″.ti,ab OR″decision type*″.ti,ab OR ″disagreements″.ti,ab OR″disagreement″.ti,ab OR″dis agreement″.ti,ab OR″dis agreements″.ti,ab OR″typology″.ti,ab OR ″typolog*″.ti,ab OR″decisional situation*″.ti,ab OR″decision characteristic*″.ti,ab OR″decision making characteristic*″.ti,ab OR″decision making typ*″.ti,ab OR″decision making situation*″.ti,ab OR″decision making preference*″.ti,ab OR ″decision preference*″.ti,ab OR″decisional preference*″.ti,ab **OR″type of decision*″.ti,ab OR″types of decision*″.ti,ab OR ((″sensitive″.ti,ab OR″effective″.ti,ab OR″situation″.ti,ab OR″situations″.ti,ab OR″type″.ti,ab OR″types″.ti,ab OR″characteristic*″.ti,ab OR″preference*″.ti,ab) ADJ2″decision*″.ti,ab) OR ((″boundaries″.ti,ab OR″boundary″.ti,ab OR″limits″.ti,ab OR″limit″.ti,ab) ADJ3″decision*″.ti,ab))**)) NOT (conference review or conference abstract).pt

PsycINFO

http://search.ebscohost.com/login.aspx?authtype=ip,uid&profile=lumc&defaultdb=psyh

TI((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR ″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR ″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR ″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR ″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR ″counterpois*″ OR″Decision situation″ OR″choice situation″ OR″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR ″disagreement″ OR ″dis agreement″ OR ″dis agreements″)) OR SU((″shared decision making″ OR ″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR ″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR″choice situation″ OR ″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR″disagreement″ OR″dis agreement″ OR″dis agreements″)) OR MA((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″))

OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR ″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR ″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR ″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR ″counterpois*″ OR″Decision situation″ OR″choice situation″ OR″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR ″disagreement″ OR ″dis agreement″ OR ″dis agreements″)) OR AB((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR ″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR″choice situation″ OR ″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR″disagreement″ OR″dis agreement″ OR″dis agreements″))

Academic Search Premier

http://search.ebscohost.com/login.aspx?authtype=ip,uid&profile=lumc&defaultdb=aph

TI((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR ″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR ″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR ″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR ″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR ″counterpois*″ OR″Decision situation″ OR″choice situation″ OR″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR ″disagreement″ OR ″dis agreement″ OR ″dis agreements″)) OR SU((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR ″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR″choice situation″ OR ″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR″disagreement″ OR″dis agreement″ OR″dis agreements″)) OR KW((″shared decision making″ OR″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR ″friends″ OR″communication″ OR″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR ″Physician-Patient Relations″ OR″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND (″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR ″nonequipoise*″ OR″equipoise″ OR″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR″choice situation″ OR″decision type″ OR″Decision situations″ OR ″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR ″disagreements″ OR″disagreement″ OR″dis agreement″ OR″dis agreements″)) OR (TI(″shared decision making″ OR ″shared decisionmaking″ OR″shared decision″ OR″shared decisions″ OR″SDM″ OR″shared decis*″ OR ((″shared″ OR ″share″ OR″sharing″) AND (″Decision Making″ OR″decision″ OR″decisions″)) OR (shar* N5 decis*) OR (″Decision Making″ AND (″social environment″ OR″family″ OR″community″ OR″friend″ OR″friends″ OR″communication″ OR ″interpersonal relations″ OR″patient participation″ OR″patient participation″ OR″Physician-Patient Relations″ OR ″Physician-Patient Relations″ OR″patient empowerment″ OR″Power, Psychological″)) OR″patient decision″ OR″patient decisions″) AND AB(″nonpreference″ OR″non preference″ OR″nonprefer*″ OR″non prefer*″ OR″sensitive decisions″ OR ″sensitive decision″ OR″effective decisions″ OR″effective decision″ OR″effective decision*″ OR″preference-sensitive″ OR″preference sensitiv*″ OR″preference effective″ OR″non equipoise*″ OR″nonequipoise*″ OR″equipoise″ OR ″counterbalance″ OR″counterpoise″ OR″equipoise*″ OR″counterbalanc*″ OR″counterpois*″ OR″Decision situation″ OR ″choice situation″ OR″decision type″ OR″Decision situations″ OR″choice situations″ OR″decision types″ OR″Decision situation*″ OR″choice situation*″ OR″decision type*″ OR″disagreements″ OR″disagreement″ OR″dis agreement″ OR ″dis agreements″))

Supplement 2.

Table 1. Decision characteristics and decision examples of all included articles. *(including the setting in which they were described)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper** [1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Decision characteristics for which SDM is deemed appropriate					
Equipoise	Equipoise - *A situation where a decision point with more than one option (including the option to maintain the status quo) exists and for which potential benefits and harms should be weighed across the options*	-	-	-	(46)
Equipoise	Equipoise - *A situation in which more than one option exists (including the option of status quo) and in which the pros and cons of each option must be weighed*	Prenatal screening for Down syndrome during pregnancy	Prenatal screening	Gynaecology	(40)
Equipoise	Equipoise - *when multiple treatment options with relatively equal effectiveness and treatment may be more based on preferences, values and goals*	-	-	Mental healthcare (setting article)	(31)
Equipoise	Clinical uncertainty or equipoise - *equipoise exists when there are two or more medically reasonable management options, either of which could be favoured based on the patient's values and preferences) AND 2) sufficient amount of time AND 3) patient able to participate in decision making*	To perform diagnostic evaluation and admission for suspicion acute coronary syndrome but with an unremarkable electrocardiogram, immediate antibiotics or 'wait and see' approach for acute otitis media, choice of anticoagulation for atrial fibrillation, initial imaging for acute flank pain and thrombolysis for acute ischemic stroke	Diagnostic, treatment, care transition	Emergency department	(45)
Equipoise	Equipoise - *where conflicting or inadequate evidence offers no single "best" intervention)*	Surgery or conservative care for sciatica	Treatment	Physiotherapy	(18)
Equipoise	1) Time to make decision, 2) clinical equipoise, 3) patient decision making ability	Disposition decision (admit versus discharge) after a negative diagnostic evaluation for low-risk chest pain, choice of anticoagulation for patients with new-onset atrial fibrillation, and the disposition decision (admit versus discharge) after a negative diagnostic evaluation for isolated syncope	Treatment (chronic care), care transition decision	Emergency department	(21)
Equipoise	Equipoise	Examples in the training of SDM: initiating longer-term medications (cholesterol medication), lifestyle modifications, or cancer screening	Treatment, (cancer) screening	Chronic care, oncology	(36)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper** [1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Equipoise	Equipoise - *evidence that there may be alternative best practice choices*	-	-	-	(28)
Equipoise	Equipoise as a step of SDM process	Items developed in SDMQ-9 related to treatment decisions, validated in depression, gynaecology, medical decisions in general practice, urology, anaesthesia	Treatment	Mental healthcare, gynaecology, primary care, urology, anaesthesia	(49)
Equipoise	Equipoise - *balance exists between harm and benefit of different options […] the existence of options that are in balance in terms of their attractiveness, or that the outcomes are to, a degree at least, equally desirable (or possibly, undesirable). This balance between options need not be perfect, indeed it is doubtful whether for any one individual that perfect equipoise between choices ever exists; but insofar as is reasonable, equipoise can be deemed to exist when a majority of people would agree that it is reasonable to consider making a choice between competing options*	Mastectomy or breast sparing surgery in case of early stage breast cancer	Treatment	Oncology	(81)
Equipoise	Equipoise - *a decision in which options really are options, must exist in order for a shared decision to successfully take place and thereby justify the term*	-	-	-	(59)
Equipoise	Clinical equipoise - *when the potential risks and the benefits of an intervention tend towards zero, balancing risks and benefits is extremely challenging, if not impossible*	Breastfeeding by HIV infected mothers (in optimal scenario with low viral load and adherent to HIV medication)	Childbearing with disease	Childbearing with disease	(66)
Equipoise	Equipoise	Hospitalization or discharge for chest pain evaluation, intensive care unit or hospice for terminal patient	Care transition decisions, end-of-life decisions	Emergency department	(67)
Equipoise	Clinical equipoise - *i.e. uncertainty about the relative therapeutic benefit of every arm of a trial alters the role of shared decision making when consenting a potential subject to participate in clinical research*	Enrolment clinical research (enrolment in clinical trials)	Enrolment in research	Research	(86)
Equipoise	Equipoise - *not one option exist*	Decisions in surgery (in general)	Treatment (surgery)	Surgery	(70)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Equipoise	Equipoise - *more than one reasonable treatment option and where none has a clear health outcome advantage, where each has benefits and disadvantages, and may vary in their scientific uncertainty*	-	-	-	(88)
Equipoise	Clinical equipoise - *clinical situations where more than one reasonable option exists for that person*	Choice of medication in epilepsy, treatment or medication withdrawal epilepsy during pregnancy	Treatment, childbearing with disease	Neurology	(89)
Equipoise	Clinical equipoise	-	-	-	(57)
Equipoise (dual)	Dual equipoise - *where both health professionals and patients, once informed, agree conceptually that individual preferences are acceptable arbitrators of choice. Dual equipoise assumes that all parties in the decision space agree that preferences are paramount that there is sufficient equivalence among options to allow personal preference to hold sway.*	Mastectomy or breast sparing surgery in case of early stage breast cancer, PSA (prostate specific antigen) testing for prostate cancer	Treatment, screening (cancer)	Oncology	(81)
Equipoise (professional)	Equipoise - *professional equipoise: in certain clinical scenarios the doctor can have no clear preference about the treatment choice to make. This is where shared decision making is most feasible. Legitimate choices exist.*	-	-	-	(43)
Equipoise (professional)	Professionally situated equipoise - *We propose that professionally- situated equipoise is a pre-condition to the existence of dual equipoise interactions, and that these in turn facilitate shared decision making, and, as a result, are a pre-condition for the implementation of decision support interventions*	Mastectomy or breast sparing surgery in case of early stage breast cancer, PSA (prostate specific antigen) testing for prostate cancer	Treatment, screening (cancer)	Oncology	(81)
Equipoise (professional)	Professional equipoise - *Professional equipoise about the outcomes of decisions is an important criterion that enables shared decision-making to take place, and which is missing in these cases. It allows patients the `freedom' to choose preferred options*	-	-	-	(58)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Equipoise (professional)	Professional equipoise - *the patient is free to choose whatever option they prefer, given that they have received the necessary information on which to base their choice*	-	-	-	(59)
Every decision	In a healthcare encounter when an issue/need is identified	-	-	-	(28)
Every decision	In all decisions, reasonable attempt to SDM should always be made	-	Diagnostic test, treatment, care transition decisions	Emergency department	(67)
Every decision	Every clinical decision	-	-	-	(86)
Every decision	All delivered care decisions independent of the level of evidence or presence of equipoise	-	-	-	(92)
Every decision	Decisions including both certainty AND uncertainty	-	-	-	(63)
Every decision	All decisions (including when there is a best choice)	-	-	-	(79)
Impact decision high	Treatment choices that have serious implications for their health outcomes and quality of life	Cancer treatment decisions, i.e. breast cancer and the decision for chemotherapy	treatment	Oncology	(24)
Impact decision high	Complex (mental health) decisions: involving number of life domains and contain both biopsychological aspects as having effects and consequences on individuals life which emerge over time	Decisions concerning psychiatric care or treatment	Treatment	Mental healthcare	(35)
Impact decision high	Decisions that potentially have major adverse effects for which the risks and benefits have to be carefully weighed against each other	Lung cancer screening with low-dose CT: potential important harms (false-positive findings with investigations of those carrying risk of morbidity and even mortality)	Screening	Primary care	(27)
Impact decision high	Options that have irreversible and enduring side effects	-	Treatment	Oncology	(48)
Impact decision high	Major decisions	Surgery decisions, chemotherapy decisions	Treatment	Primary care (setting article)	(14)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Impact decision high	Substantive everyday decisions (intermediate stakes decisions that occur dozens of times every day, yet nontrivial for patients), 'everyday SDM' is applicable here	Routine mammography starting at age 40, 45 or 50, screening decisions for cancers (prostate, cervical, colon, lung, ovarian), cardiovascular prevention decisions (statins, aspirin, and blood pressure medications: when to start them and which one(s) and at what dose; when to follow-up; when to increase dosing; or when to stop them completely)	Screening (cancer), treatment	Primary care	(14)
Impact decision high	Discrete treatment decisions for serious acute care illnesses with important and immediate consequences to the patient, for which alternatives exist	Surgical treatment choices for patients with new diagnosis of breast cancer, leg amputation vs. medical treatment or revascularization in a patient with diabetes and ischaemic limb pain and ulcer, surgical repair of bone fracture vs casting, use of thrombolytic agents to decrease long-term sequalae of an ischaemic stroke	Treatment	Emergency department, oncology	(17)
Impact decision high	Spill-over effect illness (parents and other family members affected by the child's illness), often because of potential for serious consequences (mortality, physical comorbidities, hospitalization) that causes psychological burden	Early Introduction of Allergenic Solids in food allergy, peanut allergy treatment choice in food allergy anaphylaxis management	Treatment	Allergy care	(75)
Impact decision high	Critical decisions (wrong decisions might lead to poor outcomes)	Antipsychotic treatment in psychotic patient	Treatment	Mental healthcare	(82)
Impact decision high	Decision that influence daily routines or interactions with healthcare systems	Introduction of technology in children with severe neurologic impairment	Treatment	Paediatric care	(87)
Impact decision high	Impact on patient and family	Introduction of technology in children with severe neurologic impairment	Treatment	Paediatric care	(87)
Impact decision high	Decisions potentially resulting in radical change in life and health status	Decisions in surgery (in general)	Treatment	Surgery	(70)
Impact decision high	Decisions crucially depending on individual context because of high side effect burden and modest effects	Surgery or radiation therapy for localized lung cancer with impaired lung function, addition of erlotinib to gemcitabine for metastatic pancreatic cancer	Treatment	Oncology	(71)
Impact decision high	High risk intervention: possible (long term) poor outcomes, potential unwanted outcomes or unsuccessful treatment	(Major) surgery	Treatment	Surgery	(100)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Impact decision high	The intervention of the decision-option is potentially physically, emotionally or financially harmful	Non emergent intensive care unit decisions: permanent feeding tube (percutaneous feeding tube), permanent dialysis catheter, suprapubic urinary catheter, tracheotomy, long-term venous catheter, pulmonary artery catheter, in-hospital dialysis, or temporary naso gastric feeding tube.	Treatment	Intensive care unit	(56)
Impact decision high	Decision option has profound impact on individuals life	Electroconvulsive therapy, psychosurgery, psychiatric medication during pregnancy, decision to return to work or school, psychiatric medications	Treatment, returning society, childbearing with disease	Mental healthcare	(79)
Impact decision high	Likelihood of cure of option unprecedented and high impact therapy	Medulloblastoma in child (aggressive treatment with cognitive side effects)	Treatment	Oncology (paediatric)	(94)
Impact decision high	Multiple high stakes around decisions	Decisions required when dealing with a cancer diagnosis	Treatment	Oncology	(97)
Irreversibility	Discrete decisions: single time point, irreversible, relatively urgent	Undergo surgical procedure, to have a test, to enter a screening programme	Treatment, diagnostic testing, screening	Surgery	(81)
Irreversibility	Irreversibility of decision	Decisions in surgery (in general)	Treatment	Surgery	(70)
Known to often entail misalignment in views	Decisions causing frequent disagreement patients, caregivers and HCP	Planning youth mental health (psychotherapy) treatment	Treatment	Mental healthcare	(31)
Known to often entail misalignment in views	Potential goal misalignment patients and clinicians in the decision (patients often very particular preferences for these decisions)	Food immunotherapy: oral, epicutaneous or sublingual, food allergy decisions: diagnostic testing, application new guidelines on early potentially allergenic solid food introduction, the use of formal oral food challenges or less formal supervised feeds	Treatment, diagnostic testing	Allergy care (paediatric)	(60)
Known to often entail misalignment in views	Complicated and competing interests around decision, alternative SDM proposed	Enrolment clinical research	Enrolment in research	Research	(86)
Known to often entail misalignment in views	Intervention (decision) potentially incompatible with more than one common patient goals	Non emergent intensive care unit decisions: permanent feeding tube (percutaneous feeding tube), permanent dialysis catheter, suprapubic urinary catheter, tracheotomy, long-term venous catheter, pulmonary artery catheter, in-hospital dialysis, or temporary naso gastric feeding tube.	Treatment	Intensive care unit	(56)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Long window of opportunity to make decision	Intervention can be anticipated on a non-emergent basis	Non emergent intensive care unit decisions: permanent feeding tube (percutaneous feeding tube), permanent dialysis catheter, suprapubic urinary catheter, tracheotomy, long-term venous catheter, pulmonary artery catheter, in-hospital dialysis, or temporary naso gastric feeding tube.	Treatment	Intensive care unit	(56)
Multiple options	Several treatment options exist with different possible outcomes and substantial uncertainty	Early stage breast-cancer treatment decision making	Treatment	Oncology	(11)
Multiple options	When decisions involve more than one choice	Decisions about genitoplasty for children with disorders of sex development	Treatment	Paediatric care	(25)
Multiple options	More than one reasonable treatment option available including taking no action	Early stage breast-cancer treatment decision making: lumpectomy with radiotherapy or mastectomy, surgery for urinary problems due to enlarged prostate	Treatment	Oncology, surgery	(4)
Multiple options	Alternative options exist	-	-	-	(44)
Multiple options	More than one medically reasonable option	Breast cancer and prostate cancer: when the treatment options affected patients' lifestyle and self-image (e.g., treatments for prostate cancer that affected sexual function), when deciding upon treatments for supportive or palliative care.	Treatment	Oncology	(24)
Multiple options	Both clinicians and patients have to perceive that there are treatment choices (including doing nothing as a choice), options have different possible outcomes (benefits and risks or side effects)	Early stage breast-cancer treatment decision making	Treatment	Oncology	(30)
Multiple options	More than one medically reasonable option	Decisions about diagnosis, treatment or follow up	Treatment, diagnostic testing, planning (follow up)	Not specified	(5)
Multiple options	Multiple options exist	Mental health decisions: which family members will participate in treatment, what type of communication caregivers will have with the clinician, how much confidentiality caregivers will allow the clinician to maintain with youth patients, and what type of treatment to use (or which skills to focus on)	Treatment	Mental healthcare	(31)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Multiple options	Existing several options with different possible outcomes: decisional conflict	-	-	Paediatric care (setting article)	(19)
Multiple options	Any doctor-patient encounter in which a substantive decision is made about treatment or investigation for which reasonable choices exist	-	Treatment, diagnostic testing	Oncology	(33)
Multiple options	Reasonable available options including taking no action	-		-	(43)
Multiple options	One more effective option but still multiple acceptable options given patient preferences	Hypertension treatment	Treatment	Chronic care	(83)
Multiple options	Various options with varying degrees of effectiveness and side effects	Choosing alternatives for opioids in chronic pain management, de-prescribing main medication	Treatment	Chronic care	(54)
Multiple options	Several reasonable options with different (side) effects where patients differ in their preferences for outcomes and options	Treatment choice lower urinary tract symptoms due to BPH (surgery, medication, watchful waiting), screening tests (PSA (prostate specific antigen)screening), decisions on strategies of care (overall goals of care and end of life decisions)	Treatment, screening (cancer), and end of life decisions	Oncology, chronic care	(78)
Multiple options	Alternative treatment method exists (SDM *even more* applicable)	Decisions in surgery (in general)	Treatment	Surgery	(70)
Multiple options	More than one medically reasonable option with medically reasonable defined as consistent with the standard of care	-	-	Paediatric care (setting article)	(76)
Multiple options	No consensus standard care (therefore more than one acceptable option)	Surgical intervention hypoplastic left heart syndrome or trisomy (child surgery congenital heart disease)	Treatment	Paediatric care (surgery)	(76)
Multiple options	Multiple clinically appropriate options exist	Choices among biologics for asthma with an eosinophilic phenotype	Treatment	Allergy care	(61)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Multiple options	Multiple equally suitable, or effective treatment options available	Bariatric surgery procedure selection, early stage breast cancer surgery, colorectal surgery, orthopaedic surgery for shoulder disorders; carpal tunnel syndrome or joint replacements, pelvic organ prolapse surgery, vascular surgery for abdominal aneurysms; peripheral vascular disease; varicosis or carotid stenosis, (neo)adjuvant treatments related to various oncological surgical interventions, and all indications for cosmetic or aesthetic surgery.	Treatment	Surgery	(92)
Multiple options	More than one reasonable option, three circumstances: single treatment vs trial, well-defined trade-off between different treatments, two different treatments that result in equal cure rates and long term adverse effects	Medulloblastoma in child (aggressive treatment with cognitive side effects)	Treatment	Oncology (paediatric)	(94)
Multiple options	SDM useful in complex cases where multiple options exist	Decisions required when dealing with a cancer diagnosis	Treatment	Oncology	(97)
Multiple options	All decisions that contain competing options or the different approaches need prioritization	-	-	Chronic care (setting article)	(83)
No best option	No clear-cut right or wrong answer	Early stage breast-cancer treatment decision making	Treatment	Oncology	(11)
No best option	No clear best choice treatment	Decisions about genitoplasty for children with disorders of sex development	Treatment	Paediatric care (surgery)	(25)
No best option	Best clinical option not clear	-	-	Paediatric care (setting article)	(87)
No best option	Evidence does not indicate superior option, patient preferences may heavily influence decision	Tonsillectomy or watchful waiting for children with recurrent throat infection	Treatment	Surgery	(91)
No best option	No clear best choice	-	-	.	(61)
No best option	Chance of cure is slight and there is a reasonable choice in therapies	Aggressive anticancer therapy or palliative care for adolescent with acute lymphocytic leukaemia who has had more than one bone marrow relapse	Treatment	Oncology (paediatric)	(94)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
One best option	One clear best treatment choice (though SDM is less applicable here then when there is equipoise)	Other decisions within "winner" treatment that can incorporate SDM, such as decisions about specific treatment goals, treatment participants, and other aspects of treatment that are malleable	Treatment	Mental healthcare	(31)
One best option	Evidence, practice guidelines and protocols strongly favour particular options	-	-	.	(18)
One best option	One best option	No antibiotics for 5 year old with viral upper respiratory infection	Treatment	Paediatric care	(34)
One best option AND Weight of decision (light)	Only one medically reasonable option but low severity of illness, elective nature of treatment	Antihistamine for mild seasonal allergies	Treatment	Paediatric care	(76)
One best option but likely to disagree	One best treatment, but perspectives client-clinician may differ in defining the problem to target	-	-	Mental healthcare (setting article)	(31)
One best option but likely to disagree	Best-choice decisions: professionals agree on decision but anticipate patient resistance (a better option clearly exists but also poses a risk that the patient will refuse)	Antipsychotic treatment in psychotic patient	Treatment	Mental healthcare	(82)
Patient commitment is needed to carry out decision	Active role patient needed in carrying out decision	Planning youth mental health (psychotherapy) treatment	Treatment	Mental healthcare	(31)
Patient commitment is needed to carry out decision	Active patient role needed in carrying out decision	Treatment decisions in chronic care (e.g. treatment decisions for diabetes, hypertension, asthma)	Treatment	Chronic care	(17)
Patient commitment is needed to carry out decision	Patients role during treatment administration is active (patient controls treatment administration) rather than passive (inflicted on patient)	Chronic care: lifestyle and pharmacological treatment choices for patients with new diagnosis of uncomplicated type 2 diabetes	Treatment	Chronic care	(17)
Patient commitment is needed to carry out decision	Long term commitment needed for chosen decision	Food allergy: diagnostic testing, application new guidelines on early potentially allergenic solid food introduction, oral food challenges, supervised feeds, other treatment options	Treatment, diagnostic testing	Allergy care (paediatric)	(60)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Patient commitment is needed to carry out decision	Patient adherence required in carrying out decision	Food allergy: diagnostic testing, application new guidelines on early potentially allergenic solid food introduction, oral food challenges, supervised feeds, other treatment options	Treatment, diagnostic testing	Allergy care (paediatric)	(60)
Patient commitment is needed to carry out decision	Decisions requiring significant amount of self-care, alternative SDM approach proposed: SDM and CSA=counselling selfcare and adherence	Chronic condition management in elderly	Treatment	Elderly care	(65)
Patient commitment is needed to carry out decision	Some options may require substantial time commitments	Choosing alternatives for opioid in pain management chronic pain which are time consuming such as physical therapy	Chronic pain management	Chronic care	(54)
Patient commitment is needed to carry out decision	When parents/patients are primarily responsible for implementation SDM should be calibrated to align with this responsibility (i.e. a weaker version of parent-guided SDM can be calibrated to a stronger one).	Supine sleep position, decisions regarding breastfeeding for new-borns	New born parent care	Paediatric care	(76)
Patient commitment is needed to carry out decision	Long-term potentially complicated or intensive treatments where adherence depends on patient preferences (SDM needed to explore these preferences)	Atopic disease treatments	Treatment	Allergy care	(61)
Patient commitment is needed to carry out decision	Decision implementation in patient's own 'space'	Chronic care: lifestyle and pharmacological treatment choices for patients with new diagnosis of uncomplicated type 2 diabetes	Treatment	Chronic care	(17)
Patient commitment is needed to carry out decision	Patients' needs to implement decision	Self-care in chronic disease management (taking prescribed medication, lifestyle modifications such as losing weight and exercise)	Treatment	Primary care	(16)
Preference-sensitive	Options depend heavily on decision makers values	Decisions about genitoplasty for children with disorders of sex development	Treatment	Paediatric care	(25)
Preference-sensitive	Preference-sensitive	-	-	Primary care (setting article)	(40)
Preference-sensitive	Choice best option depends on patients preferences and values *- term 'preference-sensitive' not mentioned in this article)*	Cancer treatment decisions, i.e. breast cancer and the decision for chemotherapy	Treatment	Oncology	(24)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Preference-sensitive	Preference-sensitive - *those medical decisions for which there is more than one medically reasonable approach to treatment*	-	-	-	(20)
Preference-sensitive	Preference-sensitive - *evidence lacking or weak and/or equipoise; various treatment options, only patient preferences can adjudicate*	Decisions about diagnosis, treatment or follow up	Treatment, diagnostic testing, planning	Not specified	(5)
Preference-sensitive	Preference-sensitive - *a state of uncertainty regarding a course of action and occurring when two or more clinically reasonable options involve benefits and risks that patients value differently*	-	-	Paediatric care (setting article)	(19)
Preference-sensitive	Preference-sensitive conditions - *conditions where treatment options exist that come with trade-offs between potential harms and benefits for the patient*	Hospital admission or not for diagnostic evaluation possible acute coronary syndrome with an unremarkable electrocardiogram , immediate antibiotics or 'wait and see' approach for acute otitis media, choice of anticoagulation for atrial fibrillation, initial imaging for acute flank pain and thrombolysis for acute ischemic stroke	Diagnostic testing, treatment, care transition decisions	Emergency department	(32)
Preference-sensitive	Preference-sensitive	Curative treatment decisions and decisions in chronic care (goal setting)	Treatment	Primary care	(29)
Preference-sensitive	Preference-sensitive - *several methods medically appropriate, result of decision experience influences by patient values, preferences and lived experiences*	Contraceptive counselling, pelvic examination (screening) in asymptomatic non pregnant women	Preventive /screening	Gynaecology	(22)
Preference-sensitive	Preference-sensitive - *no single best option exist*	Patient with multimorbidity: prioritizing in diseases (e.g. focus on osteoarthritis or other diseases like diabetes, hypertension, dyslipidaemia, obesity), treatment options (e.g. pain reduction options osteoarthritis; physiotherapy, paracetamol, oral NSAID, topical NSAID, hyaluronic acid injection, surgery total hip replacement).	Treatment, prioritizing comorbidity	Primary care	(23)
Preference-sensitive	Preference-sensitive zone - *uncertainty treatment outcomes and individual preferences creating a grey area for medical decision making*	-	-	Primary care (setting article)	(14)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Preference-sensitive	Preference-sensitive - *situations in which multiple treatment options, each with potential trade-offs and outcomes where the decision to choose 1 option is largely dependent on the values and personal preferences of the patient*	Food allergy: diagnostic testing, application new guidelines on early potentially allergenic solid food introduction, oral food challenges, supervised feeds, other treatment options	Treatment, diagnostic testing	Allergy care (paediatric)	(60)
Preference-sensitive	Preference-sensitive	-	-	-	(80)
Preference-sensitive	Preference-sensitive care - *describes a situation where the evidence for the superiority of one treatment over another is not available; there are therefore two or more valid approaches to care and the best choice depends on how a patient values the risks and benefits of the treatments available*	Early stage breast cancer and decision whether to have surgery that removes or conserves the breast (mastectomy or breast conservation), PSA testing for prostate cancer	Treatment, screening (cancer)	Oncology	(81)
Preference-sensitive	Preference-sensitive - *when there is no obvious 'best' treatment. Treatment choice then depends on a necessarily subjective trade-off be- tween the benefits and side-effects of treatment alter- natives. Therefore, patients' informed values and preferences should drive decision making) (...) options vary in benefit, important short and long term side effects, impossible to predict which patient will benefit*	Chemotherapy and endocrine therapy stage III breast cancer	Treatment	Oncology	(55)
Preference-sensitive	Preference-sensitive - *clinical equipoise or substantial uncertainty of effect size treatment (...) clear treatment option, but values vary significantly patient-to-patient*	Treatment thyroid nodules/cancers and laryngeal cancer: surveillance or surgery	Treatment, surveillance (cancer)	Oncology	(64)
Preference-sensitive	Preference-sensitive - when the choice of a particular option becomes dependent on what the personal preferences and values of the patient may be	Early allergenic solid introduction, pre-emptive epinephrine use when allergic exposure but no symptoms, automatic activation of EMS after using epinephrine, and choices of food allergy treatment	Treatment, prevention	Allergy care	(75)
Preference-sensitive	Preference-sensitive decisions - *several more or less equivalent options or uncertainty about best way to proceed*	Drug choice in mental healthcare	Treatment	Mental healthcare	(82)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Preference-sensitive	Preference-sensitive - *may occur when 1) multiple treatment options exist and none of them is clearly superior for all patients, 2) the evidence supporting one option is considerably uncertain or variable, and/or 3) patients' views on the most important benefits and acceptable risks vary considerably within the patient population or differ from those of health care professionals*	-	-	-	(77)
Preference-sensitive	Highly preference-sensitive decisions - *evidence about benefits and harms treatments limited, decisions involve weighing many factors (patient capacity, social support, carers, burden of treatment), best option strongly depends on which outcomes matter the most to the individual older patient and their circumstances, patients preferences will vary widely*	CVD prevention (re-evaluating, starting, adjusting medication decision) in elderly care	Prevention	Elderly care	(53)
preference-sensitive	Major preference-sensitive decisions - *major treatment decisions that may be affected by personal values, goals and preferences*	Goals of care (Intensive care Unit) including withdrawing or limiting life prolonging interventions	End-of-life decisions	Intensive care unit	(98)
Preference-sensitive	Preference-sensitive - *many reasonable options exist and patients can have different goals and preferences for treatment and each option has different trade-offs, risks and quality of life implications that may be valued differently by patients*	Managing uncomplicated stage 1 hypertension: future opportunities for SDM in hypertension may include home and ambulatory blood pressure monitoring, individualized blood pressure targets, antihypertensive medication selection, and integration of lifestyle interventions	Treatment	Chronic care	(74)
Preference-sensitive	Highly preference-sensitive - *no consensus on decision, more than one alternative treatment with a variety of benefits and risks without convincing evidence best choice, trade off survival and morbidity, psychological distress and increased health care costs*	Prostate cancer screening	Screening (cancer)	Oncology	(68)
Preference-sensitive	Preference-sensitive - *similar efficacies of available options*	Antipsychotic (medication) management	Treatment	Mental healthcare	(85)
Preference-sensitive	Preference-sensitive (SDM most easily applied here) - *no clear best option, no clear evidence, or clear evidence of benefit in tandem with significant risks or burdens and especially when prognosis is uncertain*	An array of potential health care decisions relating to medication treatment, revascularization procedures, valve replacement, and device-based therapies	Treatment	Surgery	(69)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Preference-sensitive	Preference-sensitive decisions	Introduction of technology in children with severe neurologic impairment	Treatment	Paediatric care	(87)
Preference-sensitive	Preference-sensitive	-	-	Paediatric care (setting article)	(76)
Preference-sensitive	Preference-sensitive - more than one reasonable treatment option and where none has a clear health outcome advantage, where each has benefits and disadvantages, and may vary in their scientific uncertainty i.e. where equipoise exists. Because these factors are valued by individual patients differently, they are preference-sensitive	Multiple sclerosis disease modifying therapies (immunomodulatory therapies)	Treatment	Neurology	(88)
Preference-sensitive	Preference-sensitive - *where there is equipoise between treatment options with equal or similar outcomes from a medical standpoint*	Blood pressure medication, cholesterol medication, chemotherapy in metastatic colorectal cancer	Treatment	Chronic care, oncology	(90)
Preference-sensitive	Preference-sensitive - *multiple medically appropriate options, patients preferences for risks and benefits of options are key*	Whether or not to have a prostate-specific antigen test for men aged 65 years, when to start mammography screening for women aged 40–50 years, cancer treatment decisions (e.g., whether or not to participate in a phase III clinical trial and whether or not to have chemotherapy for early-stage cancer), end- of-life care decisions (e.g., when to forgo cancer-directed therapy and focus exclusively on palliative care and whether or not to participate in a phase I or phase II clinical trial)	Screening (cancer), treatment, enrolment in research, end-of-life decisions	Oncology	(71)
Preference-sensitive	Preference-sensitive - *no best option from an evidence standpoint and patient preferences central to the choice, trade-offs between risks and benefits of options*	Prostate cancer screening (PSA, prostate specific antigen)	Screening (cancer)	Oncology	(72)
Preference-sensitive	Preference-sensitive - *where there is no one best available treatment*	-	-	.	(100)
Preference-sensitive	Preference-sensitive	non emergent intensive care unit decisions: permanent feeding tube (percutaneous feeding tube), permanent dialysis catheter, suprapubic urinary catheter, tracheotomy, long-term venous catheter, pulmonary artery catheter, in-hospital dialysis, or temporary naso gastric feeding tube.	Treatment	Intensive care unit	(56)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper [1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Preference-sensitive	Preference-sensitive - *choice involves trade-off between length and quality of life, or such competing considerations as preservation of bodily integrity, prevention of future problems, cost, and convenience*	Mastectomy versus lumpectomy plus radiation for small localized breast cancer	Treatment	Oncology	(10)
Preference-sensitive	Preference-sensitive - *more than one reasonable option*	Mastectomy versus lumpectomy for early breast cancer, PSA (prostate specific antigen) testing to screen for prostate cancer, anticoagulation (or not) for atrial fibrillation	Screening (cancer), treatment	Oncology, chronic care	(95)
Preference-sensitive	Preference-sensitive conditions - *there exist a number of available treatment options of similar efficacy, with differences in risks and benefits*	Relapsing-remitting multiple sclerosis treatment: starting steroids, immunotherapy, disease-modifying drugs early in the disease course, having a child	Treatment, childbearing with disease,	Neurology	(62)
Preference-sensitive	Preference-sensitive	Form, frequency and length of surveillance imaging and form, frequency and length of follow up consultations aimed at physical and psychosocial effects of treatments, adjuvant anti-hormonal treatment, breast reconstruction, treatment affecting fertility, getting pregnant after breast cancer, lifestyle changes, use of alternative and complementary medicine, hereditary testing,	Planning (follow up), treatment, childbearing with disease	Oncology	(63)
Preference-sensitive	Preference-sensitive decisions - *i.e. psychiatric medication that can be effective but also harmful and ineffective for some people*	Electroconvulsive therapy, psychosurgery, psychiatric medication during pregnancy, decision to return to work or school, psychiatric medications	Treatment, returning society, childbearing with disease	Mental healthcare	(79)
Reversibility	Reversibility of the decision (revisit and reverse them without important loss)	Treatment decisions in chronic care (e.g. treatment decisions for diabetes, hypertension, asthma)	Treatment	Chronic care	(17)
Short timeframe to make decision	Discrete decisions: single time point, irreversible, relatively urgent	Undergo surgical procedure, to have a test, to enter a screening programme	Treatment, diagnostic testing, screening	Surgery, not specified	(81)
Short timeframe to make decision	Decision time dependent	Cyanoacrylate or sutures, do-not-resuscitate order with advanced metastatic malignancy	Treatment, end-of-life decisions	Emergency department	(67)
Short timeframe to make decision	Narrow window of time to make decisions	Decisions required when dealing with a cancer diagnosis	Treatment	Oncology	(97)
Trade off	Each choice advantages and disadvantages	Decisions about genitoplasty for children with disorders of sex development	Treatment	Paediatric care	(25)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Trade off	Substantive risk/benefit trade-offs	Routine mammography starting at age 40, 45 or 50, screening for cancers (prostate, cervical, colon, lung, ovarian), cardiovascular prevention decisions (statins, aspirin, and blood pressure medications: when to start them and which one(s) and at what dose; when to follow-up; when to increase dosing; or when to stop them completely)	Screening (cancer), treatment	Primary care	(14)
Trade off	Similar efficacy profiles and complex risk-benefit trade-offs	Psychotropic agents medications	Treatment	Mental healthcare	(80)
Trade off	Decisions involving range of trade offs	Obese patient choosing best intervention; diet, exercise or medical	Treatment	Chronic care	(83)
Trade off	Treatments involving trade-offs that can be considered differently by individual patients	Healthcare decisions cardiovascular disease: percutaneous interventions (cardiac stents and aortic valves) to major surgeries (cardiac transplant i.e. or mechanical circulatory support)	Treatment	Surgery	(69)
Trade off	Balance of benefits and harms is a close call and determined by individual preferences	-	-	-	(99)
Trade off individual impact and public benefit	Effective care (substantial impact population but less for individual)	Vaccination	Vaccination	Vaccination	(72)
Trade-off	Trade-off in decisions, for which not all patients choose the same, because weighing importance of averting an outcome of decision depends on patients, because patients know best how a symptom will affect their lives	-		-	(99)
Uncertainty	Uncertainty	-	-	-	(28)
Uncertainty	Uncertainty	-	Treatment	Oncology	(48)
Uncertainty	Uncertainty	Lumpectomy with radiation therapy com- pared to mastectomy for early breast cancer, systemic methotrexate compared to laparoscopic salpingostomy for tubal pregnancy, choice generic compared to brand name drug, arm sling or brace for midshaft fracture clavicle.	Treatment	Surgery, oncology	(9)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Uncertainty	Implications of findings (of diagnostic tests) uncertain	Diagnostic functional neuroimaging (with incompletely understood implications)	Diagnostic testing	Neurology	(96)
Uncertainty	High level of evidence (NCCN =National Comprehensive Cancer Network category 1) but specific individual patients have strong preferences or there are specific patients for which the evidence is less certain (e.g. patients with comorbidities who might have more toxicities from chemotherapy).	Choices within the class of therapy in newly diagnosed chronic myeloid leukaemia: when the only appropriate choice may be treatment with a tyrosine kinase inhibitor, and in some patients with meta- static prostate cancer, for whom hormone-mediated therapy may be considered the only medically appropriate therapy	Treatment	Oncology	(71)
Uncertainty	Medical uncertainty (low certainty): two or more clinically reasonable alternative exits (the physician is uncertain of the right course of action, or other clinicians might have different recommendations)	-	-	-	(10)
Uncertainty of evidence	When data/evidence is lacking	Decisions about genitoplasty for children with disorders of sex development	Treatment	Paediatric care	(25)
Uncertainty of evidence	Evidence on decisions limited or incomplete or high degrees of uncertainty	Breast cancer and prostate cancer: when the treatment options affected patients' lifestyle and self-image (e.g., treatments for prostate cancer that affected sexual function); and when deciding upon treatments for supportive or palliative care.	Treatment	Oncology	(24)
Uncertainty of evidence	Insufficient scientific evidence to inform decisions	Lung cancer screening	Screening	Primary care	(27)
Uncertainty of evidence	Substantial uncertainty: research insufficient or inconclusive	-	-	Paediatric care (setting article)	(19)
Uncertainty of evidence	Evidence about decision and its utility and efficacy limited	Introduction of technology in children with severe neurologic impairment	Treatment	Paediatric care	(87)
Uncertainty of evidence	Ambiguity uncertainty (conflicting studies or strength of evidence)	-	-	-	(90)
Uncertainty of evidence	Clinical situations with significant uncertainty, such as situations where evidence is conflicting, unavailable, or not applicable to an individual patient	-	-	-	(90)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
Uncertainty of evidence	Informational uncertainty (lack of available or usable data in particular clinical context that me be a function of ambiguity)	-	-	-	(90)
Uncertainty of evidence	Level of evidence according to NCCN (National Comprehensive Cancer Network) below 2A (category 2A = the recommendation is based on lower level evidence and there is uniform NCCN consensus that the intervention is appropriate)	-	-	Oncology (setting article)	(71)
Uncertainty of evidence	Effective care (recommendations trials/evidence might not apply to individual level)	Colorectal cancer screening colonoscopy, sigmoidoscopy or faecal occult blood test at age 50	Screening (cancer)	Oncology	(72)
Uncertainty of evidence	Effective care (uncertainty about individual risk and benefit, policy groups differ in stratifying individuals into risk categories)	Taking aspirin for primary prevention of cardiovascular disease	Treatment	Chronic care	(72)
Uncertainty of evidence	Available evidence (from guidelines or randomized controlled trials) inconclusive	New surgical technologies are introduced	Treatment	Surgery	(92)
Uncertainty of evidence	Evidence based on different population than patient making patient preferences important	-	-	-	(92)
Uncertainty of evidence	Incomplete evidence	Decisions required when dealing with a cancer diagnosis	Treatment	Oncology	(97)
Uncertainty of outcomes	Outcomes vary in their impact on patients physical and psychological wellbeing	Early stage breast-cancer treatment decision making	Treatment	Oncology	(11)
Uncertainty of outcomes	Several treatment options exist with different possible outcomes and substantial uncertainty	Early stage breast-cancer treatment decision making	Treatment	Oncology	(11)
Uncertainty of outcomes	Outcomes in the individual case uncertain	Early stage breast-cancer treatment decision making	Treatment	Oncology	(30)
Uncertainty of outcomes	Outcomes vary in their impact on patients physical and psychological wellbeing	Early stage breast-cancer treatment decision making	Treatment	Oncology	(30)
Uncertainty of outcomes	Uncertainty outcomes where clinician cannot favour one option over the other	-	-	-	(77)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Uncertainty of outcomes	Implications decision hard to measure because, as they potentially affect a child's (patients) social interactions and influence parents' (patients) perceptions of their efficacy as parents	Introduction of technology in children with severe neurologic impairment	Treatment	Paediatric care	(88)
Uncertainty of outcomes	Health decisions that involve uncertain risks and benefits	Cholesterol lowering therapy prevention coronary events	Treatment	Chronic care	(72)
Uncertainty of outcomes	High risk and low certainty	Mastectomy versus lumpectomy plus radiation for small localized breast cancer	Treatment	Oncology	(10)
Uncertainty of outcomes	Low risk and low certainty	Lifestyle changes vs medication hyperlipidaemia	Treatment	Chronic care	(10)
Value sensitive	Medically uncertain and value sensitive (choice is likely to vary with religious, moral, and philosophical beliefs of patient)	Amniocentesis to screen for prenatal genetic effects	(genetic prenatal) Screening	Gynaecology	(10)
Weight decision (heavy)	Major preference-sensitive decisions (major treatment decisions that may be affected by personal values, goals and preferences)	Goals of care (Intensive Care Unit) including withdrawing or limiting life prolonging interventions	Goals of care, life prolonging decisions , treatment	Intensive care unit	(98)
Weight decision (heavy)	Major discrete decisions	Hip replacement for pain, treatment newly diagnosed breast/ prostate cancer	Treatment	Oncology, surgery	(78)
Weight decision (heavy)	Complex decisions	Multiple sclerosis disease modifying therapies (immunomodulatory therapies)	Treatment	Neurology	(88)
Weight decision (heavy)	Complex decisions (multiple treatment options, patient characteristics of multimorbidity, frailty, disability, impaired cognition and preferences both patients and professionals	Symptomatic severe aortic stenosis treatment: surgical aortic valve replacement or transcatheter aortic valve replacement	Treatment	Surgery	(73)
Weight decision (heavy)	Important (clinically important decision)	Conducting additional testing to diagnose carpal tunnel syndrome, the decision to have surgery or whether to perform a steroid injection into the carpal tunnel, distal radius fracture in patients aged greater than 65 years and the decision to have surgery, the decision to remove the implant, the type of pain medication prescribed after surgery	Diagnostic testing, treatment	Surgery	(57)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper [1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Weight decision (heavy)	Difficulty of the decision being made: meaning the perception individuals hold on how complex the decision is, which can be affected by values, preferences and experience.	-	-	-	(97)
Weight decision (heavy)	Major (treatment) decisions	Defining goals of care, major treatment decisions	Goals of care, treatment	Neurology	(96)
Weight of decision (light)	Both minor decisions and decisions with high stakes (patients and clinicians need to proficient in making shared decisions, to begin with in common problems).	-	-	-	(33)
Weight of decision (light)	Also non-major discrete decisions if more than one reasonable option with different patterns of therapeutic effects and side effects	Cholesterol medication	Treatment	Chronic care	(78)
Decision characteristics for which SDM is deemed NOT appropriate					
Behaviour change needed	Behaviour change needed instead of weighing reasonable options for which SDM would be needed, motivational interviewing could be used here	Committing patient to lose weight (previous to decision how to lose weight)	Chronic care	Primary care	(83)
Patient request for therapy in conflict with clinician's judgment	Cases (decisions) in which the patient/surrogate demands interventions the clinician believes are potentially inappropriate	-	-	.	(98)
Patient request for therapy in conflict with clinician's judgment	Always initiate SDM, but not feasible when agreement cannot be reached: in clinician professional judgement no realistic likelihood of benefit to the patient	Aggressive end-of-life measures in the face of an inevitable prognosis of death, requests of opioid medication when not indicated, requests antibiotics for (child) for viral infection, requests for hospital admission when not indicated	End-of life decisions, treatment, care transition decision	Emergency department	(67)
Patient request for therapy in conflict with clinician's judgment	Challenge SDM: competing views on decision clinician and patient	Opioid prescribing pain management	Treatment	Chronic care	(54)
Patient request for therapy in conflict with clinician's judgment	Decision patient not in best interest patient (due to patient being at risk for self-harm or lacking capacity decision making)	Antipsychotic (medication) management	Treatment	Mental healthcare	(85)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Patient request for therapy in conflict with clinician's judgment	Inappropriate parents (of patients) response to medically reasonable options	(parental refusal of) SABAs (Short-Acting Beta Agonists) and corticosteroids for moderate acute asthma exacerbation child	Treatment	Paediatric care	(76)
Immediate life-saving measures needed	Life-saving measures are required	Decisions in surgery (in general)	Treatment	Surgery	(72)
Immediate life-saving measures needed	Short time frame to make decisions	Acutely instable patient on Intensive Care Unit: cardiopulmonary resuscitation	Treatment	Intensive care unit	(56)
Immediate life-saving measures needed	Time decision making limited (acute)	Bacterial meningitis	Treatment	Neurology	(62)
No equipoise	When clinical equipoise is not met, SDM is not appropriate	-	-	.	(21)
No equipoise	No equipoise	Antibiotics viral upper respiratory tract infection	Treatment	Primary care	(59)
One best option	Only one medically reasonable management option, then informed consent and persuasion	Antibiotics for sepsis	Treatment	Emergency department	(32)
One best option	Medical benefit clearly outweighs risks and treatment in line with patient goals of care	Hospital admission for acute myocardial infarction	Care transition decisions	Emergency department	(32)
One best option	Benefits clearly outweigh the harms (no dual equipoise)	Chronic Kidney disease management decisions	Treatment	Chronic care	(81)
One best option	One optimal treatment option (outcomes of test or treatment superior in terms of effects and side effects to alternatives)	Aspirin or cholesterol lowering medication for prevention myocardial infarction in patient with proven coronary artery disease	Treatment	Chronic care	(78)
One best option	Physician guided SDM: one option favourable, medical benefit-burden ratio based on evidence based probabilities, magnitudes of medical benefits and burdens of the options, assessment certainty around those probabilities and burdens	-	-	.	(76)
One best option	Recommendations or strong recommendations for best option	Tympanostomy tubes when recurrent acute otitis media	Treatment	Surgery	(91)
One best option	One realistic option	Lumpectomy for inflammatory breast cancer rather than infiltrating ductal carcinoma, surgery when vital signs alarming, sudden abdominal pain and tubal pregnancy	Treatment	Oncology, gynaecology	(9)

Table 1. *(Continued)*

Categorization of decision characteristic	**Decision characteristic as extracted from the paper**[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	**Example decision**	**Decision type**	**Decision setting**	**Ref**
One best option	One best option (probable chance of cure or unprecedented on other side of spectrum)	Newly diagnosed Wilms tumour, metastatic osteosarcoma	Treatment, end-of-life decisions	Oncology (paediatric)	(94)
One best option	Only one medically reasonable option (no treatment choice) = not preference-sensitive, note: exception: religious argument against dominant choice	Melanoma resection, thyroid replacement for new born with no thyroid, child with ruptured spleen needing transfusion, person with primary melanoma that needs to be removed, dying steelworker discontinuation intensive treatment and starting palliative care Example exception (religious argument): adult Jehovah's witness with ruptured spleen who believes blood transfusion will jeopardize his chance on eternal life.	Treatment, end-of-life decisions	Oncology, surgery, emergency department (paediatric)	(95)
One best option	Scale of benefits and harms tip soundly to one side, almost all informed patients would make the same choice	Lacerated aorta needing surgery, not offering cardiac catheterization for fear of heart disease healthy 20 year old	Treatment, diagnostic testing	Surgery	(99)
One best option	Clear best practice	Bacterial meningitis	Treatment	Neurology	(62)
One best option (high risk)	Certainty (one clear best choice) with high risk	Laparotomy for gunshot abdomen	Treatment	Emergency department	(10)
One best option (low risk)	Certainty (one clear best choice) with low risk	Lowering diuretic because of potassium level	Treatment	Chronic care	(10)
Options restricted by legal/institutional policies	Challenge SDM: rules and limits (legal requirements) around decision constraining patient involvement in decision making	Opioid prescribing pain management	Treatment	Chronic care	(54)
Options restricted by legal/institutional policies	More than one reasonable option BUT decision constricted by institutional policy (i.e. scarce resources)	Whether or not to use ECLS (extra corporeal life support) for children (scarce resource)	Treatment	Intensive care unit (paediatric)	(93)
Physician implements decision (based on clinical expertise)	Routine care decisions (not preference-sensitive)	Choice of vasoactive drips and rates, laboratory testing, fluid rate	Routine care decisions	Intensive care unit	(98)
Physician implements decision (based on clinical expertise)	A physician is primarily responsible for implementation (towards provider guided SDM)	Ketamine versus propofol sedation for fracture reduction in the emergency department	Technical decision	Surgery	(76)

Table 1. *(Continued)*

Categorization of decision characteristic	Decision characteristic as extracted from the paper[1] *Including the description of "equipoise" and "preference-sensitive" from the paper, if available.*	Example decision	Decision type	Decision setting	Ref
Physician implements decision (based on clinical expertise)	Technical decisions based on technical expertise	Frequency with which vital signs are obtained (technical decisions)	Technical decision	Paediatric care	(93)
Potential threat for public safety	Life-or death decision situation where wrong decision imposes immediate threat to patient or others. Aim is to avoid harm.	Discharging suicidal patient	Care transition decisions	Mental health care	(82)
Potential threat for public safety	Decision in conflict with societal goal of public safety	Antipsychotic (medication) management for psychotic patient	Treatment	Mental healthcare	(85)
Short timeframe to make decision	If too little time exists, and a decision must be made quickly, exception: when lifesaving treatment is not congruent with goals (of prolonging life) patient	Exception (SDM is applicable here): terminally ill and intubation or not respiratory distress	End-of-life decisions	Emergency department	(33)
Short timeframe to make decision	Time lacking	-	-	.	(21)
Trade off individual impact and public benefit	Potential public health benefits outweigh individual burdens particularly in emergencies	Diagnostics for bloody stool child to check whether it can be an e.coli outbreak with consequences for surroundings, however fissure ani most likely diagnosis	Treatment	Paediatric care	(93)
Weight of decision (light)	Not an important decision	Postoperative porous surgical tape strings and bandages (appropriate, but not important), all-cotton elastic compression wrap or soft padding bandage orthosis (feasible but not important)	Treatment	Surgery	(57)

[1] When extracting decision characteristics from the papers, we have tried to stay close to the original wording but have taken the liberty to paraphrase for sake of brevity.

SDM= Shared Decision Making

Supplement 3 – Data extraction sheet

https://www.sciencedirect.com/science/article/pii/S0738399122004347?via%3Dihub#sec0205

PART TWO

Discussing outcome information during healthcare visits – current practice and preferences

3

Shared Decision Making in Healthcare Visits for CKD: Patients' Decisional Role Preferences and Experiences

Dorinde E.M. van der Horst
Nieneke Hofstra
Cornelia F. van Uden-Kraan
Anne M. Stiggelbout
Marinus A. van den Dorpel
Arwen H. Pieterse
Willem Jan W. Bos

Published in American Journal of Kidney Diseases, 2023 [1,2]

[1] In recognition of **World Kidney Day** on March 14, 2024, the editors of American Journal of Kidney Diseases, presented a collection of articles that highlight kidney disease research from around the world. This article was selected to be a part of this special collection. https://www.ajkd.org/content/worldkidneyday

[2] An editorial in American Journal of Kindey Disease was written regarding this article by Dale E. Lupu et al. 2023. https://www.ajkd.org/article/S0272-6386(23)00750-3/fulltext

Abstract

Rationale & Objective

Research on shared decision making (SDM) in chronic kidney disease (CKD) has focused almost exclusively on the modality of kidney replacement treatment. We aimed to explore what other CKD decisions are recognized by patients, what their preferences and experiences are regarding these decisions, and how decisions are made during their interactions with medical care professionals.

Study design

Cross-sectional study.

Setting & participants

Patients with CKD receiving (outpatient) care in one of two Dutch hospitals.

Exposures

Patients' preferred decisional roles for treatment decisions were measured using the Control Preferences Scale survey administered after a healthcare visit with medical professionals.

Outcomes

Number of decisions for which patients' experienced a decisional role that did or did not match their preferred role. Observed levels of SDM and motivational interviewing in audio recordings of healthcare visits, measured using the 4SDM and Motivational Interviewing Treatment Integrity-coding tools.

Analytical Approach

Results were characterized using descriptive statistics, including differences in scores between patients' experienced and preferred decisional roles.

Results

According to the survey (n=122) patients with CKD frequently reported decisions regarding planning (112 of 122), medication changes (82 of 122), or lifestyle changes (59 of 122). Of the 357 reported decisions in total, patients preferred that clinicians mostly (125/357) or fully (101 of 357) make decisions. For 116 decisions, they preferred a shared decisional role. For 151of 357 decisions, the patients' preferences did not match their experiences. Decisions were experienced as 'less shared/patient-directed' (76 of 357) or 'more shared/patient-directed' (75 of 357) than preferred. Observed SDM in 118 coded decisions was low (median 4, range, 0 – 22). Motivational interviewing techniques were rarely used.

Limitations

Potential recall and selection bias, and limited generalizability.

Conclusions

We identified multiple discrepancies between preferred, experienced, and observed SDM in healthcare visits for CKD. Although patients varied in their preferred decisional role, a considerable number of patients expressed a preference for shared decision making for many decisions. However, SDM behavior during the healthcare visits was observed infrequently.

1. Introduction

In nephrology, the importance of shared decision making (SDM) is increasingly recognized. SDM entails the collaborative process of sharing information and preferences between patients and clinicians in order to jointly decide on the option that best fits the patient.[1-3] International nephrology guidelines recommend SDM in the decision regarding kidney replacement therapy (KRT), a major preference-sensitive decision between the different available types of kidney replacement therapies and conservative management.[4,5] Until now, most research on decision making in nephrology has focused on the KRT decision and not on other chronic kidney disease (CKD) decisions.[6] However, an abundance of other decisions are made in the management of CKD, starting from diagnosis and during the progression toward kidney failure. Many of these decisions relate to the aim of slowing down kidney function deterioration and the prevention of cardiovascular disease. They are often considered routine care decisions, including decisions regarding lifestyle, long-term medication, and planning of care - for example, starting a salt- restricted diet, antihypertensive medication, or lipid-lowering therapy.

Although these “common CKD decisions” can be viewed as relatively minor when compared to the KRT decision, they do impact patients’ daily life. In addition, for successful treatment, adherence to these common CKD decisions de- pends on patient commitment. SDM might therefore be especially valuable here because it can help improve the fit between care and patient circumstances, enhance the patient-clinician relationship, and activate patients and in- crease their disease knowledge.[7-9] Ultimately, these factors may stimulate therapy adherence and treatment efficacy.

From other chronic conditions we know that the majority of patients prefer to make shared decisions with their clinicians.[10] However, it is as yet unclear whether this also applies to patients with CKD and the common CKD decisions they encounter. Additionally, it is unknown *how* these decisions are made. Besides SDM, motivational interviewing might be a valuable conversational approach. Motivational interviewing focuses on “strengthening patients’ personal motivation and commitment to change”[11] and is particularly applicable in case of decisions in which patients seem unwilling to make or incapable of making the required behavioral change. SDM and motivational interviewing can be applied sequentially: SDM focuses on what to choose, including weighing different options, and motivational interviewing focuses on how to carry out a decision requiring a behavioral change.[12]

Because decision making in routine CKD management to date has not been extensively studied, it is unknown whether SDM or motivational interviewing is applied in common CKD decisions. With this study, we explored (1) which decisions frequently occur during healthcare visits for CKD (other than the KRT decision), (2) what patients' preferred role is in making these decisions in comparison to their experienced role, and (3) which elements of SDM or motivational interviewing is observed during the healthcare visits.

2. Methods

This study is an observational cross-sectional study. From January 2021 through June 2021, we collected surveys filled out by patients after their healthcare visit and audio-recorded (the same) visit (1 per patient). The surveys and audio recordings were collected in the context of a larger evaluation study of a CKD dashboard. The healthcare visits were routine follow-up consultations (face to face, by telephone, or by videoconference) of patients and their known nephrologist. Data were collected in two Dutch hospitals. In both hospitals, all clinicians (both nephrologists and nurse practitioners) providing CKD outpatient care were informed. They all participated except 1 nurse practitioner due to logistic reasons. The eligible patients were adult patients with CKD stages 3b-4, sufficient in Dutch language, not cognitively impaired, and able to fill in the digital survey by themselves or with assistance from a partner or relative. To minimize selection bias, clinicians could only recruit patients from a predetermined list based on dates when patients would visit, which had been selected randomly by a research team member not con- ducting the healthcare visits. Written informed consent was obtained from all participating patients. The Medical Research Ethics Committees United (MEC-U) confirmed that the study was not subject to the Medical Research Involving Human Subjects Act, study number: W20.245.

2.1 Exposure

Patients were characterized using a post–healthcare visit survey. The survey included an assessment of patient characteristics and the patients' preferred decisional role in decisions they had encountered in their last visit for CKD. The survey was sent via email 1 day after the visit. Health literacy was measured with the Set of Brief Screening questions[13]; a score of ≤3 was considered low.[14] Education levels were measured using the International Standard Classification of Education (ISCED); levels 0-2 were considered low, 3-4 medium, and 5-8 high.[15] The patients were asked to report what decisions were discussed during their last visit from a predetermined list of decisions. This list was built by researcher D.E.M.H., who observed healthcare visits for CKD for 4 days, and nephrologist W.J.W.B., who counted the decisions that occurred in his consultations for 2 weeks. The patients were offered an open text field to add decisions that were not on the list. Subsequently, the patients were asked to report who in their experience had made the decision and what their preferred decisional role would be in making such decisions. The Control Preferences Scale (CPS) was used for both questions (**Box 1).**[16]

Box 1. Control Preferences Scale.

Participants were asked to select one of five statements of the CPS on preferred and experienced role in decision making:
'**Only patient'**: the patient makes the decision alone
'**Mostly patient**': the patient makes the decision after seriously considering the clinician's opinion
'**Shared**': the patient makes the decision together with the clinician
'**Mostly clinician**': the clinician makes the decision after seriously considering the patient's opinion
'**Only clinician**': the clinician makes the decision alone

2.2 Outcomes

Outcomes include the number of (mis)matches between the patient-reported experience and the preferred decisional role, measured with the CPS, and the observed levels of SDM and motivational interviewing in audio recordings of the healthcare visits. The observed level of SDM was measured with the 4-step SDM instrument (4SDM) coding scheme.[17] The 4SDM assesses whether and how the 4 steps of SDM are applied (**Box 2**). It allows for an explicit distinction between the 4 SDM steps and focuses on both clinicians' and patients' behavior.[17,18] The possible scores per SDM step range from 0- 6, and the total SDM score ranges from 0-24. Additionally, we coded per item of the 4SDM whether the behavior corresponding with the item was initiated by the patient or by the professional. Decisions were transcribed and immediately coded. Two researchers (D.E.M.H. and N.H.) coded the audio recordings. In case of disagreement a third researcher (A.H.P.) was consulted. In **Box S1**, 2 illustrative examples of coded decisions are provided. Per healthcare visit a maximum of 2 decisions were coded on SDM. If there were more than 2 decisions, the 2 most prominently discussed during the healthcare visit were coded. For the decisions that were coded on the level of SDM, we also coded what decision characteristics were mentioned during the conversation. Decision characteristics are features that define a particular decision, such as uncertainty regarding the options, the existence of 1 best option, or a decision being preference-sensitive.[19] When a behavioral change goal was explicitly mentioned during the healthcare visit, for example, and when a decision resulted in the need for a behavior change, we used the Motivational Interviewing Treatment Integrity (MITI) coding scheme to get an overall impression on whether/how motivational interviewing was used. The MITI provides global ratings of relational components (partnership and empathy, scale 1-5, where >3.5 is sufficient), and technical components (cultivating change talk and softening sustain talk, scale 1-5, where >3 is sufficient). For a full list of MITI items, see **Box S2**.[20]

Box 2. Items of the 4SDM

STEP 1 **Setting the agenda**
Item 1. It is stated (or re-affirmed) that a decision about management or treatment needs to be made.
Item 2. It is stated (or re-affirmed) that the decision depends on the values and preferences of the patient.

STEP 2 **Informing about options**
Item 3. The available management or treatment options are stated (or re-affirmed).
Item 4. The pros and cons of each option are stated or re-affirmed.

STEP 3 **Exploring values and preference construction**
Item 5. The patient states the outcomes that are important to him/her (values).
Item 6. The patient states how s(h)e appraises the (characteristics of) the management or treatment options.

STEP 4 **Making or deferring a decision in agreement**
Item 7. The patient expresses or confirms his/her preference or the (provisional) lack of a preference
Item 8. The moment of making (or deferring) the decision is explicit and decision making occurs in agreement
Every item is scored as **0 (no behavior identified)**; **1 (minimal); 2 (sufficient)** or **3 (good).**[17]

Every item is scored as 0 (no behavior identified), 1 (minimal), 2 (sufficient), or 3 (good).[17] Abbreviations: SDM, shared decision making; 4SDM, 4-step shared decision making instrument.

2.3 Statistical Analyses

Data from the audio recordings and surveys were analyzed with SPSS Statistics 27 (IBM SPSS Inc). Data were presented either as mean and standard deviation, median and interquartile range, or number with percentage, depending on the distribution. Experienced decisional role and preferred decisional role were compared at the patient level by subtracting the CPS "preferred" from the CPS "experienced." To compare observed levels of SDM to the patients' experienced decisional role, the level of SDM of coded decisions was recoded into 3 groups: (1) no to minimal SDM, 0-8; (2) minimal to sufficient SDM, 9-16; (3) sufficient to good SDM, [17-24]. Kruskal-Wallis H tests were used to compare SDM scores between different decisional topics.

3. Results

3.1 Patient Characteristics

In total, 122 patients (75 male and 47 female) filled in the post–healthcare visit survey. **Table 1** shows the patients' and clinicians' characteristics. Education levels were predominantly low or medium. Health literacy was high (median, 4.5 [IQR, 1.0]). Patients had been visiting their nephrologists for a median of 6.5 years (IQR, 7.2).

Table 1. Characteristics of participants

Patient characteristics, total survey participants	**N=122 (100%)**
Sex (male), n % [a]	75 (61.5%)
Age, median (IQR) [a]	73 (15.3)
Number of years since first nephrologist visit, median (IQR) [a]	6.5 (6.9)
SBSQ score, median (IQR)	4.5 (1.0)
Education level, n(%)	
Low (ISCED [b] levels 0-2)	52 (42.6%)
Medium (ISCED levels 3-4)	38 (31.1%)
High (ISCED levels 5-8)	29 (23.8%)
Etiology of CKD [a]	
Hypertension/vascular disease	53 (43%)
Diabetes (with or without vascular disease)	20 (16%)
Glomerulonephritis	15 (12%)
Unknown	8 (7%)
Polycystic kidney disease	5 (4%)
Obstructive kidney disease	5 (5%)
Other [c]	14 (11%)
Comorbidities [a]	
Myocardial infarction	29 (9.7%)
Peripheral vascular disease	27 (9.1%)
Diabetes with chronic complication	27 (9.1%)
Any malignancy without metastasis	24 (8.1%)
Rheumatic disease	19 (6.4%)
Chronic pulmonary disease	15 (5.0%)
Diabetes without chronic complication	11 (3.7%)
Cerebrovascular disease	10 (3.4%)
Congestive heart failure	8 (2.7%)
Leukemia	3 (1.0%)
Metastatic solid tumor	3 (1.0%)
Peptic Ulcer disease	2 (0.7%)

Table 1. *(Continued)*

Patient characteristics, total survey participants	**N=122 (100%)**
Clinician characteristics, total clinicians recording healthcare visits n=14 (100%)	
Age, median (IQR)	49 (18.3)
Sex (male), n%	8 (57.1%)
Function	
Nephrologist	13 (92.8%)
Nurse practitioner	1 (7.1%)
Years of experience in current position	
0-5 years	2 (14.3%)
6-10 years	4 (28.6%)
11-15 years	3 (21.4%)
>15 years	5 (35.7%)

IQR=Interquartile range. SBSQ= Set of Brief Screening Questions (self-report health literacy measure), CKD=Chronic Kidney Disease

a) Extracted from electronic health record

b) ISCED = International Standard Classification of Education framework [15]

c) Other = mono-kidney, repeated urinary infections, prerenal (heart failure), nephrotoxic medication, nephroptosis, myeloma cast nephropathy, acute tubular necrosis (due to sepsis)

3.2 Patient-reported Decisions in Healthcare Visits for CKD

The median number of decisions per healthcare visit was 4 (IQR 3.0). Only 3 patients reported that no decision was made during the visit. In total, the 122 patients reported 357 different decisions. Patients most frequently reported decisions regarding care planning (e.g., time to next follow-up visit, or whether patients preferred face-to-face or telephone/video conference consultations; 112 of 122 patients, 92%), followed by decisions regarding medication changes (82 of 122 patients, 67%), and decisions regarding lifestyle (59 of 122 patients, 48%).

Table 2. Survey: Patients' preferred role in decision making

		Patients Who *Preferred* the Following Decisional Roles				
Decision topic	**Patients Who Indicated Having Discussed the Decision in the Previous Healthcare Visit**	**Only clinician**	**Mostly clinician**	**Clinician and patient equally**	**Mostly patient**	**Only patient**
Planning	112	46 (41%[a])	37 (33%)	28 (25%)	1 (1%)	0 (0%)
Medication change [b]	82	17 (21%)	35 (43%)	28 (34%)	2 (2%)	0 (0%)
Lifestyle [c]	59	6 (10%)	18 (31%)	24 (41%)	9 (15%)	2 (0%)
Treatment goals	45	8 (18%)	20 (44%)	16 (36%)	1 (2%)	0 (0%)
Diagnostic testing	33	14 (42%)	7 (21%)	12 (36%)	0 (0%)	0 (0%)
Referral	10	2 (20%)	6 (60%)	2 (20%)	0 (0%)	0 (0%)
Other [d]	16	8 (50%)	2 (13%)	6 (38%)	0 (0%)	0 (0%)
Total decisions mentioned by patients	**357**	**101 (28%[5])**	**125 (35%)**	**116 (32%)**	**13 (4%)**	**2 (1%)**

Table 3. Survey: Patients' experienced role in decision making

		Patients Who *Experienced* the Following Decisional Roles				
Decision topic	**Patients Who Indicated Having Discussed the Decision in the Previous Healthcare Visit**	**Only clinician**	**Mostly clinician**	**Clinician and patient equally**	**Mostly patient**	**Only patient**
Planning	112	52 (46%[a])	35 (31%)	24 (21%)	1 (1%)	0 (0%)
Medication change [b]	82	24 (29%)	27 (33%)	29 (35%)	2 (2%)	0 (0%)
Lifestyle [c]	59	3 (5%)	15 (25%)	34 (58%)	5 (8%)	2 (3%)
Treatment goals	45	9 (20%)	13 (29%)	23 (51%)	0 (0%)	0 (0%)
Diagnostic testing	33	14 (42%)	12 (36%)	7 (21%)	0 (0%)	0 (0%)
Referral	10	3 (30%)	3 (30%)	2 (20%)	2 (20%)	0 (0%)
Other [d]	16	7 (44%)	2 (13%)	7 (44%)	0 (0%)	0 (0%)
Total decisions mentioned by patients	**357**	**112 (31%[5])**	**107 (30%)**	**126 (35%)**	**10 (3%)**	**2 (1%)**

Abbreviation: CPS, Control Preferences Scale.

a) Percentage of total patients who experienced that decision.

b) Medication change is a combination of 4 decision topics regarding medication change: (1) starting new medication (n = 56), (2) change medication dosage (n = 63), (3) stop medication (n = 17), (4) start erythropoietin injections (n = 7). When 1 patient experienced multiple decisions regarding medication change the mean CPS was calculated.

c) Lifestyle interventions are a combination of 4 decision topics regarding lifestyle interventions: (1) limit salt intake (n = 44), (2) lose weight (n = 25), (3) stop smoking (n = 7), (4) limit protein intake (n = 9). When 1 patient experienced multiple decisions regarding medication change the mean CPS was calculated.

d) Other decisions that patients reported related to vaccination against COVID-19, desire to have children, vitamin B12 injections, medication (unspecified), diagnostics (Xrays,thyroid function, additional blood tests), cholesterol, melanoma resection, and potassium-restricted diet.

e) Percentage of total amount of experienced decisions.

3.3 Patients' Preferred and Experienced Decisional Role in CKD Decisions

The patients' preferred decisional role for making the re- ported decisions is shown in **Table 2**. Taking all decisions together, the patients most frequently preferred to leave the decision "mostly" to the clinician (125 of 357), closely followed by wanting to "share" decision making (116 of 357) or leave the decision completely to the clinician (101 of 357). The patients preferred these 3 decisional roles for each decision topic. Which decisional approach was most prominent varied per decision topic. A patient-directed approach (mostly/only patient) was preferred in 15 of 357 decisions, mainly for the decisions regarding lifestyle. **Table 3** shows that patients' experienced decisional roles show a similar distribution: both clinician-directed (only/mostly clinician) and a shared decisional role were experienced most frequently in the decisions they encountered.

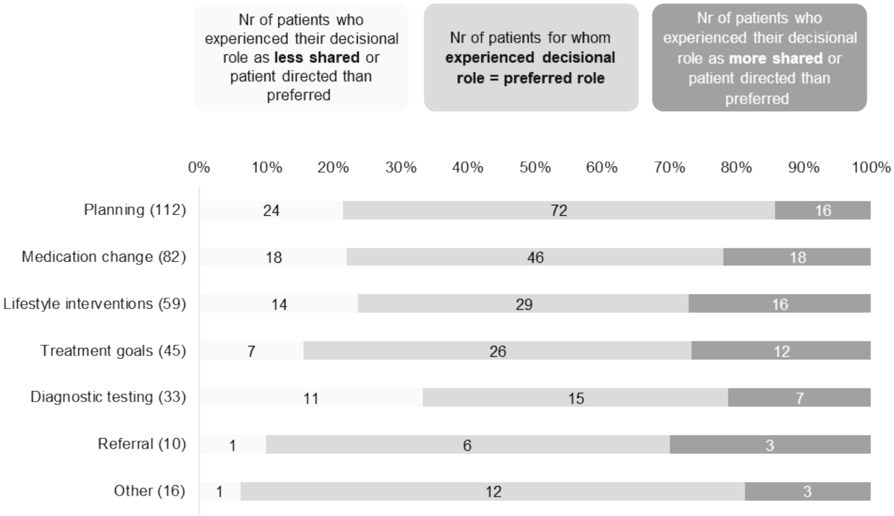


Figure 1: Survey: patients' experienced versus preferred decisional role per decision topic

Survey: patients' experienced versus preferred decisional role per decision topic: visualization per decision topic of the total number of patients whose preferred decisional role did or did not match their experienced role. In the left column, the decision topic includes the number of patients who indicated having discussed the decision in the previous healthcare visit. Light grey: number of patients who experienced their decisions as less shared or patient directed than preferred; darker grey: number of patients for whom experienced decisional role matched their preferred role; darkest grey: number of patients who experienced their decisional role as more shared or patient directed than preferred.

Figure 1 illustrates the number of patients whose preferred decisional role did or did not match their experienced role. In 151 out of 357 decisions, the patients experienced their decisional role as either less or more shared or patient-directed than they would have preferred. The proportion of mismatches was highest in the decisions regarding lifestyle, diagnostic testing, and medication changes. For most decision topics, the proportion of patients who felt "more" versus "less" involved than they would have preferred was relatively balanced.

3.4 Healthcare Visit Observations

In total, 93 healthcare visits by 14 different clinicians were successfully recorded. All healthcare visits were conducted by a nephrologist except 1, which was done by a nurse practitioner. In 64 healthcare visits (69%) the clinician was male. The median length of the visits was 10.05 minutes (IQR, 7.0). From the 93 recorded visits, 141 decisions were identified (median of 1.0 per visit [IQR, 1.0]) of which 118 were coded on the level of SDM.

3.4.1. Decision Characteristics

Table 4 shows how often clinicians explicitly mentioned decision characteristics for the 118 decisions. The most frequently mentioned decision characteristics were needing patients' commitment to carry out the decision (18 of 118), the decision having multiple options (16 of 118), the decision entailing a trade-off (14 of 118), or the decision being preference-sensitive (14 of 118).

Table 4: Audio recordings: Number of decision characteristics mentioned for the coded decisions (n=118)

Decision characteristics	Decisions in which the decision characteristic was coded[a]
None mentioned	50
Patient commitment needed to carry out decision	18
Multiple options	16
Preference-sensitive	14
Trade-off	14
Long window of opportunity to make decision	11
Impact of the decision	10
Reversibility of the decision	9
Uncertainty	3
Certainty	3
Value-sensitive decision	1
Total weight of decision	1

a) Absolute numbers (multiple decision characteristics may have been mentioned per decision).

3.4.2. SDM Scores of the Decisions

Of all coded decisions, the median SDM score was 4.0 (IQR 8.0), min-max: 0-22. **Figure 2** illustrates all coded decisions and their total SDM scores. There was no statistically significant difference in total SDM score between different topics of decisions (χ2 [10,118] = 13.4, P = 0.199). **Table 5** presents the different SDM steps and mean scores of observed SDM behavior in these steps. Behaviors related to step 2 (informing about options) and 4 (making or deferring a decision in agreement) were observed slightly more frequently than those related to the other steps.

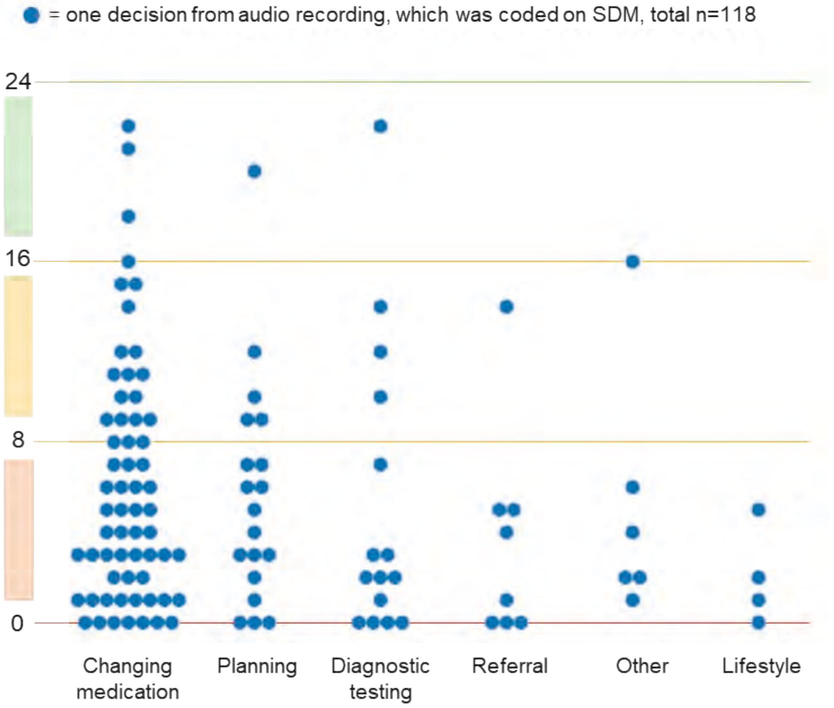


Figure 2: Audio recordings: All coded decisions and their 4SDM score

(note: the higher on the y-axis the higher the 4SDM scores/more SDM behavior observed)
Audio recordings: all coded decisions and their 4SDM score. Each plotted blue dot represents a decision that was observed from the audio recordings of healthcare visits and coded for the level of SDM. On the x-axis, the different decision topics are plotted in which the decisions are categorized. The yaxis represents the SDM score—the level of SDM, coded with the 4SDM coding scheme: 0-8 = no SDM to minimal SDM (red); 9-16 = minimal to sufficient SDM (yellow); and 17-24 = sufficient to high SDM (green). The higher on the y-axis indicates the higher the 4SDM scores/more SDM behavior observed. Abbreviation: SDM, shared decision making.

Table 5: Audio recordings: Overview of the 4SDM scores and who initiated the corresponding behaviors

Steps 4SDM	Mean score step (min-max, range 0.0-6.0)	Items 4 SDM	Mean score Item (min-max, range 0.0-3.0)	Who initiated (valid percent)
Step 1: setting the agenda	1.2 (0.0-6.0)	1. It is stated (or re-affirmed) that a decision about management or treatment needs to be made.	0.7 (0.0-3.0)	37.3% Patient[a] 63.7% HCP
		2. It is stated (or re-affirmed) that the decision depends on the values and preferences of the patient.	0.5 (0.0-3.0)	8.3% Patient 91.7% HCP
Step 2: Informing about options	1.5 (0.0-6.0)	3. The available management or treatment options are stated (or re-affirmed).	0.9 (0.0-3.0)	11.1% Patient 88.9% HCP
		4. The pros and cons of each option are stated or re-affirmed.	0.6 (0.0-3.0)	2.7% Patient 97.3% HCP
Step 3: Exploring values and preference construction	1.3 (0.0-6.0)	5. The patient states the outcomes that are important to him/her (values).	0.5 (0.0-3.0)	81.8% Patient 18.2% HCP
		6. The patient states how s(h)e appraises the (characteristics of) the management or treatment options.	0.8 (0.0-3.0)	88.9% Patient 11.1% HCP
Step 4: Making or deferring a decision in agreement	1.7 (0.0-6.0)	7. The patient expresses or confirms his/her preference or the (provisional) lack of a preference	0.9 (0.0-3.0)	71.4% Patient 28.6% HCP
		8. The moment of making (or deferring) the decision is explicit and decision making occurs in agreement	0.8 (0.0-3.0)	11.1% Patient 88.9% HCP

a) Patient or patient companion.

3.4.3. Initiation of SDM Behaviors

The majority of behaviors corresponding with the items of the 4SDM (**Table 5**) were initiated by clinicians, in particular step 1 (setting the agenda) and step 2 (informing about options). Exploration of values and preferences (step 3) and the expression or confirmation of patients' preferences (step 4) were mostly initiated by patients.

3.4.4. Motivational Interviewing

In 15 healthcare visits a behavioral change was explicitly discussed. The mean global scores were 1.9 ± 1.0 (SD) for cultivating change talk; 3.3 ± 1.0 (SD) for softening sustain talk; 2.9 ± 0.9 (SD) for partnership; 2.7 ± 1.3 (SD) for empathy. The global scores for relational components and technical components were 2.7 ± 1.0 (SD) and 2.6 ± 0.6 (SD), respectively.

3.4.5. Observed Versus Patient-reported Decision Making

Of the 118 coded decisions, 87 decisions were also reported by patients in the post–healthcare visit survey. For these 87 decisions, **Table 6** presents the correspondence between patients' experienced decisional role and observed level of SDM. In 29 of 87 decisions (33%), the patients' experiences about who made the decision did not seem to match the observed level of SDM. For the decisions that were coded as "no to minimal SDM" (n = 66 of 87), 21 of those 66 patients (32%) reported that the decision had been shared. In decisions in which "minimal to sufficient" or "sufficient to good" SDM behavior was observed, some patients (n = 8) still reported that the clinician alone made the decision.

Table 6: Audio recordings versus survey: Correspondence between observed level of SDM and patients' experienced decisional role (n=87 decisions)

Observed SDM (audio recordings)	**No. of decisions**[a]	**Patients' experience who made decision (survey):**				
		Only clinician	Mostly clinician	Shared	Mostly patient	Only patient
17-24 sufficient-good SDM	**4**	3	0	1	0	0
9-16 minimal-sufficient SDM	**17**	5	5	6	1	0
0-8 no-minimal SDM	**66**	27	18	21	0	0

a) Only the decisions that were both mentioned by patients in the post- healthcare visit surveys and coded in the audio recordings of the same visits. Red= mismatch, Green= patients' experiences (largely) resemble observational SDM scores.

4. Discussion

We identified a variety of decisions that occur frequently in routine healthcare visits for CKD: decisions regarding planning, medication changes, lifestyle changes, treatment goals, and diagnostic testing. For all these decision topics, around a third of the patients preferred a shared decisional role, another third preferred to leave the decision mostly to the clinician, and almost a third preferred to leave the decision completely up to the clinician. Patients seldom preferred to make the decision (largely) by themselves, except for some lifestyle change decisions. In the audio recordings of the healthcare visits, the overall observed level of SDM behavior was low. The results include 2 main comparisons. First, the patients' preferred decisional role was compared with their experienced decisional role, which matched in the majority of decisions that patients had encountered. For the decisions in which patients' experienced and preferred decisional roles did not match, the patients equally often experienced being "more" or "less" involved in making the decision than preferred. Second, the patients' experiences were compared with the observations based on audio recordings of their healthcare visits. Patients' experiences did not always match the observations; for a substantial number of the patients who had experienced decisions as "shared," the observers rated as low levels of SDM; and some patients experienced decisions as having been made fully by the clinician that observers rated as high levels of SDM. Patients also re- ported a larger number of decisions being made than the observers identified from the audio recordings.

There may be several reasons for the discrepancies be- tween the patients' experiences and the observations from the audio recordings. The patients may have reported more decisions than were observed in the audio recordings because of (1) recall bias—the patients may have reported decisions that were made in earlier healthcare visits; and (2) the patients might have a different perception of what a decision entails. Patients may be quicker to view topics that were discussed as a decision than would an independent observer because the topics concern themselves and their lives. The discrepancy between patients' experiences and observed levels of SDM may be explained by the different metrics that were used; patients were asked who made the final decision, while observers coded SDM behaviors throughout the decision process. Additionally, patients might have a different understanding of what sharing a decision incorporates, compared with how SDM is currently framed in literature. A study showed that in healthcare visits that scored high on SDM, patients were still often uncertain who had made the decision.[21]

Another explanation for the discrepancy between patient-reported and observed decision making in this study is that the coding scheme used might be too strict for the evaluation of SDM levels for routine care decisions. The 4SDM was developed in the context of palliative cancer care decisions, which can be considered major preference-sensitive decisions, dissimilar to the routine care decisions identified in this study. This may also be one of the reasons that the SDM scores were low in this study. Driever et al [22] also reported low levels of SDM in routine care decisions. They coded 727 healthcare visits for different specialties on the level of SDM with the OPTION-5, an observer- based coding instrument for SDM based on the 3-talk model of Elwyn et al,[12] which covers largely the same dimensions as the 4SDM coding instrument yet with a focus on clinician behavior. They found that treatment decisions scored significantly higher on SDM than did the diagnostic, follow-up, or “other” decisions.[23] Lower SDM scores for these nontreatment decisions may be the result of limited awareness that SDM might apply in these circumstances; or SDM might be less appropriate in these decisions, and coding on all SDM steps may be too strict.

This raises the question whether the full SDM process is required in routine care decisions, such as the common CKD decisions identified in this study, and if not, which elements of SDM could be particularly important. “Exploring patient preferences” is often proposed as an important element of SDM, both in cases of “major preference-sensitive” decisions and for less major decisions.[19] In both our observations and those of Driever et al [22] “exploring preferences” is less frequently observed compared with other SDM elements such as “informing on options.” Notably, in this study the patients often initiated the exploration of preferences. However, the patients participating in this study might not reflect the level of communicative initiative of the average patients with CKD, as suggested by the high level of health literacy in the present sample. “Making explicit that a decision needs to be made” may be another essential element of SDM in common CKD decisions. Because our study suggests that SDM is currently not integrated in these routine care decisions, patients may not anticipate being actively involved and may adopt a passive role. Making it clear that a decision is required and that the patients’ input is essential, can encourage them to participate more actively. [24]

Motivational interviewing was observed to a limited extent. Key elements and skills of motivational interviewing—including partnership, empathy, exchanging information, active listening, and summarizing—are not limited to discussions regarding behavioral changes, and are also relevant in SDM. Educating clinicians on motivational interviewing and its sequential application with SDM could improve healthcare visits for CKD and enhance patients’ involvement in CKD management. [12]

This study can inform training and educational pro- grams for clinicians to create awareness that SDM may be warranted in more decisions than the KRT decision alone. Patient preferences regarding their role in decision making differ between patients and between topics. Also, patients might hold different perspectives on what sharing a decision looks like. It is therefore important that clinicians explore patients' desired decisional role throughout the decisional process. Attempts to involve patients in common CKD decisions should always be made to the extent that patients prefer. Not attempting a SDM process might result in overlooking hidden preferences and resistance, which could affect patients' commitment to the treatment plan. Furthermore, increasing application of SDM in common CKD decisions may better prepare patients to participate more actively in major decisions, such as the KRT decision, later on.[25]

There are several limitations to our study, which are important to consider. First, selection bias may have occurred, even though we tried to minimize this by letting clinicians recruit patients from a randomly selected patient sample based on consultation dates. Second, reflexivity issues need to be addressed: 2 participating nephrologists, 1 from each hospital, were also members of the research team. Although they were not involved in the analysis, they knew the study's outcomes, which could have led to bias. Furthermore, SDM training was provided to the clinicians of both hospitals months before the start of this study and in the context of another project. This training focused on the KRT decision, which differs from the decisions included in this study. Nevertheless, the clinicians participating in this study were potentially more familiar with the concept of SDM than are other clinicians in nephrology. Third, being aware that the healthcare visits were recorded may have resulted in desirable behavior of patients and clinicians, although studies indicate that this effect is often minimal.[26,27] In the study information, patients and clinicians were made aware that decision making would be evaluated. Although some impact cannot be ruled out, we feel that the impact of this on participants' behavior was limited because the information was provided several weeks before the recordings. Fourth, it is unknown how many patients filled in the survey with assistance from a partner or relative, which may have influenced their answers. We do not believe that such influence would be systematic. Fifth, most of the healthcare visits were conducted by male clinicians, and clinician gender may have implications regarding the observed SDM levels. A meta-analysis of 7 RCTs has suggested these implications may be limited because they did not show significant differences in the level of observed SDM depending on the gender of the clinician.[28] Finally, there was no patient involvement in conducting this study; however, 2 CKD patient representatives and 1 representative from the Dutch Kidney Patient Association had a steering role in the program of which this study was an essential part.

In conclusion, by analyzing healthcare visits for CKD from 2 perspectives, the patients (including their experiences and preferences) and observations, we identified a set of common CKD decisions. Depending on the decisional topic, patients with CKD varied in whether they wanted to share these decisions or preferred a more clinician-directed approach. A considerable number of patients expressed a preference to share decisions, which is currently not met according to the low levels of observed SDM during the healthcare visits. When the decisions entailed a behavioral change, motivational interviewing was applied to a limited extent, which indicates a need for training clinicians in the use of motivational interviewing in CKD care. The findings of this study create awareness that in nephrology SDM is not to be reserved for the major KRT decision. Future research may help to further explain what elements of SDM are minimally required for more common CKD decisions.

References

[1] Bomhof-Roordink H, Gartner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision making models: a sys- tematic review. BMJ Open. 2019;9(12):e031763. doi:10. 1136/bmjopen-2019-031763

[2] Stiggelbout AM, Pieterse AH, de Haes JCJM. Shared decision making: concepts, evidence, and practice. Patient Educ Couns. 2015;98(10):1172-1179. doi:10.1016/j.pec.2015.06.022

[3] Makoul G, Clayman ML. An integrative model of shared deci- sion making in medical encounters. Patient Educ Couns. 2006;60(3):301-312. doi:10.1016/j.pec.2005.06.010

[4] Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2012 clinical practice guideline for the evaluation and management of chronic kidney disease. Kidney Int Suppl. 2013;3:1-150.

[5] Renal Physicians Association Working Group. Shared Deci- sion Making in the Appropriate Initiation and Withdrawal From Dialysis: Clinical Practice Guideline. 2nd ed. Renal Physicians Association; 2010.

[6] Murray MA, Brunier G, Chung JO, et al. A systematic review of factors influencing decision-making in adults living with chronic kidney disease. Patient Educ Couns. 2009;76(2):149-158. doi:10.1016/j.pec.2008.12.010

[7] Montori VM, Gafni A, Charles C. A shared treatment decision- making approach between patients with chronic conditions and their clinicians: the case of diabetes. Health Expect. 2006;9(1): 25-36. doi:10.1111/j.1369-7625.2006.00359.x

[8] Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CP, de Jong CA. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. Psychother Psychosom. 2008;77(4):219-226. doi:10.1159/000126073

[9] Langford AT, Williams SK, Applegate M, Ogedegbe O, Braithwaite RS. Partnerships to improve shared decision making for patients with hypertension—health equity implica- tions. Ethn Dis. 2019;29(suppl 1):97-102. doi:10.18865/ed. 29.S1.97

[10] Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: a sys- tematic review. Patient Educ Couns. 2012;86(1):9-18. doi:10. 1016/j.pec.2011.02.004

[11] Miller W, Rollnick S. Motivational Interviewing: Helping People Change. 3rd ed. Guilford Press; 2013.

[12] Elwyn G, Dehlendorf C, Epstein RM, Marrin K, White J, Frosch DL. Shared decision making and motivational inter- viewing: achieving patient-centered care across the spectrum of healthcare problems. Ann Fam Med. 2014;12(3):270-275. doi:10.1370/afm.1615

[13] Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med. 2004;36(8): 588-594.

[14] Fransen MP, van Schaik TM, Twickler TB, Essink-Bot ML. Applicability of internationally available health literacy measures in the Netherlands. J Health Commun. 2011;16(suppl 3):134-149. doi:10.1080/10810730.2011.604383

[15] UNESCO Institute for Statistics. The International Standard Classification of Education (ISCED). UNESCO-UIS; 2012. https://uis.unesco.org/sites/default/files/documents/international- standard-classification-of-education-isced-2011-en.pdf

[16] Degner L, Sloan J, Venkatesh P. The Control Preferences Scale. Can J Nurs Res. 1997;29(3):21-43.

[17] Henselmans I, Smets EMA, de Haes JCJM, Dijkgraaf MGW, de Vos FY, van Laarhoven HWM. A randomized controlled trial of a skills training for oncologists and a communication aid for pa- tients to stimulate shared decision making about palliative systemic treatment (CHOICE): study protocol. BMC Cancer. 2018;18(1):1-13. doi:10.1186/s12885-017-3838-8

[18] Henselmans I, Laarhoven HWM, Maarschalkerweerd P, et al. Effect of a skills training for oncologists and a patient communication aid on shared decision making about palliative systemic treatment: a randomized clinical trial. Oncologist. 2019;25(3):578-588. doi:10.1634/theoncologist.2019-0453

[19] Van der Horst DEM, Garvelink MM, Bos WJW, Stiggelbout AM, Pieterse AH. For which decisions is shared decision making considered appropriate? A systematic review. Patient Educ Couns. 2023;106:3-16. doi:10.1016/j.pec.2022.09.015

[20] Moyers TB, Manuel JK, Ernst D. Motivational Interviewing Treatment Integrity Coding Manual 4.2.1. Author; 2014. https://casaa.unm.edu/download/miti4_2.pdf

[21] Edwards A, Elwyn G. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. Health Expectations. 2006;9(4):307-320. doi:10.1111/j.1369-7625.2006.00401.x

[22] Driever EM, Stiggelbout AM, Brand PLP. Do consultants do what they say they do? Observational study of the extent to which cli- nicians involve their patients in the decision-making process. BMJ Open. 2022;12(1):e056471. doi:10.1136/bmjopen-2021-056471

[23] Driever EM, Stiggelbout AM, Brand PLP. Shared decision- making in different types of decisions in medical specialist consultations. J Gen Intern Med. 2022;37(12):2966-2972. doi:10.1007/s11606-021-07221-6

[24] Joseph-Williams N, Edwards A, Elwyn G. Power imbalance prevents shared decision making. BMJ. 2014;348(3):291-309. doi:10.1016/j.pec.2013.10.031

[25] Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. BMJ. 1999;319(7212):766- 771. doi:10.1136/bmj.319.7212.766

[26] Arborelius E, Timpka T. In what way may videotapes be used to get significant information about the patient-physician rela- tionship? Med Teach. 1990;12(2):197-208. doi:10.3109/ 01421599009006697

[27] Pringle M, Stewart-Evans C. Does awareness of being video recorded affect doctors' consultation behaviour? Br J Gen Pract. 1990;40(340):455-458.

[28] Wyatt KD, Branda ME, Inselman JW, et al. Genders of patients and clinicians and their effect on shared decision making: a participant-level meta-analysis. BMC Med Inform Decis Mak. 2014;14:81. doi:10.1186/1472-6947-14-81

Supplement 1 Box S1 – Illustrative examples of coded decisions

Box S1. Examples of decisions coded with the 4SDM (translated from Dutch)

Example 1: high SDM score

Clinician: Your blood pressure remains a bit too high. Living more healthy and exercising did make it go down enough. Patient: I really changed my lifestyle drastically… I did so much. Even started playing tennis again regularly… My blood pressure went down a bit, didn't it? Clinician: It is not your fault, once the kidneys are damaged, the body's blood pressure regulation doesn't work that well anymore. You cannot always influence that. Not that I want to discourage you.. If you had not done all these things it might have worsened even quicker. […] An extra reason to want to lower blood pressure is to prevent protein leakage in the kidneys. We want to reduce the pressure on the kidneys and slow down deterioration of kidney function. Patient: but with those medication we get those problems again.. those other problems occur.. with Viagra and stuff.. Clinician: Yes, it's easy for me to say: just take that [antihypertension] pill. However, it causes you those kind of problems. Patient: yeah, I don't know.. Clinician: it was the reason why we stopped the diuretic. Now, we could start amlodipine instead, which is less known to cause those side effects. Let's try that? If you don't try you don't know. Let's see whether your blood pressure then decreases and whether the erection problems stay away. Patient: and that choice is not worse for the kidneys right? Do I understand it correctly that it actually helps the kidneys? Clinician: that's right. Patient: what would you propose? Clinician: I would propose stating a new pill for the blood pressure, amlodipine, which causes erection problems less often than the diuretic you had before. For now, I think that is the main thing we can improve in order to prevent further kidney function deterioration. Patient: OK, so that's what you propose? Clinician: if this does not work we can always stop the new tablets. So, I will prescribe amlodipine. Do you agree? Patient: yeah I do. And I don't think I have many options now, right? None maybe. Clinician: yes I do think we need to try everything to prevent kidney damage.

4 SDM scoring: Step 1 item 1: 2; step 1 item 2: 2; step 2 item 3: 3; step 2 item 4:3; step 3 item 5: 3; step 3 item 6: 3; step 4 item 7: 2; step 4 item 8: 3. Total: 21.0

Example 2: low SDM score

Clinician: your blood pressure was good earlier, and if you say that you are currently retaining fluid, I would like to start a diuretic tablet in order to reduce fluid retention on the one hand, but on the other hand also reduce potassium levels. So that is a win-win. The only reason not to start a diuretic would be when the blood pressure is too low, but I don't expect it is actually, since it has always been quite stable. Patient: but then I need to go to the toilet a lot of times… Clinician: yes, that's probably correct, because of the diuretic you pee salt which means you have to pee more often. However, I would only give the diuretic once a day and only in the morning, so you don't have this is issue during the night, because that may be annoying. At night, the effect of the pill will have worn off. Yeah.. because with my lung disease I notice that when I go to the toilet at night, my saturation levels are quite low. Clinician: losing fluid will probably benefit your lungs as well at night. If you have fluid retention in your legs it is likely that you have some fluid in your lungs as well. [examines legs] Alright, so there is fluid in your legs, so we will start the diuretic. Once a day. Patient: hm yeah…

4SDM scoring: Step 1 item 1: 0; step 1 item 2: 0; step 2 item 3: 0; step 2 item 4:2; step 3 item 5: 0; step 3 item 6: 2; step 4 item 7: 1; step 4 item 8: 1. Total: 6.0

These two transcripts of decisions illustrate how they were coded. In the first example, the decision scored high on SDM. Preferences are explicitly discussed, which led to choosing an alternative treatment option that better fits the patients' preferences and circumstances. In the second the SDM score is low. The score is only 'sufficient' on informing on pros and cons of the proposed treatment and (the patient) explaining what she feels regarding the proposed treatment.

Supplement 2 Box S2 – Items MITI (Motivational Interviewing Treatment Integrity)

Box S2 Global scores Motivational Interviewing Treatment Integrity [20]

Cultivating change talk

1. Clinician shows no explicit attention to, or preference for, the client's language in favor of changing.
2. Clinician sporadically attends to client language in favor of change – frequently misses opportunities to encourage change talk.
3. Clinician often attends to the client's language in favor of change, but misses some opportunities to encourage change talk.
4. Clinician consistently attends to the client's language about change and makes efforts to encourage it.
5. Clinician shows a marked and consistent effort to increase the depth, strength, or momentum of the client's language in favor of change.

Softening sustain talk

1. Clinician consistently responds to the client's language in a manner that facilitates the frequency or depth of arguments in favor of the status quo.
2. Clinician usually chooses to explore, focus on, or respond to the client's language in favor of the status quo.
3. Clinician gives preference to the client's language in favor of the status quo, but may show some instances of shifting the focus away from sustain talk.
4. Clinician typically avoids an emphasis on client language favoring the status quo.
5. Clinician shows a marked and consistent effort to decrease the depth, strength, or momentum of the clients language in favor of the status quo.

Partnership

1. Clinician actively assumes the expert role for the majority of the interaction with the client. Collaboration or partnership is absent.
2. Clinician superficially responds to opportunities to collaborate.
3. Clinician incorporates client's contributions but does so in a lukewarm or erratic fashion.
4. Clinician fosters collaboration and power sharing so that client's contributions impact the session in ways that they otherwise would not.
5. Clinician actively fosters and encourages power sharing in the interaction in such a way that client's contributions substantially influence the nature of the session.

Empathy

1. Clinician gives little or no attention to the client's perspective.
2. Clinician makes sporadic efforts to explore the client's perspective. Clinician's understanding may be inaccurate or may detract from the client's true meaning.
3. Clinician is actively trying to understand the client's perspective, with modest success.
4. Clinician makes active and repeated efforts to understand the client's point of view. Shows evidence of accurate understanding of the client's worldview, although mostly limited to explicit content.

5. Clinician shows evidence of deep understanding of client's point of view, not just for what has been explicitly stated but what the client means but has not yet said.

Calculation global scores: Global scores are assigned on a five-point Likert scale: minimum =1, maximum = 5. Relational global score is calculated by partnership + empathy / 2, and the technical global score is measured by cultivating change talk + softening sustain talk / 2.

4

Clinicians' and patients' perspectives on discussing outcomes during healthcare visits – Qualitative study with dyadic interviews

Dorinde E.M. van der Horst
Ellen G. Engelhardt
Mariska Hackert
Philip J. van der Wees
Willem Jan W. Bos
Cornelia F. van Uden-Kraan

Published in Patient Education and Counseling, 2025

Abstract

Objective

We aimed to explore patients' and clinicians' perspectives on discussing different types of outcomes during healthcare visits: clinical outcomes, patient reported outcomes (PROs), calculated prognostic outcomes and comparisons of individual patient outcomes with aggregated data.

Methods

Dyadic interviews (n = 22) with patients with breast cancer or chronic kidney disease and their treating clinician.

Results

Participants varied in their preference in what outcomes to discuss depending on: their emphasis on numerical data, perceived control over outcomes, patients' approach to uncertainty regarding the future, and the impact of outcomes on patient's motivation. Patients and clinicians agreed that avoiding information overload and enabling a trust-based patient-clinician relationship were important facilitators for discussing outcomes. The interviews revealed that assumptions from patients and clinicians about each other were not always correct. Discussion of these misassumptions led to new insights; patients realized their (non-medical) information is relevant to clinicians, and clinicians recognized they sometimes misjudge which outcomes patients wish to hear.

Conclusion & Practice implications

We identified varying preferences in discussing different types of outcomes among both patients and clinicians. The dyadic interview method proved to be effective in revealing misassumptions. Interviews revealed adverse effects of discussing outcomes, highlighting the importance of open dialogue and exploring information needs rather than assuming them.

1. Introduction

The concept of Value Based Health Care (VBHC) is increasingly being implemented in healthcare globally since its introduction in 2006[1]. VBHC entails a strategic agenda from an economic background to structure care in such a way that value in healthcare is increased. Value is determined in quality of care (measured through care outcomes) relative to the cost. Thus, information on care outcomes, in particular outcomes that matter to patients, are required to determine value of care. Since the introduction of VBHC there is an increased focus on measuring outcomes to determine value of care[2, 3]. Standard sets of patient-centred outcomes have been developed for an increasing number of conditions[4]. These outcomes can be used on an aggregated level to drive quality and process improvements[5, 6], and on the individual patient-clinician level during healthcare visits. Discussing outcomes during healthcare visits, facilitates: 1) informing patients on their health status, 2) identifying patients' problems and disease monitoring, and 3) enabling shared decision making (SDM)[6–8]. SDM entails the collaborative process between patient and clinician in making healthcare decisions[9, 10]. We distinguish four different types of outcomes that may be discussed during healthcare visits: 1) individual clinical outcomes (e. g., blood pressure or laboratory results), 2) individual patient reported outcomes (PROs)[11], 3) prognostic outcomes (e.g., estimating probability of survival or disease progression), and 4) comparisons between individual- and aggregated outcomes (e.g., comparing patients' 'experienced symptoms' to a group with similar (disease) characteristics).

These outcomes are increasingly available including their use in decision aids and PRO dashboards[12–14]. However, in daily practice their use is often limited. Potential barriers for effective use of outcomes in making medical decisions may exist in clinicians and patients having different views regarding discussing outcomes. Clinicians typically focus on the physical aspects of disease, while patients may prioritize PROs[15–19]. Additionally for prognostic outcomes, patients may be more reluctant towards discussing prognostic information than clinicians [20–22].

Understanding how patients and clinicians view different outcomes (clinical outcomes, PROs, prognostic models and comparisons with aggregate outcomes), can guide meaningful use of these outcomes during healthcare visits. Until now, studies reporting clinicians' and patients' views regarding outcome information studied these perspectives separately. However, clinicians often base their views on assumptions regarding the patient and vice versa. When the clinician's and patients' perspectives can interact directly, views can be shared and compared, potentially building new perspectives[23, 24]. Therefore, we used a dyadic approach to explore patients' and clinicians' shared and diverging perspectives on discussing various types of outcome information during consultations.

2. Methods

In this study, we conducted dyadic interviews to capture data from the interaction between patients and clinicians. In a dyadic interview, the interview was held with a patient and their treating clinician together. This approach enables participants to enrich their viewpoints by exchanging and contrasting their experiences. Existing treatment relationships serve as a shared foundation, making it easier to share and compare experiences on the topic[23, 24].

2.1.Setting and participants

Participants in the dyadic interviews included patients in follow-up care for early-stage breast cancer (BC) (N =8), women undergoing treatment for metastasized BC (N = 3), patients with chronic kidney disease (CKD) (N = 10), one patient with kidney failure receiving conservative therapy, and their treating clinicians. BC differs from CKD in that BC is a potentially curable disease depending on tumour characteristics, for which treatment is provided with the goal of achieving progression free survival. CKD is a progressive disease of nature, which lacks curative treatment. The treatment goal is slowing down kidney function decline towards kidney failure (and the need for kidney replacement therapy such as dialysis or kidney transplantation). The aim of this study was not to compare the two disease contexts, but rather to incorporate diverse clinical contexts to explore individual perspectives on discussing various types of outcomes. Participating clinicians could be nephrologists, medical oncologists, surgical oncologists or BC/ CKD nurse practitioners. Participants were all recruited from Santeon hospitals. Santeon is a hospital group of large non-academic Dutch teaching hospitals.

2.2.Participant recruitment

All clinicians were approached individually via e-mail, by telephone or in person by the researchers. Patients were recruited through their treating clinicians. To limit selection bias, a predetermined date was set on which the clinician would ask the first outpatient patient to participate in the study. If this patient was not interested, the second patient would be asked and so forth. Exclusion criteria for patients included insufficient command of Dutch of English or being cognitively impaired. Patients recruited by their clinician were contacted by a researcher (DH or EE) to further inform them about the study procedure. Informed consent was obtained from all participants.

2.3.Procedure

Before the interview, a brief online questionnaire was sent to patients to collect patient characteristics (i.e., birthyear, sex, educational level, health literacy scale)[25]. Researchers DH and EE, both experienced in qualitative research, conducted the dyadic interviews. Patients' partners/companions were welcomed to participate. To address power imbalances, researchers emphasized before the start of the interview that it should feel as a conversation between two persons, regardless of their roles, and let patients start in the interviews. Additionally, we tried to not do the interviews in consultation rooms in the hospital. When this was unavoidable due to practical reasons, we adjusted seating arrangements in the consultation rooms. Researchers minimized interference using topic cards derived from a predefined list. Participants were free to use the cards as desired, with researchers intervening only for clarification. Visual examples supported outcome discussion (see **Supplement 1**). Data was collected until both DH and EE agreed data saturation was reached (no new topics emerged). The Medical research Ethics Committees United in Nieuwegein (MEC-U), the Netherlands, assessed the study protocol to determine whether the Medical Research Involving Human Subjects Act (WMO) was applicable. In their evaluation, they concluded that the study does not fall under the scope of the WMO, as it does not involve burdensome or physically invasive procedures and requires only a limited time commitment from participants. They also concluded that the study is in congruence with the Good Clinical Practice Guidelines (W20.158).

2.4.Topic list

The topic list was developed together with a patient with CKD, a nephrologist (WB), a research coordinator- and a representative from the Dutch Kidney Patient association. The topic list included examples of four different types of outcome information specified to either BC or CKD: 1) clinical outcomes, 2) PROs, 3) prognostic estimates (estimates based on prognostic models including individual- and aggregated patient data), and 4) comparing individual patients' PRO's to aggregated PRO data. For the latter, as these kind of outcomes are not yet routinely used in todays practice, example visuals were shown in which a patient could compare their own PROs (PRO scores on physical and mental health) with a general population. To explain the concept of PRO's, example PRO questions were shown, such as 'how would you rate your quality of life?'. Prognostic estimates appropriate for the BC and CKD context were used in the interviews. In **Supplement 2** the full topic list is provided.

2.5.Data analysis

All interviews were transcribed. In this qualitative interview study we performed a deductive thematic analysis; we coded with an inductive approach within the predetermined themes of the topic list. Coding was performed independently by DH and EE. After every 2–3 interviews codes were discussed. Final codes were determined by discussion until consensus was reached. Atlas.ti 9 was used for analysis. At the end of the analysis a validity check was done with all authors. Findings are reported following the consolidated criteria for reporting qualitative research (COREQ)[26]. Per type of outcome information (clinical outcomes, PROs, prognostic estimates, comparing individual patients' PRO's to aggregated PRO data) we report patient-specific views, clinician-specific views and their shared views or misconceptions in which the patient's and clinician's view overlap or differ.

3. Results

3.1 Participant characteristics

In total, 22 interviews (N=44 participants) were conducted: 11 in BC and 11 in CKD. Interviews were live (n=16) or held via videoconferencing (n=6). The duration of the interviews was between 45-60 minutes. **Table 1** shows the participants' characteristics. Patients' health literacy scores and education levels were moderate to high. The majority of patients had known their clinician for at least 1-2 years. In CKD, most clinicians were medical specialists. In BC five medical specialists participated and six nurse practitioners.

Table 1. Patient and clinician characteristics

	CKD (n=11 interviews)	*BC (n=11 interviews)*
Patient characteristics		
Sex (female), n %	2 (18.2%)	11 (100%)
Age, median (IQR)	67 (64.0-76.0)	55 (51.0-71.0)
SBSQ score[1], median (IQR)	4.7 (4.3-5.0)	4.6 (4.7-5.0)
Education level, n(%)		
Low (ISCED [2] levels 0-2)	0	2 (18.2%)
Medium (ISCED levels 3-4)	4 (40.0%)	3 (27.3%)
High (ISCED levels 5-8)	6 (60.0%)	6 (54.5%)
Missing	1	0
How long patient has known clinician, n(%)		
< 1 year	0	3 (27.3%)
1-2 years	1 (9.1%)	5 (45.5%)

Table 1. *(Continued)*

	CKD (n=11 interviews)	*BC (n=11 interviews)*
3-5 years	3 (27.3%)	2 (18.2%)
>5 years	7 (63.6%)	1 (9.1%)
Clinician characteristics		
Sex (female), n%	5 (45.5%)	9 (81.8%)
Function		
Specialist [3]	10 (90.9%)	5 (45.5%)
Nurse practitioner	1 (9.1%)	6 (54.5%)

IQR= interquartile range (25th percentile – 75th percentile).

[1] *SBSQ score=Set of Brief Screening Questions (measure for health literacy), >3 is considered adequate (REF)*

[2] *ISCED= Education levels based on International Standard Classification of Education,*

[3] *= In BC, specialists were: 4 surgical oncologists, one medical oncologist and in CKD all specialists were nephrologists.*

3.2 Patients' and clinicians' perspectives on discussing different types of (outcome) information during patient-clinician healthcare visits

The interactions between patients and clinicians revealed shared and diverged views regarding discussing outcomes during healthcare visits, as well as misconceptions about each other. **Table 2** provides an overview of these findings.

Table 2: Overview of patient-specific, clinician-specific and their shared perspectives or misconceptions regarding each other on discussing outcomes during healthcare visits

		Patient-specific views	Shared views	Clinician-specific views
3.2.1 Clinical outcomes		• Clinical outcomes can give a sense of control over the disease. • Aversion to sugar-coating unfavourable results. • Clinicians should judge how much information a patient can handle based on their emotional state.	• Evaluating health = clinical outcomes + how a patient is doing/feeling. • Discussing clinical outcomes is essential for monitoring and identifying problems. • Positive feedback can provide comfort and can motivate. • Clinical outcomes are not neutral, it can provoke an emotional response. • Discussing too many clinical outcomes may result in information overload.	• Patients can be too focused on the 'numbers'. • Clinical outcomes can give a false sense of security when it is all that is focused on. • Sharing unfavorable results can demotivate and reduce commitment to treatment.
	Misconception	• Patients thought their clinician primarily focuses on clinical outcomes and disease-related outcomes, unaware that most clinicians wanted to discuss mental health as well. • Clinicians and patients sometimes focused on different treatment goals (and therefore on different outcomes), e.g. short- or long-term goals of treatment. • Patients did not always realize that next to clinical outcomes, information regarding daily life and (social) functioning is relevant for the clinician.		

Table 2: *(Continued)*

		Patient-specific views	Shared views	Clinician-specific views
3.2.2 PROs		• For effective use of PROs a good patient-clinician relationship is needed because it lowers the threshold to discuss symptoms.	• PROs can help in: prioritizing patients problems and needs, evaluating disease progress, understanding symptoms, preparing consultations, discussing symptoms that patients might not feel comfortable to bring up themselves • Downsides: PROMs do not always include the right questions, regular conversation without PROs may suffice. • PROMs need to be concise and specific. • Consultations may take longer.	• Risk of information overload when discussing both clinical information and PRO's . • Increase in number of symptoms to discuss with patients because of PROs.
	Misconception	• Patients thought PROs are mainly for the clinician, while clinicians argued it can help patients as well in preparing and bringing up (sensitive) topics. • Patients argued not to need PROs for themselves (they already know their problems), but did not always realize the PROs matter to clinicians as well. • Patients assumed clinicians were already aware of most of their problems (making PROs unneeded), but clinicians often expressed a need for more insight in patients’ symptoms and functioning. • Patients often thought it is a burden for the clinician when patients share complaints that do not relate to their expertise, but clinicians countered they want to know and get a holistic view to provide best care. • Clinicians thought filling out PROs is a burden for patients, but patients were more than willing to fill it out when asked (and if intended for use as part of care).		

Table 2: *(Continued)*

		Patient-specific views	Shared views	Clinician-specific views
3.2.3 Prognostic estimates		• Predictions help to cope with the uncertain future. • The preference for receiving predictive information may change over time. • When calculated predictions are inaccurate, they may negatively impact life choices.	• Discussing predictions is particularly important when something can still be changed/improved. • Predictions may stimulate motivation in treatment. • Predictive information may be difficult to hear/process. • Its best to share predictive information based on estimates, without exact numbers.	• It is difficult to determine which patients want to hear predictions, and in what level of detail. • Predictions may lag behind recent developments. • Patients can cling too much to predictions. • Explaining predictions is challenging. Graphical support may help.
	Misconception	• Clinicians tend to assume they know whether patients want to hear predictions and do not always check these assumptions. However, patients varied from wanting to hear even negative predictions to patients not wanting to hear predictions at all. Made assumptions were not always correct. • Some patients expect clinicians to estimate whether they are (emotionally) ready to hear predictions.		
3.2.4 Comparing individual PROs to aggregated PRO data		• Doing worse than others when comparing on PROs is difficult to process. • Knowing what others choose in treatment decisions could be a useful comparison of data. • Some patients had no interest in comparisons, because: every individual trajectory is unique, they value the opinion of the clinician over the data-comparisons, or worry comparisons are invalid because of comorbidity. • Comparisons may affect patients' own symptom experience.	• Comparing an individual patient to aggregated PRO data helps inform what symptoms to expect and it can guide treatment decisions. • Doing better than others on PROs motivates.	• Sharing data on comparisons with others on PROs adds to being as transparent as possible.
	Misconception	• Some clinicians tended to share such comparisons because transparency of available knowledge was considered important, but not all patients wanted to receive such information and expressed it may even negatively affect them.		

3.2.1 Clinical outcomes

When patients primarily mentioned **physical aspects** when considering evaluation of their health during the interviews, different clinicians responded that **mental aspects** were also important. From their conversations it became clear that both considered clinical outcomes essential for **disease monitoring** and **timely identification of problems**. Both clinicians and patients stressed the importance of **positive feedback**, reporting 'good' clinical results, because it can provide comfort and it can motivate patients. Clinicians mentioned that **negative feedback in clinical outcomes** could demotivate patients to commit to their treatment(s).

Patients varied in focusing on clinical outcomes and 'numbers' versus qualitative information such as 'how they are feeling'. Those without symptoms often prioritized clinical outcomes during healthcare visits. In one discussion, a clinician noted that a patient that preferred clinical outcomes, focused too much on 'the numbers' (**Box 1**). This discussion highlights the patient's need to feel a sense of control over their kidney function decline. Discussing kidney function (eGFR) is the ultimate measure for patients in gaining insight into their disease progress. However, the clinician responds that focusing too much on the kidney function can hinder exploring other important factors related to (progress of) CKD. The clinician adds that patients may misinterpret kidney function when they lack an understanding of the overall course of the kidney function. As a result, patients may perceive the decline both as more stable ('*false sense of security*' or less stable '*shaken because of small decline*') than observed over time by the clinician.

Box 1 (CKD), ***p=patient, c=clinician***

P: I think- from my perspective, I only want to know to what extent the kidneys no longer function properly and what can be done about that.

C: That is actually what I very often hear in the discussions I have with patients when they come to see me, because that's the first thing they want to know, what is the kidney function? Whereas, I understand that, I really do, that that's important to them, but I always try to look beyond just that number. And to also see if people do indeed have health problems associated with poor kidney function, especially when that points towards the need for dialysis. (...) And even though I really try to emphasise in those discussions with patients that that number is really not the only thing that matters, you often see that patients latch on to that number. That's actually one of the things they always want to know about first.
P: Of course, because that's what you always notice. I'm now at an eGFR (kidney function) of 32 and I have this and I have that. So that's clear. But well, I- In the end, it's about what you can do with it.

C: And it sometimes also gives people sort of a false sense of security, because- Or perhaps false sense of security is not the right way to say it, but sometimes people's kidney function is one or two per cent lower and it upsets them tremendously, whereas that's just a variation in the measurement itself. On the one hand that number is something they latch on to, but I try to get them to look beyond just that number.

Another clinician pointed out to their patient, that when patients focus a lot on 'medical numbers', it can hinder the clinician in adequately assessing the patients' **social network and daily life functioning**. The patient responded to never have realized that this was important information as well (**Box 2**.)

Box 2 (CKD), *p=patient, c=clinician*

C: I have to know about your overall fitness as well. There is sometimes a huge urge to zoom in on the numbers, whereas I actually want to know about the combination, about how you do things and what you're able to do in your daily life, combined with the numbers. You are the sort of person who quickly wants to know about those numbers, I recognise that.

P: That's true. Because for me, that shows you immediately where I stand. That's what I want to know. That's just how it is.

C: Well, but I think that sometimes I would like to have a slightly better idea of how people are doing at home. I don't always have a clear insight with everyone into what they actually can and cannot do at home. So that's something I would sometimes like to know more about.

P: Yes, sure. And the home situation, I never thought about that. So, but I don't mind talking about that.

In CKD interviews, clinicians and patients often had **differing views on treatment goals,** leading them to focus on different outcomes. When discussing reasons for prescribing medication (e.g. blood pressure or anti-diabetic drugs), clinicians emphasized the long-term goal of slowing kidney function decline, whereas patients were more focused on immediate goals such as lowering blood pressure or losing weight, without considering the broader picture. Patients did not always seem to be aware of the connection between these treatments and the goal of slowing kidney function decline. Several CKD clinicians reported difficulties in effectively communicating this information to patients.

Finally, patients and clinicians agreed that **'numbers' (i.e., clinical outcomes) are not neutral:** they can provoke a certain emotional response. However, patients **discouraged "sugar-coating" of the results**. Different clinicians mentioned that they try to estimate the amount of unfavourable information their patient can tolerate. One patient with CKD reacted to this by saying they expected their clinician to do so as he considered it 'part of the job' to sense what information to tell based on the emotional state the patient is in.

3.2.2 PROs

Participants' opinions on PROs varied. While some clinicians actively promoted PROs, others were unconvinced of their usefulness and reluctant to use them in practice. The patients' opinions showed similar contrasts. When clinician and patient agreed on views regarding PROs, they reinforced each other's perspective.

Clinicians and patients who shared positive attitudes towards PROs, mentioned several benefits. They emphasized that PROs can help **prioritize patients' most important problems and needs**. When measured over time, PROs are valuable for **evaluating disease progress**, especially in chronic conditions like CKD, where changes may occur gradually and go unnoticed. Additionally, PROs can help patients **understand the symptoms** of their disease and **prepare** themselves for healthcare visits, as exemplified in **Box 3.**

Box 3 (BC), ***p=patient, c=clinician***

P: And I personally experienced those PROMs as that it really forces you to take pause and reflect, what does it feel like to me? How do I experience it? Where do I stand? It is actually not that bad or should I in fact change something because I actually feel a bit less in certain areas. That's where it helps.

In interviews where both participants expressed skepticism about PROs, they reinforced each other's arguments against their use. In one CKD interview, clinician and patient preferred discussing topics through regular conversation than using PROs to set the agenda. They mentioned that, based on their experience, PRO-questionnaires **do not always include the right questions** for the situation making them difficult to fill out. They also expressed being fatigued with today's '**survey-culture'.**

Several clinicians also warned of **potential information overload** for patients due to the challenge of balancing both PROs and clinical information during the healthcare visits. A patient with CKD responded in agreement and assumed clinicians are more than capable of efficiently exploring symptoms of patients without using PROs (**Box 4**).

Box 4 (CKD), ***p=patient, c=clinician***

C: So yes, there is that- That's also what makes me a bit hesitant to hand out many of them. Because they have so many PRO questions and like I just said, you already discuss so many things. And if you don't do anything with them [PRO's], then I feel- Then it's unfair towards patients, so you really need to pay attention to what you do with them. So you should indeed to be very aware of that, what do I want to use it for? And what- And then pick out a few things that you can do something about. I certainly think that for some people, especially those who don't easily share issues without being asked, it can have a lot of added value. But I can also imagine that it does indeed add another big chunk of information and that people don't always have the time or are not always willing to discuss it all.

P: Personally, I feel it would actually be a semi-substitute for the conversation, and I feel the conversation is more important than those forms. (...) And I think that a professional would already know those kind of things [of PROs]; questions like: do you have health issues regarding these areas? you suffer from that, that or that? That takes just two seconds, I would think. But, well. Perhaps that's me being old fashioned, but so be it.

In other interviews clinicians were enthusiastic about PROs and presented counterarguments to patients' hesitations. In one interview, a patient states that discussing PROs was unnecessary, because this person was already aware of their own symptoms and quality of life. However, the clinician emphasized that this information was also important for the treating clinician. Additionally, patients who argued that a good conversation was enough were countered by clinicians, who pointed out that PROs help **structure the conversation and facilitate discussion of sensitive topics (Box 5).**

Box 5 (CKD), ***p=patient, c=clinician***

P: Sometimes I struggle with it quite a bit, thinking: what do they mean by that? And I'll admit it, I don't always enjoy filling in all those questionnaires. It feels like a chore. But of course it's very important for you.

C: What do you find stupid about it? Is it having to complete the questions, or the time it takes?

P: It's just that I think we could simply discuss it during the appointment instead. But of course for you it works better to have everything on paper.

C: But- Because as you say, we could discuss it when we get to it, but if I were to ask you a frank question in our conversation, such as if you have had problems sometimes, say, in your sexual functioning, you might say no, not all, everything is fine. Whereas if you had filled in the questionnaire at home, you might have answered, yes, sometimes; and then I would have said, I understand that you occasionally have difficulties- Would you like to get something for that or can we discuss that? Or I would use different words to refer to it, because then you would have to, in one way or another, when you're sitting in front of the doctor- We know that people sometimes sort of sweep things under the carpet or would rather not discuss them, even though it might be very important for that patient. You wouldn't be afraid to tick a box in the form, but in the consulting room you would-

P: Not mention it.

C: Not bring it up. I believe that is what those questionnaires are for, right?

Multiple patients expressed concerns about **limited consultation time** and the **fear of burdening** their **clinician** by discussing PROs unrelated to their medical expertise. Some clinicians agreed, feeling that they 'cannot fix everything'. However, other clinicians argued that discussing 'minor problems' or issues outside their expertise can offer a better **overall understanding of the patient**, helping to deliver the best care and make necessary referrals (**Box 6**).

Box 6 (CKD), *p=patient, c=clinician*

C: As a doctor, you hear about a great number of health problems from patients, most of which you actually cannot fix. And that creates the risk of raising false expectations, because as a doctor you can lower the blood pressure, but many other health problems you cannot do all that much about. But on the other hand, I do think that as a doctor I can help people better when I have a better understanding of what is going on exactly. And I do think that it's important that patients also have proper insight into what exactly you can do with it.

While clinicians often mentioned that completing PROMs could be burdensome for patients, many patients, including those who were initially uncertain about the value of PROMs, said they would be willing to do so if their clinician asked. According to one clinician, 'framing' PROMs as part of routine care (e.g., resembling a blood test) and explaining their relevance is key to encourage patient willingness to complete them.

3.2.3 Prognostic estimates

Most patients, particularly those with BC, preferred to hear personalized predictions, because **uncertainty about the future can be challenging to cope with**. Clinicians noted that they often make assumptions about whether patients want to hear specific prognostic information, but the interviews revealed that these assumptions were not always accurate (**Box 7**).

Box 7 (Metastatic BC), *p=patient, c=clinician*

C: To show this [personalized prediction regarding survival rate], that's just such a hard reality. And fortunately that is not true in most cases, but I do notice that with, with those patients [that have negative prospects] I tend to do show that less often- what I, we, do when we know the prospects are very poor, then I keep- sometimes I withhold it from them for a bit, until they have seen the oncologist, because they will discuss it with the patient anyway. I notice that I do that, but if people ask for it, then I will obviously show it, but then I just don't like doing it, I just hate it, it's so shit.

P: But even if the outlook is, er, poor or, er, five years-

C: Would you still like to see it?

P: Yes, then I would still want to know.

C: Fair enough, so I-

P: Then I could take it into account.

C: Fair enough, so I am actually too much in the habit of assuming what the patient in front of me would want, because even if you have a very poor prognosis, some people absolutely don't want to know about it, but others actually prefer to know what they can expect.

Different BC patients explained that their desire to receive prognostic outcomes, such as 'survival', depended on when the outcomes were shared, and that these **preferences could change over time (Box 8)**.

Box 8 (BC), ***p=patient, c=clinician***

C: If people in the beginning say, no, I don't want to know survival outcomes, would you advise to bring it up again at a later time or to leave it at that?

P: I would say yes, you should, because people's perspectives can change over time. Looking at myself, with the studies, for example; in hindsight, I feel that I would have wanted to do that. So I get it that you may not want to know about it in the beginning, but you may want to know halfway through. So you can always offer it again.

In CKD, several patients mentioned wanting to know predictions about disease progression only **if they could still take action to prevent it**. For some, these predictions acted as a 'wakeup call' to commit to their treatment. CKD clinicians explained that they often use predictions as a **motivator** for patients. However, when a patient cannot take steps to improve their prognosis, communicating prognostic estimates can have a negative impact and **discourage** them, according to both a CKD- and BC clinician (**Box 9**).

Box 9 (CKD), ***p=patient, c=clinician***

P: I seize every moment of life, so no, I wouldn't want to know [calculated risk on the need for kidney replacement therapy in 2 and 5 years]. Then I would build my life around the prospect of those two or five years. No, I don't want to do that. Let me just enjoy each day. Would you recommend it to anyone?

C: Well, if the model contains elements you can actually influence, it could be helpful. For example: if it includes smoking, it would be possible to show a particular percentage depending on whether or not someone smokes, perhaps it might motivate them to quit.

P: Well, yes.

C: Yes, that would be useful, but I think it's very difficult. Particularly with something like a decline in kidney function. That is actually also what you basically said. You can give people a whole lot of information, but if they actually have no influence on what happens, that can really only have a very negative effect.

Some patients preferred not to receive any prognostic estimates. Both CKD and BC patients emphasized that every patient is unique, and therefore, **predictions may not be accurate** for the individual. Patients also expressed concerns that incorrect prognostic estimates could **significantly impact their life choices and how they experience life (Box 10)**.

Box 10 (CKD), ***p=patient, c=clinician, p1= patient's partner***

C: Would you want to know about such as a prediction [calculated risk on the need for kidney replacement therapy in 5 years]?

P: I don't know if I would want to, to know about such a prediction.

P1: But, well, it would of course create a bit more clarity if you were going to start with dialysis, if that were necessary.

P: Yes, but it's a prediction, sort of like the weather forecast. And you would base your whole outlook on it, telling yourself that you can expect to be left with a certain number in five year's time. But things may turn out differently. Plus, I personally don't feel the need to know about it. It would consume far too much of your life and, you also want to have a normal life aside from it.

Acknowledging the varying patient preferences, CKD and BC clinicians expressed difficulty in deciding how much prognostic information to disclose. Clinicians either asked patients before sharing such information or, more often, made their **own judgment** about whether patients wanted to know **(Box 11).**

Box 11 (BC), ***p=patient, c=clinician***

C: With some patients, they very clearly don't want to know about things [predictions regarding mortality], so then I just don't tell them, or when you, when you sense that someone doesn't- But okay, that's of course a bit subjective, that I then think I can sense that, but that's why I deliberately don't tell some women about certain things. That, those are never really important things, because then, with those I know you're expected to-

P: Over the course of the conversation you get a sense of, er-

C: You get a bit of a sense of what their needs are, so to say. That's what I hope, I hope that I am able to do that.

Many clinicians opted to discuss disease prospects in a more ‘**general way’** rather than providing patients with probabilities and exact numbers, because patients may cling too much on the latter. This view was often shared by the patient.

3.2.4 Comparing individual PROs to aggregated data

Opinions on the usefulness of comparing individual patient’s PROs to those of a group of comparable patients varied. Several clinicians found such a comparison helpful to inform patients about **disease prospects,** including expected symptoms. Patients felt it would be useful to **understand the symptoms** they experienced. Patients explained that they used it as a global reference, for motivation or to guide treatment decisions. Whether a patient was performing better or worse than the reference group seemed to affect their preference for hearing comparisons based on aggregated data. Both patients and clinicians agreed that **doing better can be motivating**, while some BC patients remarked that **doing worse can be difficult to hear and demotivating,** especially when they don’t know how to improve their PROs. This led some patients to wanting to avoid hearing the comparisons.

Other patients also did not want to compare themselves to aggregated data, as they believed: **every individual’s disease experience is unique.** They valued the opinion of the clinician over the comparisons with aggregated data. Some patients believed that such comparisons could negatively affect their own symptom experience. A patient added that it may depend on **personality traits** whether patients see added value in the comparisons. When this was brought up in an interview, the clinician came to realize that such comparisons may not suit everybody, and realized they needed to check whether patients want to receive such information before discussing it.

Box 12. Reflections on doing dyadic interviews

- Power imbalances may exist between a patient and their treating clinician. This may go two ways; patients feeling less empowered compared to the clinician who has medical knowledge and guides their treatment, and clinicians may feel limited in expressing themselves freely to maintain a good patient-clinician relationship and being professional and polite. Considering the potential power imbalances, we noticed the following:
    - Clinicians often let the patient respond first, perhaps they did not want to ‘overrule’ them.
- Both parties frequently spoke up and did not seem to hold back when they disagreed with each other. This was more evident in some interviews than others. Overall, we do think there was room for both to share honest opinions.
- Patients did not look for confirmation with their clinician when they stated something.
- Patients were often not convinced by clinicians in a discussion or when there was disagreement.

- We do think there was room for both to share honest opinions, as even critical remarks regarding the other were sometimes shared (both ways).

- Participants were enthusiastic about the interviews and having a 'different' conversation with each other.
- Multiple 'light-bulb-moments' arose from the interaction between participants, because they were able to directly reflect on each other's statements. These findings were particularly relevant and cannot be achieved using individual interviews.
- Using question cards proved effective in maintaining the conversation between the two participants while allowing the researcher to remain minimally involved in the interaction.
- The dyadic interviews appeared to strengthen the patient-clinician relationship by juxtaposing their perspectives and allowing them to hear each other's reasoning, fostering a deeper mutual understanding.

4. Discussion and conclusion

4.1. Discussion

We aimed to better understand what meaningful use of outcome information during healthcare visits entails. To achieve this, we conducted dyadic interviews to study both patients' and clinicians' perspectives on different types of outcome information, including outcomes, PROs, prognostic estimates, and comparisons of individual PROs to aggregated data. The interviews uncovered that assumptions about one another were not always accurate. Addressing these misconceptions sparked new insights: patients realized that their non-medical information holds value for clinicians, while clinicians recognized that they sometimes do not correctly assume which outcomes patients prioritize hearing about.

We identified variability in the preferences of both patients and clinicians regarding which outcomes were considered important to discuss during healthcare visits. This individual variability is in line with earlier research regarding outcomes [20,22]. For patients, preferences depended on their verbal assertiveness in raising topics and whether they needed PROMs for this end and their strategies for coping with uncertainty about the future. In addition, patients who emphasized that 'every individual is different' focused less on predictions and comparisons with others based on aggregated data, compared to those with a less individualistic perspective. Regarding prognostic outcomes, patients' preferences in receiving the outcomes was also determined by the patients' ability to change the outcomes.

In this study we identified a difference between patients with a focus on numerical outcomes and patients who focused more on qualitative outcomes, such as how they are feeling. In CKD interviews, some patients fixated on the kidney function (measured with eGFR) overshadowing other important topics of conversation including overall functioning and treatment goals to slow down kidney function decline. Patients were also not always aware of the treatments related to slowing down kidney function decline (e.g., blood pressure regulation). Rather than a misalignment in views regarding which outcomes CKD clinicians and their patients consider important, it highlights a knowledge gap within CKD patients. Use of additional information tools for patients to better understand the treatment goals related to slowing down kidney function decline may be helpful.

Although less evident, clinicians also differed in the emphasis on numerical outcomes. An explaining factor for this difference may be the numeric-self efficacy (one's own confidence in numerical data). In Peters et al., they found that people with lower subjective numeracy were less motivated in numeric tasks and had more negative reactions to numbers [27]. This relates to both clinicians who provide numerical information and patients who receive it. Clinicians and patients with higher numeric-self efficacy may tend to numerical outcomes more than when having lower numeric-self efficacy. Additionally, patients may react differently to provided numerical information depending on their level of numeric-self efficacy. Thus, differences in numeric-self efficacy should be acknowledged, as they can influence how numerical information is interpreted and applied in medical decision making [28].

Another important finding was the identified assumptions of patients and clinicians regarding each other. The dyadic interviews enabled participants to directly respond to each other's statements, which revealed that these assumptions were not always accurate. Three main misconceptions will now be discussed. First, patients were often unaware that the information they can provide, such as preferences, daily life circumstances, and social functioning were valuable alongside clinical information. In a review by Joseph Williams et al., they explain that this believe hinders shared decision making. Efforts should be made to help patients recognize that their lived experiences are important[29]. A genuine curiosity among clinicians to gain a holistic understanding of their patients will support this effort. Second, patients did not always realize that PROs could benefit them personally, not just help clinicians monitor disease. In discussing PROs during interviews, these patients realized they could use them to prepare for healthcare visits. Clinicians often assumed PROs were burdensome for patients, as often mentioned in literature [30], however patients refuted this during the interviews.

Patients expressed a willingness to complete PROs, particularly when they were relevant to their care. Moreover, patients had realistic expectations about discussing PROs, considering time constraints and their clinician's ability to offer care outside the scope of their specialization. Third, clinicians did not always correctly assume their patient's information needs, particularly regarding prognostic outcomes. Clinicians mentioned to judge per patient what outcomes to share with them, but some patients disagreed with their judgment (e.g. not wanting to hear the outcomes). During these conversations, clinicians realized that sharing certain outcomes could have unforeseen negative effects, and not every patient wants to hear them. Importantly, patients added that they may change their view over time about whether they want to receive outcome information.

4.2 Practice implications

This study has several implications for clinical practice. First, our findings identified different factors that contribute to effective use of outcome information: 1) clinical outcomes alone do not suffice to understand patients' overall health status and patients should be made aware that their lived experience is important to discuss, 2) when using PROs, the goal of its use should be clear to both clinicians and patients, 3) information-overload should be avoided, in particular when both PROs and clinical outcomes are discussed, and 4) patients' individual information needs vary and should be explored by clinicians rather than assumed.

A key strength of this study is the method of dyadic interviewing. This method proved highly effective for thoroughly exploring diverse perspectives. By facilitating direct reactions to each other's arguments, the dyadic interviews enabled participants to generate new insights. Shared opinions were reinforced, while conflicting views prompted the emergence of new arguments or clarification of differences. Future research on diverse topics regarding both the perspective of patient and clinician could similarly benefit from employing this method.

This study has several limitations. Although we aimed to minimize power imbalances during interviews, we cannot exclude the possibility of social desirability bias affecting the candour of patients and clinicians. However, our observations suggest that this bias was probably limited, as both parties openly discussed 'negative' aspects of certain outcome information and frequently disagreed with each other. Secondly, outcome information based on comparisons with aggregated data was not yet routinely used in consultations, and therefore discussion of this topic was abstract despite visual examples. Thirdly, there may have been some residual selection bias as clinicians were responsible for selecting participating patients, which could have influenced the results despite efforts to mitigate this bias. Fourthly, health literacy scores of patients included in this study were high as well as the average education levels. This may limit generalizability of the results. Additionally, we did not test the illness understanding of participating patients. Illness understanding may affect which outcomes patients prefer to (not to) discuss. Lastly, patient input into the study's topic list was derived only from CKD patients and not BC patients. Furthermore, although noted in the COREQ guidelines, we did not perform validity checks with all participants.

4.3. Conclusion

In conclusion, conducting dyadic interviews with patients and clinicians revealed a variation in individual preferences for discussing different types of outcome information during healthcare visits. For patients, these variations were partly shaped by the level of disease insight (being able to link outcomes to their disease status), but also personal traits such as how to cope with uncertainty about the future and verbal assertiveness in raising topics during healthcare visits (for which PROMs were considered helpful). The dyadic interview method proved to be effective in revealing misconceptions between patients and clinicians. Patients were not always aware that their information was important to discuss, and clinicians sometimes misjudged their patient's information needs. Through genuine curiosity in one another and open dialogue such incorrect assumptions can be avoided. Exploring (information) preferences, rather than assuming them, is key.

References

[1] D. J. van Staalduinen, P. van den Bekerom, S. Groeneveld, M. Kidanemariam, A. M. Stiggelbout, and M. E. van den Akker-van Marle, "The implementation of value-based healthcare: a scoping review," *BMC Health Serv. Res.*, vol. 22, no. 1, pp. 1–8, 2022, doi: 10.1186/s12913-022-07489-2.

[2] M. Porter and E. Teisberg, *Redefining Health Care: Creating Value-Based Competition on Results*. Boston: Harvard Business School Press, 2006.

[3] N. A. Kampstra, N. Zipfel, P. B. Van Der Nat, G. P. Westert, P. J. Van Der Wees, and A. S. Groenewoud, "Health outcomes measurement and organizational readiness support quality improvement: A systematic review," *BMC Health Serv. Res.*, vol. 18, no. 1, pp. 1–14, 2018, doi: 10.1186/s12913-018-3828-9.

[4] W. R. Verberne *et al.*, "Development of an International Standard Set of Value-Based Outcome Measures for Patients With Chronic Kidney Disease: A Report of the International Consortium for Health Outcomes Measurement (ICHOM) CKD Working Group," *Am. J. Kidney Dis.*, vol. 73, no. 3, pp. 372–384, Mar. 2019, doi: 10.1053/j.ajkd.2018.10.007.

[5] M. E. Porter, S. Larsson, and T. H. Lee, "Standardizing Patient Outcomes Measurement," *N. Engl. J. Med.*, vol. 374, no. 6, pp. 651–653, 2016, doi: 10.1111/hae.13072.

[6] P. van der Wees, M. Nijhuis-van der Sanden, J. Ayanian, N. Black, G. Westert, and E. Schneider, "Integrating the Use of Patient-Reported Outcomes for Both Clinical Practice and Performance Measurement: Views of Experts from 3 Countries," *Milbank Q.*, vol. 92, no. 4, pp. 754–775, 2014.

[7] G. Steinmann, H. Van De Bovenkamp, A. De Bont, and D. Delnoij, "Redefining value: a discourse analysis on value-based health care," *BMC Health Serv. Res.*, vol. 20, no. 1, pp. 1–13, 2020, doi: 10.1186/s12913-020-05614-7.

[8] O. C. Damman *et al.*, "The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients," *J. Eval. Clin. Pract.*, vol. 26, no. 2, pp. 524–540, 2020, doi: 10.1111/jep.13321.

[9] A. M. Stiggelbout, A. H. Pieterse, and J. C. J. M. De Haes, "Shared decision making: Concepts, evidence, and practice," *Patient Educ. Couns.*, vol. 98, no. 10, pp. 1172–1179, 2015, doi: 10.1016/j.pec.2015.06.022.

[10] G. Elwyn, M. Tsulukidze, A. Edwards, F. Légaré, and R. Newcombe, "Using a 'talk' model of shared decision making to propose an observation-based measure: Observer OPTION5 Item," *Patient Educ. Couns.*, vol. 93, no. 2, pp. 265–271, 2013, doi: 10.1016/j.pec.2013.08.005.

[11] S. D. Weisbord *et al.*, "Development of a symptom assessment instrument for chronic hemodialysis patients: The dialysis symptom index," *J. Pain Symptom Manage.*, vol. 27, no. 3, pp. 226–240, 2004, doi: 10.1016/j.jpainsymman.2003.07.004.

[12] F. Légaré *et al.*, "Interventions for increasing the use of shared decision making by healthcare professionals," *Cochrane database Syst. Rev.*, vol. 7, p. CD006732, 2018, doi: 10.1002/14651858.CD006732.pub4.

[13] M. Q. Hackert *et al.*, "Effectiveness and implementation of making supported by SHared decision-OUTcome information among patients with breast cancer , stroke and advanced kidney disease : SHOUT study protocol of multiple interrupted time series," *BMJ Open*, vol. 12, pp. 1–12, 2022, doi: 10.1136/bmjopen-2021-055324.

[14] F. Yang, "Data Visualization for Health and Risk Communication," *Handb. Appl. Commun. Res.*, vol. 1, pp. 222–223, 2020, doi: 10.1002/9781119399926.ch13.

[15] K. D. Coulman *et al.*, "A Comparison of Health Professionals' and Patients' Views of the Importance of Outcomes of Bariatric Surgery," *Obes. Surg.*, vol. 26, no. 11, pp. 2738–2746, 2016, doi: 10.1007/s11695-016-2186-0.

[16] S. Lubberding, C. F. van Uden-Kraan, E. A. Te Velde, P. Cuijpers, C. R. Leemans, and I. M. Verdonck-de Leeuw, “Improving access to supportive cancer care through an eHealth application: A qualitative needs assessment among cancer survivors,” *J. Clin. Nurs.*, vol. 24, no. 9–10, pp. 1367–1379, 2015, doi: 10.1111/jocn.12753.

[17] L. Y. Yang, D. S. Manhas, A. F. Howard, and R. A. Olson, “Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication,” *Support. Care Cancer*, vol. 26, no. 1, pp. 41–60, 2018, doi: 10.1007/s00520-017-3865-7.

[18] T. R. House, A. Wightman, A. R. Rosenberg, G. Sayre, K. Abdel-Kader, and S. P. Y. Wong, “Challenges to Shared Decision Making About Treatment of Advanced CKD: A Qualitative Study of Patients and Clinicians,” *Am. J. Kidney Dis.*, vol. 79, no. 5, pp. 657-666.e1, 2022, doi: 10.1053/j.ajkd.2021.08.021.

[19] Y. de Jong *et al.*, “Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies,” *BMC Nephrol.*, vol. 22, no. 1, pp. 1–16, 2021, doi: 10.1186/s12882-021-02489-6.

[20] D. E. M. van der Horst *et al.*, “Predicting outcomes in chronic kidney disease: needs and preferences of patients and nephrologists,” *BMC Nephrol.*, vol. 24, no. 1, pp. 1–12, 2023, doi: 10.1186/s12882-023-03115-3.

[21] E. G. Engelhardt *et al.*, “Breast cancer specialists’ views on and use of risk prediction models in clinical practice: A mixed methods approach,” *Acta Oncol. (Madr).*, vol. 54, no. 3, pp. 361–367, 2015, doi: 10.3109/0284186X.2014.964810.

[22] J. W. Ankersmid, C. H. C. Drossaert, Y. E. A. van Riet, L. J. A. Strobbe, and S. Siesling, “Needs and preferences of breast cancer survivors regarding outcome-based shared decision-making about personalised post-treatment surveillance,” *J. Cancer Surviv.*, no. 0123456789, 2022, doi: 10.1007/s11764-022-01178-z.

[23] D. L. Morgan, S. Eliot, R. A. Lowe, and P. Gorman, “Dyadic Interviews as a Tool for Qualitative Evaluation,” *Am. J. Eval.*, vol. 37, no. 1, pp. 109–117, 2016, doi: 10.1177/1098214015611244.

[24] T. Klevan, R. Jonassen, K. T. Sælør, and M. Borg, “Using Dyadic Interviews to Explore Recovery as Collaborative Practices: Challenging the Epistemic Norm of the Single Person Perspective,” *Int. J. Qual. Methods*, vol. 19, pp. 1–9, 2020, doi: 10.1177/1609406920967868.

[25] L. D. Chew, K. A. Bradley, and E. J. Boyko, “Brief Questions to Identify Patients With Inadequate Health Literacy,” *Fam. Med.*, pp. 588–594, 2004, [Online]. Available: https://fammedarchives.blob.core.windows.net/imagesandpdfs/fmhub/fm2004/September/Lisa588.pdf.

[26] A. Tong, P. Sainsbury, and J. Craig, “Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups,” *Int. J. Qual. Heal. Care*, vol. 19, no. 6, pp. 349–357, 2007, doi: 10.1093/intqhc/mzm042.

[27] E. Peters and P. Bjalkebring, “Multiple numeric competencies: When a number is not just a number,” *J. Pers. Soc. Psychol.*, vol. 108, no. 5, pp. 802–822, 2015, doi: 10.1037/pspp0000019.

[28] E. Peters and B. Shoots-Reinhard, “Numeracy and the Motivational Mind: The Power of Numeric Self-efficacy,” *Med. Decis. Mak.*, vol. 42, no. 6, pp. 729–740, 2022, doi: 10.1177/0272989X221099904.

[29] N. Joseph-Williams, G. Elwyn, and A. Edwards, “Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making,” *Patient Educ. Couns.*, vol. 94, no. 3, pp. 291–309, 2014, doi: 10.1016/j.pec.2013.10.031.

[30] H. J. Westerink *et al.*, “Evaluating patient participation in value-based healthcare: Current state and lessons learned,” *Heal. Expect.*, vol. 27, no. 1, 2024, doi: 10.1111/hex.13945.

Supplement 1 – Examples provided of outcome information during the interviews.

1A.Examples of patient reported outcome measures (PROMs), used in both CKD and BC interviews.

For both breast cancer and CKD, examples of PROM-questions regarding physical and mental health were shown:

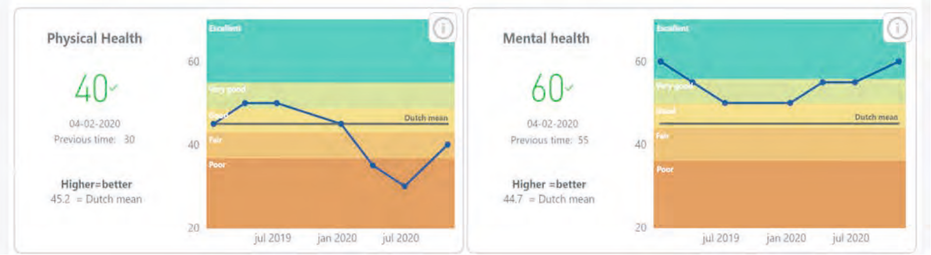
How would you rate your overall pain levels: 0 (no pain) until 10 (worst imaginable pain)

How would you rate your overall tiredness?
- none
- mild
- moderate
- severe
- very severe

How would you rate your overall quality of life?
- poor
- fair
- good
- very good
- excellent

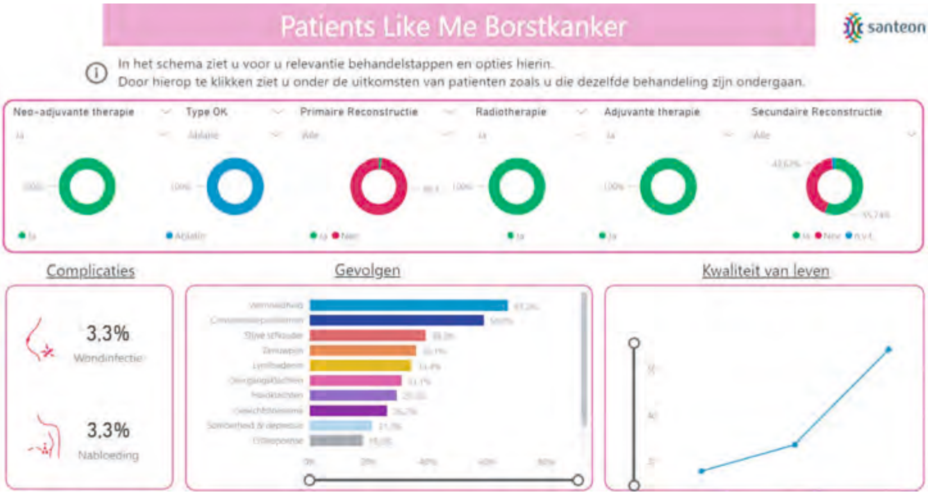
1B. Examples provided of individual PROs to aggregated PRO data used in both CKD and BC interviews

For patient-aggregated data comparisons examples included comparing patient individual mean PROM scores on physical and mental health with the mean scores of the Dutch population, visualized in a graph.



1C. Example of comparing individual PROs to aggregated data used in BC interviews.

A visual (in Dutch) of a Santeon – made dashboard was shown that visualizes the complications, effects (patient reported/PROs) and quality of life of patients grouped per therapy modality.


Patients Like Me Borstkanker

In het schema ziet u voor u relevantie behandelstappen en opties hierin.
Door hierop te klikken ziet u onder de uitkomsten van patienten zoals u die dezelfde behandeling zijn ondergaan.

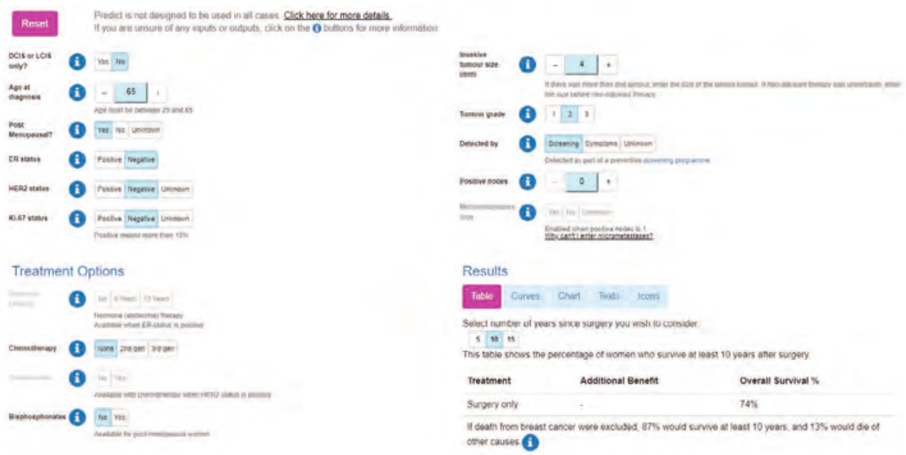
1D. Example of a prediction model used in CKD interviews

The Kidney Failure Risk Equation was used as a model that predicts risk of progression to kidney failure (and needing kidney replacement therapy such as dialysis). This model provided the following information:

> The chance on kidney failure and needing kidney replacement therapy in two years = ... %
> The chance on kidney failure and needing kidney replacement therapy in five years = ... %

1E. Example of a prediction model used in BC interviews

The visual example of a prediction model in breast cancer was the PREDICT (https://breast.v3.predict.cam/tool) for breast cancer prognostic model predicting survival with/without adjuvant systemic treatment.



Predict is not designed to be used in all cases. Click here for more details.
If you are unsure of any inputs or outputs, click on the ⓘ buttons for more information

DCIS or LCIS only?: Yes [✓ No]
Age at diagnosis: 65
Post Menopausal?: [✓ Yes] No Unknown
ER status: Positive [✓ Negative]
HER2 status: Positive [✓ Negative] Unknown
Ki-67 status: Positive [✓ Negative] Unknown
Positive means more than 10%

Invasive tumour size (mm): 4
Tumour grade: 1 [✓ 2] 3
Detected by: [✓ Screening] Symptoms Unknown
Detected as part of a preventive screening programme
Positive nodes: 0
Enabled when positive nodes is 1
Why can't I enter micrometastases?

Treatment Options

Hormone (endocrine) therapy
Available when ER-status is positive
Chemotherapy: [✓ None] 2nd gen 3rd gen
Bisphosphonates: [✓ No] Yes
Available for post-menopausal women

Results

Select number of years since surgery you wish to consider: 5 [✓ 10] 15
This table shows the percentage of women who survive at least 10 years after surgery

Treatment	Additional Benefit	Overall Survival %
Surgery only	-	74%

If death from breast cancer were excluded, 87% would survive at least 10 years, and 13% would die of other causes

Supplement 2 – Topic list used

During this dyadic-interview, or duo-interview, we ask you, as patient and healthcare provider, to have a conversation with each other about different types of information shared during a healthcare visit.
Here is how the duo-interview works:
In front of you are cards with questions related to the condition for which you as a patient are being treated by your healthcare provider. The cards are color-coded by theme. One of you picks a card at a time and reads the question out loud. You may each take a moment to think about your answer to the question. If you like, you can write your thoughts down. Then, you will discuss the question with each other. You may ask each other follow-up questions and spend as much time on each card as you wish. Once you feel the question has been sufficiently discussed, you can move on to the next card.
The aim is for the conversation to take place mainly between the two of you, while I, as the interviewer, stay in the background as much as possible. Of course, you can always ask me questions if anything is unclear. I may also occasionally explain certain definitions during the conversation.

Theme 1: Which outcomes?

Card 1:

What does **'good health'** look like for you as a patient?

Explanation: We ask you as a healthcare provider to think about that good health looks like for this particular patient. For the following cards, we will also ask you to answer the questions with this specific patient in mind.

Alternative phrasing/clarification:

To the patient: Describe what good health looks like for you.

To the healthcare provider: Describe what you think good health looks like for this patient.

Card 2:

Which information do you need to know how it is going with your condition?

Alternative phrasing/clarification:

To the healthcare provider: What information do you need in order to understand how this patient's condition is progressing?

Card 3:

Which information do you need to determine whether a treatment is successful?

Try to think of a treatment recently started.

Alternative phrasing/clarification:

To the healthcare provider: On which factors do you determine whether a treatment for this patient was successful?

Card 4:

What information do you sometimes feel is missing after a consultation? In other words, what is not discussed that you would find useful?

Theme 2: Clinical outcomes and PROMS

Explanation (by the interviewer)

Results/effects of provided care (treatment outcomes) can be discussed in different forms: clinical- or medical- outcomes and outcomes reported by patients themselves. Clinical outcomes derive from the healthcare provider and include things like blood test results or blood pressure measurements. Next to these clinical outcomes, outcomes exist that say something about how a patient is feeling or doing. Only the patient him/herself can provide this information. These outcomes are called patient reported outcomes or PROMS. PROMs are collected by questionnaires send to the patient to fill out. Example of PROM-topics include level of fatigue, level of pain or emotional well-being.

What kind of information is mainly discussed during conversations between you two during healthcare visits?

Additionally:

- Are PROMs sometimes discussed?

- Is information sometimes visualized during the healthcare visit?

Card 5:

Which information do you need to determine the effects of a treatment?

(try to think of a recently started treatment).

Alternative phrasing/clarification:

To the healthcare provider: Which information do you need to determine potential effects of a treatment of this patient?

Card 6:

What can discussing both medical information and patient-reported information during the consultation lead to? Can you think of any positive and negative effects of each?

Explanation (by the interviewer)

Sometimes we can compare information of one patient to information of a group of patients with similar characteristics (such as age and sex) and similar condition. You can compare your scores on clinical information or PROMs to the other patients.

[A visual example is shown.]

What do you think of this kind of information?

Card 7:

You as a patient, did you ever experience being compared to a group of similar patients? If so, what kind of information was the comparison about?

Alternative phrasing/clarification:

To the healthcare provider: Do you ever use comparisons of information of the patient to a group of patients?

Card 8:

Discuss with each other whether you find it useful to discuss such comparisons of yourself to a group of similar patients? Why or why not?

Alternative phrasing/clarification:

To the patient: Would you want to compare information about yourself with a similar group of patients? Why or why not?

To the healthcare provider: Do you find it useful to compare this kind of information across similar patients? Why or why not?

Card 9

Which information would you like to compare with a group of similar patients, and why?

Additionally: Is there information that you would absolutely not wish to compare with a group of similar patients, and why?

Alternative phrasing/clarification:

To the patient: In what aspects would you like to compare yourself with a group?

To the healthcare provider: What information from this patient would you find useful to compare with a group?

Theme 3: prediction model

(Explanation by the interviewer)

For CKD:

Calculation programs exist that, based on information about you, such as kidney function, age, and sex, can predict something about your condition. For example, the chance on needing kidney replacement therapy in a few years. A prediction like that calculated on information of you is called a prediction model. A prediction is always an estimate; just like a weather forecast, it may not always be accurate.

For BC:

Calculation programs exist that, based on information about you, such as, age, sex, tumour characteristics, can predict something about your condition. For example, the chance on survival in 5 or 10 years. A prediction like that calculated on information of you is called a prediction model. A prediction is always an estimate; just like a weather forecast, it may not always be accurate.

[A visual example is shown]

Card 10

Are such predictions ever discussed in the consultation room between you?

Card 11

Would you like to know such a prediction?

Closing remarks:

-Thank you!

-Any feedback for the researcher?

5

Predicting outcomes in chronic kidney disease: needs and preferences of patients and nephrologists

Dorinde E. M. van der Horst[1]
Noel Engels[1]
Jos Hendrikx
Marinus A. van den Dorpel
Arwen H. Pieterse
Anne M. Stiggelbout
Cornelia F. van Uden–Kraan
Willem Jan W. Bos

[1] *(shared first author)*

Published in BMC Nephrology, 2023

Abstract

Introduction

Guidelines on chronic kidney disease (CKD) recommend that nephrologists use clinical prediction models (CPMs). However, the actual use of CPMs seems limited in clinical practice. We conducted a national survey study to evaluate: 1) to what extent CPMs are used in Dutch CKD practice, 2) patients' and nephrologists' needs and preferences regarding predictions in CKD, and 3) determinants that may affect the adoption of CPMs in clinical practice.

Methods

We conducted semi-structured interviews with CKD patients to inform the development of two online surveys; one for CKD patients and one for nephrologists. Survey participants were recruited through the Dutch Kidney Patient Association and the Dutch Federation of Nephrology.

Results

A total of 126 patients and 50 nephrologists responded to the surveys. Most patients (89%) reported they had discussed predictions with their nephrologists. They most frequently discussed predictions regarded CKD progression: when they were expected to need kidney replacement therapy (KRT) (n = 81), and how rapidly their kidney function was expected to decline (n = 68). Half of the nephrologists (52%) reported to use CPMs in clinical practice, in particular CPMs predicting the risk of cardiovascular disease. Almost all nephrologists (98%) reported discussing expected CKD trajectories with their patients; even those that did not use CPMs (42%). The majority of patients (61%) and nephrologists (84%) chose a CPM predicting when patients would need KRT in the future as the most important prediction. However, a small portion of patients indicated they did not want to be informed on predictions regarding CKD progression at all (10–15%). Nephrologists not using CPMs (42%) reported they did not know CPMs they could use or felt that they had insufficient knowledge regarding CPMs. According to the nephrologists, the most important determinants for the adoption of CPMs in clinical practice were: 1) understandability for patients, 2) integration as standard of care, 3) the clinical relevance.

Conclusion

Even though the majority of patients in Dutch CKD practice reported discussing predictions with their nephrologists, CPMs are infrequently used for this purpose. Both patients and nephrologists considered a CPM predicting CKD progression most important to discuss. Increasing awareness about existing CPMs that predict CKD progression may result in increased adoption in clinical practice. When using CPMs regarding CKD progression, nephrologists should ask whether patients want to hear predictions beforehand, since individual patients' preferences vary.

1. Introduction

The course of chronic kidney disease (CKD) and the risk of progression to end-stage kidney disease (ESKD) vary among patients [1–3]. Guidelines recommend that nephrologists use clinical prediction models (CPMs) to help identify patients at increased risk of CKD progression and adjust their treatment to help limit further kidney function decline [2, 3]. In addition, multiple studies showed that patients are interested in prognostic information, and that they value this information for behavioural change and treatment planning [4–6]. CPMs can also be used to help establish the optimal timing of starting education on kidney replacement therapy (KRT) when patients do progress to the more advanced stages of CKD. Timely education and decisional support allow for effective decision-making, and may prevent delays in the decision-making process which are associated with increased patient morbidity, mortality and healthcare costs [7].

Numerous CPMs have been developed for CKD practice over the years. These include models that predict the risk of progression to ESKD [8–16] or adverse outcomes of different KRT modalities, such as: 1) mortality after dialysis initiation [17–34], and 2) rejection after kidney transplantation [35, 36]. Some of these models, such as the Kidney Failure Risk Equation (KFRE), have been extensively validated and offer good predictive performance [9–11, 37–41]. Even though well-validated models are readily available and guidelines recommend that nephrologists use CPMs, the actual use of CPMs in CKD practice seems limited [6, 42–44]. This may be related to the CPMs themselves (e.g., limitations in predictive performance or user friendliness), and/or to the intended users (e.g., doubts about the reliability and generalizability of CPMs) [43, 44]. CPMs are also often developed without the input of end-users (i.e., patients and nephrologists), and as a consequence, lack clinical relevance [42, 43]. In addition, patients and nephrologists often prioritize different (treatment) outcomes [45, 46] and may have different needs and preferences regarding the use and purpose of CPMs in CKD practice.

Therefore, the aim of this study was to: 1) evaluate to what extent CPMs are currently used in the Dutch CKD practice, 2) identify patients' and nephrologists' needs and preferences regarding predictions in CKD, and 3) explore determinants that may affect the adoption of CPMs in CKD practice. Our results can be used to guide implementation of CPMs and inform future development of CPMs.

2. Material and methods

2.1 Study design

A national survey study among CKD patients and nephrologists in The Netherlands was conducted. First, patients' attitudes towards different CPMs predicting the course of CKD were explored in semi-structured interviews. Next, two online surveys were developed and distributed: one for patients and one for nephrologists.

2.2 Semi-structured interviews

Patients with CKD were interviewed to explore their attitudes towards the use of CPMs in CKD practice. These interviews were held in the context of a larger study on the development of a CKD dashboard [47]. During these interviews, two different predictions were introduced: 1) the prediction from the KFRE: a 2- and 5-year risk of progression to kidney failure for stages 3 to 5 CKD patients (in %), and 2) a prediction about the time until kidney failure (in years). Mock-ups were used to present these predictions in a similar lay-out to have patients focus on the meaning of the predictions rather than on how these were presented (**Supplement 1**). Patients were asked to 'think-out-loud' and give their first impressions on the presented predictions. Patients were subsequently asked whether they would want to be provided with these pre- dictions in (including reasons why), and how they would prefer to receive this information.

2.3 Online surveys

Two surveys were developed: one for CKD patients and one for nephrologists. Each survey started with an introductory text and an explanation of the definition of a CPM (**Supplement 2**). This explanation was supplemented with an infographic to facilitate understanding (**Supplement 2**). Both surveys consisted of questions assessing: 1) the current use of CPMs in Dutch CKD practice, 2) preferences for predictions in CKD, 3) preferences for predictions about CKD progression (to ESKD), and 4) barriers and facilitators for the adoption of CPMs in clinical practice.

The patient surveys also included questions about educational levels, which was measured according to the International Standard Classification of Education [48] and health literacy, which was measured with the Set of Brief Screening questions (SBSQ) [49]. The SBSQ assesses perceived difficulties with health information based on three 5-point Likert scale statements ranging from 1–5. An average score of ≤ 3 indicates inadequate health literacy and a score of > 3 adequate health literacy. In the patient survey, the Threatening Medical Situations Inventory (TMSI) was used to assess whether patients handle medically threatening information with either monitoring (attending to the problem) or blunting (avoiding the problem) coping behaviour, since this may affect their views on receiving predictions [50, 51]. In the TMSI, patients are asked how they would handle hypothetical situations. They report on a 5-point Likert scale how likely it would be for them to apply three monitoring and three blunting strategies. Total scores for both the monitoring and blunting strategies are subsequently calculated (ranging from 6–30) [50, 51].

In the nephrologist survey, the Measurement Instrument for Determinants of Innovations (MIDI) was used to identify enablers for the adoption of CPMs in clinical practice [52]. For three domains (the innovation, the user, and the organization), nephrologists had to pick the two most important determinants that may facilitate the adoption of CPMs in clinical practice. **Supplement 3** shows the validated survey instruments used and the study-specific survey questions.

2.4 Pretesting the surveys

Both surveys were tested and amended for face validity by a: 1) communication scientist (CvU), 2) professor of medical decision-making (AS), 3) nephrologist (WB), and 4) cognitive psychologist specialised in communication research (AP). The patient survey was written at the B1 level of the common European framework of reference for languages (CEFRL) to ensure comprehensibility [53]. It was also tested for face validity by five CKD patients recruited by the Dutch Kidney Patients Association.

2.5 Participants, recruitment and informed consent

Patients with CKD were recruited for the interviews by their nephrologists in two Dutch hospitals (St. Antonius hospital and Maasstad hospital) in February 2021. All participants gave informed consent.

For the surveys, CKD patients and nephrologists were recruited from November 2021 until March 2022. Patients were approached via e-mail through the online platform of the Dutch Kidney Patients Association. The nephrologists were approached via e-mail through the online platform of the Dutch Federation for Nephrology. Both surveys were anonymous; no personal identifying information was registered. The patients and nephrologists who agreed to participate were asked to consent with the use of their answers for research and publication purposes when they started the survey. According to the Dutch medical research involving human subjects act, ethical approval was not required for the surveys because participants were not subjected to (medical) procedures or behavioural alternations and the survey was anonymous and limited in its burden (i.e., topics and length).

2.6 Data analysis

All interviews were recorded and transcribed verbatim. The transcripts were coded inductively to identify different themes in the data. One researcher (DH) conducted the primary analysis, which were checked by a second coder (NE). All survey data were analysed with IBM SPSS Statistics (version 28). Descriptive statistics were used to describe the demographic characteristics of the participants. Continuous data are expressed as a mean with standard deviation (SD) or as the median with interquartile range (IQR) when appropriate. Categorical data are presented as valid percent (i.e., percentages when missing data are excluded from the calculations), except for data deriving from multiple answer questions; here absolute frequencies were used. One-way ANOVA or Kruskal– Wallis tests were used (depending on the distribution of the data) to determine whether patients' mean monitor and blunting scores on the TMSI were associated with patients' preferences for wanting to know predictions.

3. Results

3.1 Semi-structured interviews

Seven CKD patients (four men, three women) with a mean age of 54 years (SD = 15) participated in the interviews. A total of five themes were identified in the data (shown in **Table 1**). All illustrative quotations can be found in **Supplement 4**. More than half of the patients (*n* = 5) understood the two predictions visualized in the mock-ups (theme one, understanding predictions about CKD progression). All but one patient indicated they wanted to know both predictions. Three patients preferred the prediction about the time until kidney failure (in years) over the KFRE, and two patients proposed combining them (theme two, preferences for predictions about CKD progression). In theme three 'how predictions about CKD progression can help patients', different reasons were mentioned why patients considered these predictions useful. Patients argued that the predictions could: 1) help them with life planning, 2), provide them with more clarity on the stage of their CKD), 3) help them focus on preserving their kidney function for as long as possible, and 4) provide them with comfort or consolation. Potential negative effects of discussing predictions about CKD progression (theme four) included: 1) the predictions could cause increased worrying, and 2) that individual trajectories may vary from the predictions. Lastly, patients indicated how to discuss predictions about CKD progression with patients (theme five). Several patients emphasized that these predictions can be very confrontational and stressed the importance of appropriate guidance and support when the predictions are discussed.

Table 1: Identified themes with illustrative quotes from the interviews

Theme	Illustrative quotes
1. Understanding predictions about CKD progression	• *P7 ['prediction in %[1] + 'prediction in time to[2]']: My initial impression is that this is clear.* • *P4: Well, now I see that in 5 years' time I have a 10% chance of needing kidney replacement therapy and that this isn't even 3% in two years' time – what does that add? I don't understand it very well.*
2. Preferences for predictions about CKD progression	• *P6: yeah, it's about your own health, isn't it? Why wouldn't I want to know that? And you indeed realise that, goodness, in nine years' time I'll need a donor kidney or kidney dialysis or something of that nature.* • *P8: ['prediction in time to + prediction in %'] I feel that it has some relevance. I know, yeah, maybe for some patients that may be something you'd be able to estimate, but... just considering my own case and then to think that I was on the edge and that I'm so much better now. It might not be worth all that much. I mean, yeah, no, that's a tough one. I don't know whether I would want to know that, whereas of course other people do want to know that kind of thing.*
3. How predictions about CKD progression can help patients	• *P4: ['prediction in time to'] Of course that would help, because it would help me consider the fact that, well... I guess it's not that crazy... whether I'd still want to go on another trip or whatever... what would be best: do it now and not in 9 years' time, because then I'd have to take my dialysis materials with me, or I'd need have to have had a kidney transplantation. I mean, yeah, this is... it's preparing yourself for the fact that you're going to have to take that step in 9 years' time.* • *P5: ['prediction in time to'] Yes, yeah, at the times when you're faced with kidney failure... you do start asking 'how long have I got before?'... especially in relation to how long I've got before I need to turn my life upside down. So, erm, yeah, this would definitely help. [...] yeah, I would ['prediction in % + prediction in time to'] want to know. That way you'd be able to make or cancel plans. I think that once you're confronted with kidney failure you really just want to know what the score is.*
4. Potential negative effects of discussing predictions about CKD progression	• *P7: Well, what I went through myself is that it was quite a shock when the doctor suddenly told me the ['prediction in %']. It's really... I was in absolute floods of tears, so, yeah, I found the whole thing very, very confronting.* • *P8: No, of course, it'll be different for each patient. That makes sense, in terms of ... should I start worrying more or should I start slacking off? Anyway, that is more or less my opinion.*
5. How to discuss predictions about CKD progression with patients	• *P9: Well, look, I would want to be told by the nephrologist in any case and if I were to be able to review that information myself in the future, that would be fine. But if I had no idea whatsoever and then came across this information, I'd be scared out of my mind [...] and it's likely, and this may not even apply to me per se, but if I were to come across this information all at once, I'd want the specialist to tell me that they were keeping an eye on things and recording it in this way.* • *P8 Yeah, look, if you're aware beforehand and know that this information will be adjusted every time... then you might be less shocked. But imagine reading 92%, then I think you would be shocked. I think it'd be better for a doctor to do that. I would only give a patient that result during a consultation – especially if the news is bad.*

CKD= Chronic Kidney Disease

[1]= ['prediction in %'] refers to mock-up of KFRE: % risk to get kidney failure after 2 and 5 years.

[2]= ['prediction in time to'] refers to mock-up predicting amount of years until CKD progresses to kidney failure.

3.2 Online surveys

In total, 126 out of 407 patients responded to the survey invitation. This amounts to a response rate of 31%. Moreover, 50 out of 438 nephrologists responded to the survey invitation. This amounts to a response rate of 11%. The basic demographics of both the patients and nephrologists are presented in **Table 2**. The majority of patients (*n* = 113, 90%) had been under nephrology care for at least 5 years. Most patients had undergone kidney transplantation (*n* = 89, 71%) or were not yet on KRT (*n* = 23, 19%). The SBSQ score for health literacy had a median of 4.7 (IQR = 0.7). Most patients (*n* = 100, 79%) were highly educated. Mean scores on the TMSI for monitoring and blunting coping behaviours were comparable, with a mean of 19.4 and 18.6 respectively. At the time of the survey, the nephrologists had been practicing nephrology for a mean of 14.3 years (SD 9.1).

Table 2: Demographic characteristics of survey participants

Patients (n=126)			
Sex (male), n %		66 (52%)	*Missing 2 (2%)*
Age, median years (IQR)		62 (54-69)	*Missing 3 (2%)*
Education level[1], n(%)	Low (levels 0-2)	8 (6%)	*Missing 5 (4%)*
	Medium (levels 3-4)	13 (10%)	
	High (levels 5-8)	100 (79%)	
SBSQ score, median (IQR)		4.6 (0.7)	
Currently treated in hospital by nephrologist for CKD?	Yes	122 (97%)	*Missing 2 (2%)*
	No	2 (2%)	
How long under nephrology care? n (%)	< 1 year	3 (2%)	*Missing 4 (3%)*
	1-2 years	2 (2%)	
	3-5 years	4 (3%)	
	>5 years	113 (90%)	
Current treatment, n (%)	No KRT Dialysis	23 (18%)	*Missing 2 (2%)*
	Peritoneal dialysis	10 (8%)	
	Kidney transplantation	2 (2%)	
	Conservative care	89 (71%)	
	management	0	
Coping strategy threatening information (TMSI)	Monitor score, mean (SD)	19.4 (4.7)	*Missing 3 (2%)*
	Blunter score, mean (SD)	18.6 (3.5)	*Missing 3 (2%)*
Nephrologists (n=50)			
Sex (male), n %		29 (58%)	
Age, mean years (SD)		49.2 (8.8)	*Missing 2 (4%)*
Number of years working in current function, mean (SD)		14.3 (9.1)	

All percentages calculated on total population (not valid percentages).

SD=standard deviation, IQR- interquartile range, SBSQ = Set of Brief Screening Questions for health literacy, KRT= Kidney Replacement Therapy, TMSI = Threatening Medical Situations Inventory

1 = Education levels based on International Standard Classification of Education [48]

3.3 Current use of, and experience with, CPMs

Patients

The majority of patients (*n* = 111, 89%) reported that they had discussed predictions with their nephrologists. The most-commonly discussed predictions were: when they were expected to need KRT (*n* = 81) and how rapidly their kidney function was expected to decline (*n* = 68) illustrated in **Fig. 1a.** Only two patients indicated that, in retrospect, they would rather not have known these predictions. Patients indicated that discussing these predictions had helped them in the deliberation (pros vs cons) about their KRT options (*n* = 77) and the realization that they had to make a KRT choice (*n* = 71) (illustrated in **Fig. 1b**).

Figure 1: Patients' experiences with - and preferences in - discussing predictions with their nephrologist

Fig.1. a. Predictions that patients had discussed with their nephrologist.

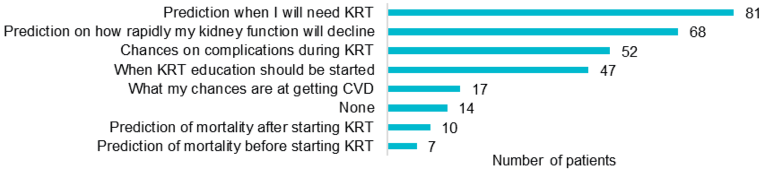


Fig. 1. b. How the predictions helped patients.

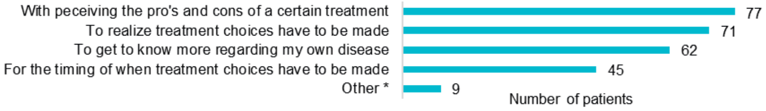


Fig. 1. c. Which predictions would the patients like to know about themselves?

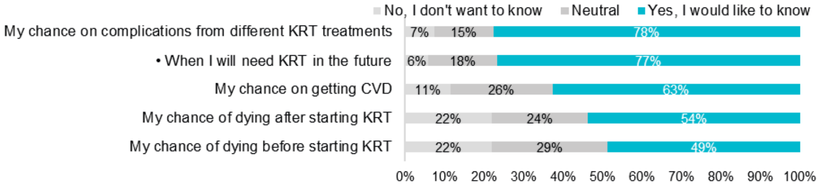
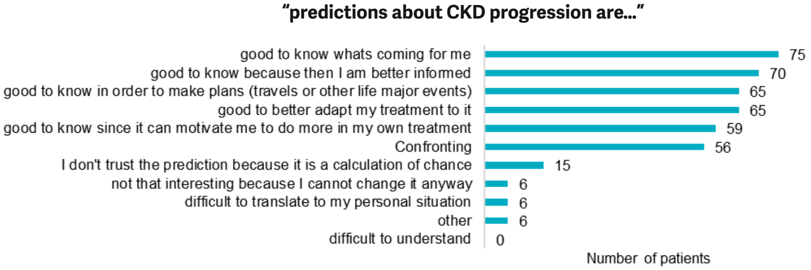


Fig. 1.d. General attitudes of patients towards discussing predictions about CKD progression.


"predictions about CKD progression are…"

KRT = kidney replacement therapy, CVD = cardiovascular disease, KF= Kidney function,

CVD = cardiovascular disease

** Other included: realizing what my treatment choices would entail, realization the severity of the problem.*

• = Chosen as most important prediction, when allowed to choose one.

Nephrologists

Just over half of the nephrologists (*n* = 26, 52%) indicated that they used CPMs at the time of the survey. Most nephrologists mentioned using a CPM predicting the risk of cardiovascular disease (CVD) (*n* = 24), followed by a CPM predicting when patients will need KRT (*n* = 8), a CPM predicting the risk of complications associated with different KRT modalities (*n* = 3) and a CPM predicting how blood pressure affects kidney function (*n* = 3). CPM's predicting mortality before or after starting KRT were mentioned twice. Although a large proportion of nephrologists (*n* = 21, 42%) did not use CPMs or did not know whether they had used them (*n* = 3, 6%), all but two (*n* = 48, 98%) discussed the expected kidney disease trajectory with patients. The majority (*n* = 44, 92%) used graphs of the estimated glomerular filtration rate (eGFR) for this purpose. Nephrologists who did not use CPMs provided different reasons why. The most mentioned reason for not using CPMs was "not knowing any models" (*n* = 11) followed by "not knowing enough about CPMs to use them" (*n* = 6), "not knowing where to find them" (*n* = 4), and "believing currently available CPMS are not reliable enough" (*n* = 4). Less frequently mentioned were "not having enough time to use CPMs during consultations" (*n* = 2), "believing currently available CPMs are impractical and difficult to use" (*n* = 2) and "not seeing the point of using CPMs in providing CKD care" (*n* = 1).

3.4 Preferences for predictions in CKD

Patients

Most patients indicated that they wanted to know predictions about: 1) the risk of developing complications associated with the different KRT modalities (*n* = 94, 78%), and 2) when they would need KRT (*n* = 92, 77%) (illustrated in **Fig. 1c**). When asked to pick the most important prediction, the majority of patients chose "when I will need KRT in the future" (*n* = 42, 61%). Predictions about the risk of dying before or after starting KRT were most frequently chosen as something patients did not want to know (*n* = 27, 22%, and *n* = 26, 22%, respectively).

Patients who wanted to know predictions had a significantly higher mean monitoring score compared to those who were neutral, or those who did not want to know these predictions. This was true for patients who desired knowing predictions concerning: 1) the risk of developing CVD (F (2,12) = [10.88], *p* = < 0.001), 2) when patients would need KRT (F (2,12) = [6.71], p = 0.002), and 3) the risk of dying before starting KRT (F (2,12) = [6.73], *p* = 0.002). The post hoc analyses are provided in **Supplement 5**. The mean monitoring scores of patients who wanted to know predictions about the risk of developing complications associated with the different KRT modalities, and the risk of dying after starting KRT did not significantly differ from mean monitoring scores of patients who were neutral, or who did not want to know these predictions. There were no significant differences between mean blunting scores as a function of patients' preferences for wanting to know the different predictions in CKD.

Regarding CPMs about CKD progression, 56 patients indicated that they perceived these predictions as confronting. Nevertheless, patients also agreed that such a

prediction could help them to: 1) better know what they can expect (n = 75), 2) become better informed about their CKD (*n* = 70), and 3) help with their (life) planning (*n* = 65) (see **Fig. 1d**). When patients were shown the mock-up of the prediction from the KFRE, most patients considered it understandable (*n* = 100, 80%). Likewise, most patients (*n* = 105, 84%) understood the mock-up of the prediction in time to kidney failure (in years). The majority of patients wanted to know the prediction from the KFRE (*n* = 89, 72%), 20 (16%) were neutral, and 14 (11%) did not want to know. Similarly, the majority of patients (*n* = 96, 77%) wanted to know the prediction of time to kidney failure (in years), 10 (8%) were neutral, and 18 (15%) did not want to know. Fifty-four patients (45%) preferred the time to kidney failure (in years) prediction compared to 43 (36%) patients preferring the prediction from the KFRE; 24 patients (20%) were neutral. For both predictions, patients indicated that these could help them to: 1) better plan when they have to make a KRT decision, and 2) realize that a KRT decision needs to be made.

Nephrologists

The nephrologists indicated that they would most likely use a CPM to predict: 1) when CKD patients will need KRT, 2) how medication and blood pressure will affect a patient's CKD trajectory, and 3) the risk of CVD in patients (illustrated in **Fig. 2a**). Twenty-three nephrologists (47%) picked a model predicting "when CKD patients will need KRT" as the most useful one. When the nephrologists were asked for what purpose they would want to develop a new CPM, 23 nephrologists (46%) chose "to better inform patients on the expected kidney function trajectory". Other purposes for developing a new CPM included: "better being able to estimate the effects of treatment on slowing down kidney function deterioration" (*n* = 15, 30%), "better being able to estimate when patients should start KRT education" (*n* = 6, 12%), "better being able to estimate whether or not patients should start a certain kind of KRT" (*n* = 4, 8%) and "better being able to estimate what the expected effects of a certain kind of KRT will be" (*n* = 2, 4%).

Figure 2: Nephrologists' preferences and views regarding CPMs

Fig. 2. a. Would you (nephrologist) use the following CPMs?

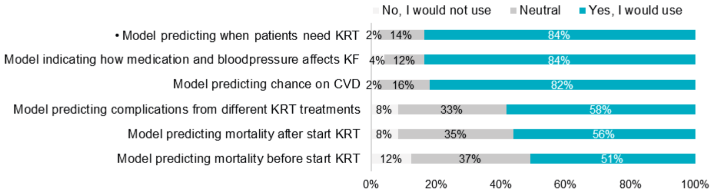


Fig. 2. b. Do you (nephrologist) agree with the following statements?

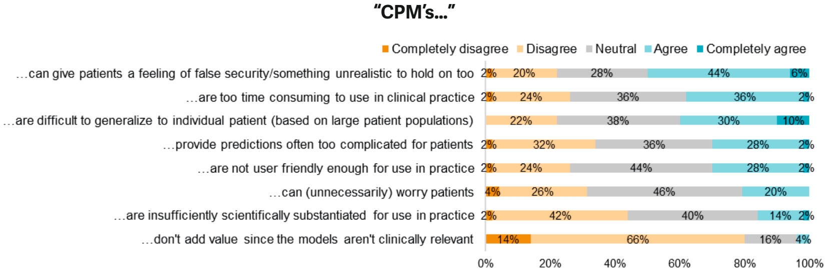
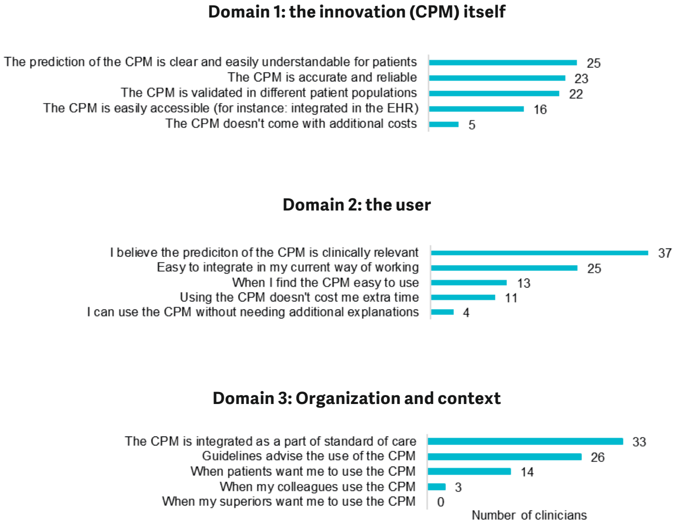

"CPM's..."

Fig. 2. c. Nephrologists' views on enablers for successful adoption of a (new) CPM in clinical practice


Domain 1: the innovation (CPM) itself

Domain 2: the user

Domain 3: Organization and context

CPM= clinical prediction Model, KRT = kidney replacement therapy, KF = kidney function, CVD = cardiovascular disease, EHR = electronic health record. • = Chosen as most useful prediction, when allowed to choose one

When they were asked whether they had already used the KFRE in the past, the majority (*n* = 46, 92%) had not; mostly (*n* = 38, 83%) because it was unknown to them. When they were asked whether they would use a CPM to predict the time to kidney failure in years (if available), more than half (*n* = 28, 56%) indicated that they would. The prediction of time to kidney failure (in years) was preferred over the prediction from the KFRE by 31 nephrologists (62%). Four nephrologists explained that they expected patients would better understand a 'time to'-prediction compared to a 'risk of'-prediction.

3.5 Barriers and facilitators for the adoption of CPMs in clinical practice

Patients

Sixty patients (49%) were neutral on the statement: "nephrologists should use CPMs during their consultations with patients", 52 (41%) agreed, and 11 (9%) disagreed. Fifty-six patients (46%) wanted nephrologists to explain predictions during consultations, while 45 patients (37%) wanted to view predictions before their consultations so that they could discuss these with their nephrologist. Seventeen patients (14%) wanted to view predictions at any time, regardless of professional guidance.

Nephrologists

When the nephrologists were presented with statements arguing against the use of CPMs, the majority agreed that CPMs: 1) can give patients false expectations or a false sense of security (*n* = 22, 50%), 2) don't say anything about individual patients (*n* = 20, 40%), and 3) are too time-consuming to use (*n* = 18, 38%) **(see Fig. 2b).** Most nephrologists agreed (*n* = 26, 52%) or completely agreed (*n* = 11, 22%) that CPMs should only be used under professional guidance during consultations, rather than being available for patients at home.

The nephrologists were asked to choose two factors from each of the domains of the MIDI (innovation, user, organisation) that they deemed most important in enabling successful use of a (new) prediction model (**see Fig. 2c**). For domain one (the innovation), the majority of nephrologists (*n* = 25) considered the determinant "The prediction is clear and easily understandable for patients" as the most important determinant for successful adoption in clinical practice. For the second domain (the user), the majority (*n* = 37) considered the determinant "If I believe the prediction from the CPM is clinically relevant" as the most important determinant. For the last domain (the organisation), most (*n* = 33) considered the determinant "The CPM is integrated as a part of standard of care" as the most important determinant for adoption. All but two nephrologists (*n* = 48, 96%) agreed that they would want to know the performance metrics of CPMs, such as confidence intervals, before they would consider using them. Twenty-three (46%) indicated that they would always discuss these performance metrics with their patients compared to 17 (34%) who would only discuss it with their patients if they believed the patients could understand these metrics and 9 (18%) who would refrain from discussing these metrics because they believed it would be too com- plicated for patients to understand. About two-thirds of the nephrologists (*n* = 30, 60%) indicated that they would always discuss the uncertainty of an estimated prognosis with their patients, regardless of whether they would use a CPM to make these estimations. Eighteen nephrologists (36%) reported that they would discuss it “in most cases”, one nephrologist (2%) would discuss it “sometimes” and one (2%) would “never” discuss it with patients.

4. Discussion

We conducted a national survey study to explore the cur- rent use of CPMs in Dutch CKD practice and to identify patients’ and nephrologists’ needs and preferences regarding the use of CPMs, as well as barriers and facilitators for the adoption of CPMs in clinical practice. Even though previous studies suggest that CPMs are used to a limited extent in clinical practice [43, 44], more than half of the nephrologists who participated in our survey reported using CPMs. Likewise, the majority of patients reported that they had discussed predictions with their nephrologist in the past; mostly predictions about their risk of progression to kidney failure. On the contrary, nephrologists reported discussing a CPM for the risk of CVD in patients most frequently. This discrepancy could be explained by the fact that almost all nephrologists reported discussing expected kidney disease trajectories with their patients, and that most of them used graphs of their patients’ eGFR (not a CPM) for this purpose. Patients who participated in this study may have misinterpreted these extrapolations as predictions made with CPMs. For patients, knowing the details of the origin of the prediction might not matter much. However, nephrologists should be aware of this discrepancy when they discuss expected kidney disease trajectories with their patients, since both nephrologists and patients tend to overestimate the risk of progression to ESKD [54].

The majority of both patients and nephrologists advocated for the use of CPMs in CKD practice. These findings are consistent with previous studies [4–6]. Even though a large proportion of patients considered predictions confrontational (particularly predictions about CKD progression), almost none of them regretted discussing predictions with their nephrologists in the past. Reasons for nephrologists why they did not currently use CPMs were most often related to their limited knowledge about, or unfamiliarity with, existing models. Barriers relating to intrinsic motivation, user friendliness or reliability, as often mentioned in the literature [43, 44], were infrequently reported. Perhaps these barriers are overvalued when implementation initiatives are formulated; hindering the widespread adoption of CPMs in CKD practice. Instead, we should focus more on the facilitators for the adoption of CPMs in clinical practice. In this study, facilitators for the adoption of CPMs related to presenting CPMs in a clear and understandable way, incorporating them as a part of standard care, and the CPMs being clinically relevant. Even though previous studies suggest that nephrologists and patients prioritize different treatment outcomes [45], both patients and nephrologists considered CPMs predicting CKD progression as the most relevant prediction, preferably predicting the time to KRT (in years) instead of a 2- and 5-year risk (in %). Patients indicated that this prediction could help them better plan when they have to make a KRT decision and realize that a KRT decision has to be made. The latter is an important enabler for patient empowerment in starting a shared decision making process [55].

When we explored patients' normative beliefs about whether or not nephrologists should use CPMs during consultations, most were neutral or agreed that they should. However, it should be noted that there was a small proportion of patients who did not want to know any predictions when we explored their preferences for both CPMs in general, and CPMs related to CKD progression. This is especially relevant considering that the participating patients are potentially taking on a more active role in treatment decision-making compared to the general patient population (since they were highly educated, had high health literacy and were recruited from the Dutch Kidney Patients Association). The actual number of patients that do not want to know these predictions could potentially be higher in clinical practice. Although we did identify that higher monitor scores might be associated with wanting to know certain predictions, we did not find higher monitor scores in our study population when compared to their individual blunting scores, or to scores from other studies [50, 56]. Similar to others who studied patient preferences for receiving prognostic information [57], we propose that nephrologists simply ask, and provide patients with the opportunity to make their own decisions about whether or not they want predictive information to be shared with them. In addition to the highly educated patient population, the majority of the patients included in this study were patients who had received a kidney transplant and were under treatment for more than 5 years with their nephrologist. This affects generalization of the results towards the whole CKD population. Hypothetically, patients earlier in their disease phase might have different information needs regarding the use of CPMs.

Additionally, participating patients might have discussed the predictions regarding CKD progression a longer time ago, increasing changes on recall bias. For the clinician's survey, issues with generalization should also be noted; these survey results may not be indicative for all Dutch nephrologists. Since the response rate to the survey was low, we cannot exclude non-response bias. Nephrologists who were willing to fill in the survey may hold more positive attitudes towards CPMs than nephrologists who didn't.

We are among the first to provide quantitative data on what both patients and nephrologists prefer regarding the use and purpose of CPMs, and what predictions they prioritise. Moreover, we collected information on important determinants for the successful adoption of CPMs in clinical practice, which may be used to guide the implementation of CPMs. In addition, researchers and developers can use our findings for improving existing CPMs or for developing new CPMs. When the latter is considered, our study shows that patients and nephrologists prefer a 'time to kidney failure' prediction, rather than a 'risk of progression to kidney failure' prediction. This study focused on currently available CPMs in CKD. Future research may explore newly developed CPMs, such as CPMs predicting patient reported outcomes.

5. Conclusion

In this study, both nephrologists and the majority of patients want to discuss CPMs in Dutch CKD practice, especially those that predict CKD progression. Validated and freely available CPMs, that largely meet the needs and preferences expressed by patients and nephrologists in this study, already exist (e.g. the KFRE). However, these CPMs appear to be underused due to lack of knowledge regarding where to find them and how to use them meaningfully. We should focus on improving the accessibility of these CPMs and provide guidance on how to communicate the predictions effectively. Additionally, whether or not patients want to hear particular predictions varies among individual patients, and their preferences should therefore be explored during consultations. all but two (*n* = 48, 98%) discussed the expected kidney disease trajectory with patients.

References

[1] Tsai WC, Wu HY, Peng YS, Ko MJ, Wu MS, Hung KY et al. Risk Factors for Development and Progression of Chronic Kidney Disease: A Systematic Review and Exploratory Meta-Analysis. Medicine (Baltimore). 2016;95(11):e3013. doi:10.1097/MD.0000000000003013

[2] The International Society of Nephrology. ISN. KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease [Internet]. Available from: https://kdigo.org/wp-content/uploads/2017/02/KDIGO_2012_CKD_GL.pdf [Accessed 14th of February 2022].

[3] National Institute for Health and Care Excellence. NICE. Chronic Kidney disease: assessment and management. [Internet]. Available from: https://www.nice.org.uk/guidance/ng203/chapter/Recommendations [Accessed 14th of February 2022].

[4] Chiu, H.H.L., Tangri, N., Djurdjev, O. Barrett BJ, Hemmelgarn BR, Madore F, et al. Perceptions of prognostic risks in chronic kidney disease: a national survey. Can J Kidney Health Dis 2, 53 (2015). https://doi.org/10.1186/s40697-015-0088-z

[5] Thorsteinsdottir B, Espinoza Suarez NR, Curtis S, Hargraves I, Shaw K, Wong SPY, et al. Older Patients with Advanced Chronic Kidney Disease and Their Perspectives on Prognostic Information: a Qualitative Study. J Gen Intern Med. 2022;37(5):1031-1037. doi:10.1007/s11606-021-07176-8

[6] Forzley B, Chiu HHL, Djurdjev O, Carson RC, Hargrove G, Martinusen D, et al. A Survey of Canadian Nephrologists Assessing Prognostication in End-Stage Renal Disease. Can J Kidney Health Dis. 2017;4:2054358117725294. Published 2017 Aug 18. doi:10.1177/2054358117725294

[7] Mendelssohn DC, Malmberg C, Hamandi B. An integrated review of "unplanned" dialysis initiation: reframing the terminology to "suboptimal" initiation. BMC Nephrol. 2009 Aug 12;10:22. doi: 10.1186/1471-2369-10-22

[8] Johnson ES, Thorp ML, Platt RW, Smith DH. Predicting the risk of dialysis and transplant among patients with CKD: a retrospective cohort study. Am J Kidney Dis. 2008;52(4):653-660. doi:10.1053/j.ajkd.2008.04.026

[9] Tangri N, Stevens LA, Griffith J, Tighiouart H, Djurdjev O, Naimark D, et al. A predictive model for progression of chronic kidney disease to kidney failure. JAMA. 2011;305(15):1553-1559. doi:10.1001/jama.2011.451

[10] Drawz PE, Goswami P, Azem R, Babineau DC, Rahman M. A simple tool to predict end-stage renal disease within 1 year in elderly adults with advanced chronic kidney disease. J Am Geriatr Soc. 2013;61(5):762-768. doi:10.1111/jgs.12223

[11] Marks A, Fluck N, Prescott GJ, Robertson L, Simpson WG, Smith WC, et al. Looking to the future: predicting renal replacement outcomes in a large community cohort with chronic kidney disease. Nephrol Dial Transplant. 2015;30(9):1507-1517. doi:10.1093/ndt/gfv089

[12] Norouzi J, Yadollahpour A, Mirbagheri SA, Mazdeh MM, Hosseini SA. Predicting Renal Failure Progression in Chronic Kidney Disease Using Integrated Intelligent Fuzzy Expert System. Comput Math Methods Med. 2016;2016:6080814. doi:10.1155/2016/6080814

[13] Tangri N, Inker LA, Hiebert B, Wong J, Naimark D, Kent D, et al. A Dynamic Predictive Model for Progression of CKD. Am J Kidney Dis. 2017;69(4):514-520. doi:10.1053/j.ajkd.2016.07.030

[14] Schroeder EB, Yang X, Thorp ML, Arnold BM, Tabano DC, Petrik AF, et al. Predicting 5-Year Risk of RRT in Stage 3 or 4 CKD: Development and External Validation. Clin J Am Soc Nephrol. 2017;12(1):87-94. doi:10.2215/CJN.01290216

[15] Hasegawa T, Sakamaki K, Koiwa F, Akizawa T, Hishida A; CKD-JAC Study Investigators. Clinical prediction models for progression of chronic kidney disease to end-stage kidney failure under pre-dialysis nephrology care: results from the Chronic Kidney Disease Japan Cohort Study. Clin Exp Nephrol. 2019;23(2):189-198. doi:10.1007/s10157-018-1621-z

[16] Grams ME, Sang Y, Ballew SH, Carrero JJ, Djurdjev O, Heerspink HJL, , et al. Predicting timing of clinical outcomes in patients with chronic kidney disease and severely decreased glomerular filtration rate [published correction appears in Kidney Int. 2018 Nov;94(5):1025-1026]. Kidney Int. 2018;93(6):1442-1451. doi:10.1016/j.kint.2018.01.009

[17] Foley RN, Parfrey PS, Hefferton D, Singh I, Simms A, Barrett BJ. Advance prediction of early death in patients starting maintenance dialysis. Am J Kidney Dis. 1994;23(6):836-845. doi:10.1016/s0272-6386(12)80137-5

[18] Barrett BJ, Parfrey PS, Morgan J, Barré P, Fine A, Goldstein MB, et al. Prediction of early death in end-stage renal disease patients starting dialysis. Am J Kidney Dis. 1997;29(2):214-222. doi:10.1016/s0272-6386(97)90032-9

[19] Geddes CC, van Dijk PC, McArthur S, Metcalfe W, Jager K, Zwinderman A, et al. The ERA-EDTA cohort study--comparison of methods to predict survival on renal replacement therapy. Nephrol Dial Transplant. 2006;21(4):945-956. doi:10.1093/ndt/gfi326

[20] Mauri JM, Clèries M, Vela E; Catalan Renal Registry. Design and validation of a model to predict early mortality in haemodialysis patients. Nephrol Dial Transplant. 2008;23(5):1690-1696. doi:10.1093/ndt/gfm728

[21] Couchoud C, Labeeuw M, Moranne O, et al. A clinical score to predict 6-month prognosis in elderly patients starting dialysis for end-stage renal disease. Nephrol Dial Transplant. 2009;24(5):1553-1561. doi:10.1093/ndt/gfn698

[22] Dusseux E, Albano L, Fafin C, et al. A simple clinical tool to inform the decision-making process to refer elderly incident dialysis patients for kidney transplant evaluation. Kidney Int. 2015;88(1):121-129. doi:10.1038/ki.2015.25

[23] Weiss JW, Platt RW, Thorp ML, et al. Predicting mortality in older adults with kidney disease: a pragmatic prediction model. J Am Geriatr Soc. 2015;63(3):508-515. doi:10.1111/jgs.13257

[24] Thamer M, Kaufman JS, Zhang Y, et al. Predicting Early Death Among Elderly Dialysis Patients: Development and Validation of a Risk Score to Assist Shared Decision Making for Dialysis Initiation. Am J Kidney Dis. 2015;66(6):1024-1032. doi:10.1053/j.ajkd.2015.05.014

[25] Doi T, Yamamoto S, Morinaga T, et al. Risk Score to Predict 1-Year Mortality after Haemodialysis Initiation in Patients with Stage 5 Chronic Kidney Disease under Predialysis Nephrology Care. PLoS One. 2015;10(6):e0129180. Published 2015 Jun 9. doi:10.1371/journal.pone.0129180

[26] Wick JP, Turin TC, Faris PD, et al. A Clinical Risk Prediction Tool for 6-Month Mortality After Dialysis Initiation Among Older Adults. Am J Kidney Dis. 2017;69(5):568-575. doi:10.1053/j.ajkd.2016.08.035

[27] Chen LX, Josephson MA, Hedeker D, et al. A Clinical Prediction Score to Guide Referral of Elderly Dialysis Patients for Kidney Transplant Evaluation. Kidney Int Rep. 2017;2(4):645-653. doi:10.1016/j.ekir.2017.02.014

[28] Haapio M, Helve J, Grönhagen-Riska C, et al. One- and 2-Year Mortality Prediction for Patients Starting Chronic Dialysis. Kidney Int Rep. 2017;2(6):1176-1185. Published 2017 Jun 24. doi:10.1016/j.ekir.2017.06.019

[29] Schmidt RJ, Landry DL, Cohen L, et al. Derivation and validation of a prognostic model to predict mortality in patients with advanced chronic kidney disease. Nephrol Dial Transplant. 2019;34(9):1517-1525. doi:10.1093/ndt/gfy305

[30] Obi Y, Nguyen DV, Zhou H, et al. Development and Validation of Prediction Scores for Early Mortality at Transition to Dialysis. Mayo Clin Proc. 2018;93(9):1224-1235. doi:10.1016/j.mayocp.2018.04.017

[31] Lin SY, Hsieh MH, Lin CL, et al. Artificial Intelligence Prediction Model for the Cost and Mortality of Renal Replacement Therapy in Aged and Super-Aged Populations in Taiwan. J Clin Med. 2019;8(7):995. Published 2019 Jul 9. doi:10.3390/jcm8070995

[32] Yoshida, M., Otsuka, M., Watanabe, Y. et al. A clinical nomogram for the prediction of early mortality in elderly patients initiating dialysis for end-stage renal disease. Ren Replace Ther 6, 11 (2020). https://doi.org/10.1186/s41100-020-0259-y

[33] Santos J, Oliveira P, Malheiro J, et al. Predicting 6-Month Mortality in Incident Elderly Dialysis Patients: A Simple Prognostic Score. Kidney Blood Press Res. 2020;45(1):38-50. doi:10.1159/000504136

[34] Ramspek CL, Verberne WR, van Buren M, et al. Predicting mortality risk on dialysis and conservative care: development and internal validation of a prediction tool for older patients with advanced chronic kidney disease. Clin Kidney J. 2020;14(1):189-196. Published 2020 Mar 17. doi:10.1093/ckj/sfaa021

[35] Rao PS, Schaubel DE, Guidinger MK, et al. A comprehensive risk quantification score for deceased donor kidneys: the kidney donor risk index. Transplantation. 2009;88(2):231-236. doi:10.1097/TP.0b013e3181ac620b.

[36] Massie AB, Leanza J, Fahmy LM, et al. A Risk Index for Living Donor Kidney Transplantation. Am J Transplant. 2016 Jul;16(7):2077-84. doi: 10.1111/ajt.13709. Epub 2016 Feb 26. Erratum in: Am J Transplant. 2020 Jan;20(1):324. PMID: 26752290; PMCID: PMC6114098.

[37] Grams ME, Li L, Greene TH, et al. Estimating time to ESRD using kidney failure risk equations: results from the African American Study of Kidney Disease and Hypertension (AASK). *Am J Kidney Dis*. 2015;65(3):394-402. doi:10.1053/j.ajkd.2014.07.026.

[38] Lennartz CS, Pickering JW, Seiler-Mußler S, et al. External Validation of the Kidney Failure Risk Equation and Re-Calibration with Addition of Ultrasound Parameters. Clin J Am Soc Nephrol. 2016;11(4):609-615. doi:10.2215/CJN.08110715

[39] Peeters MJ, van Zuilen AD, van den Brand JA, et al. Validation of the kidney failure risk equation in European CKD patients. Nephrol Dial Transplant. 2013;28(7):1773-1779. doi:10.1093/ndt/gft063

[40] Prouvot J, Pambrun E, Antoine V, et al. Low performance of prognostic tools for predicting death before dialysis in older patients with advanced CKD. J Nephrol. 2022;35(3):993-1004. doi:10.1007/s40620-021-01180-1

[41] Tangri N, Grams ME, Levey AS, et al. Multinational Assessment of Accuracy of Equations for Predicting Risk of Kidney Failure: A Meta-analysis [published correction appears in JAMA. 2016 Feb 23;315(8):822]. JAMA. 2016;315(2):164-174. doi:10.1001/jama.2015.18202

[42] Engels N, de Graav GN, van der Nat P, et al. Shared decision-making in advanced kidney disease: a scoping review. BMJ Open 2022;12:e055248. doi: 10.1136/bmjopen-2021-055248

[43] Ramspek CL, de Jong Y, Dekker FW, van Diepen M. Towards the best kidney failure prediction tool: a systematic review and selection aid. Nephrol Dial Transplant. 2020;35(9):1527-1538. doi:10.1093/ndt/gfz018

[44] Kadatz MJ, Lee ES, Levin A. Predicting Progression in CKD: Perspectives and Precautions. Am J Kidney Dis. 2016;67(5):779-786. doi:10.1053/j.ajkd.2015.11.007

[45] de Jong Y, van der Willik EM, Milders J, et al. Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies : Care planning in CKD: which outcomes matter?. BMC Nephrol. 2021;22(1):309. Published 2021 Sep 13. doi:10.1186/s12882-021-02489-6

[46] Ramer SJ, McCall NN, Robinson-Cohen C, et al. Health Outcome Priorities of Older Adults with Advanced CKD and Concordance with Their Nephrology Providers’ Perceptions. J Am Soc Nephrol. 2018;29(12):2870-2878. doi:10.1681/ASN.2018060657

[47] van der Horst DEM, van Uden-Kraan CF, Parent E, et al. Optimizing the use of patients’ individual outcome information - Development and usability tests of a Chronic Kidney Disease dashboard. Int J Med Inform. 2022;166:104838. doi:10.1016/j.ijmedinf.2022.104838

[48] International Standard Classification of Education (ISCED 2011) [Internet]. Available from: http://uis.unesco.org/en/topic/international-standard-classification-education-isced. [Accessed 6th of July 2022].

[49] Chew LD., Bradley KA, and Boyko EJ. 2004. "Brief Questions to Identify Patients with Inadequate Health Literacy." Family Medicine 588–94

[50] van Zuuren FJ, de Groot KI, Mulder N, et al. Coping with medical threat: an evaluation of the threatening medical situations inventory (TMSI). Pers Individ Differ 1996;21:21–31.

[51] Ong LM, Visser MR, van Zuuren FJ, et al. Cancer patients' coping styles and doctor-patient communication. Psycho-Oncology 1999; 8:155–166.

[52] Fleuren MAH; Paulussen TGWM; Van Dommelen P; et al. Towards a measurement instrument for determinants of innovations. International Journal for Quality in Healthcare , 26 (5), 2014: 501-510; doi: 10.1093/intqhc/mzu060.

[53] The Common European Framework of Reference for Languages (CEFRL) [Internet]. Available from: https://www.coe.int/en/web/common-european-framework-reference-languages/level-descriptions. [Accessed July 2022].

[54] Potok OA, Nguyen HA, Abdelmalek JA, et al. Patients,' Nephrologists,' and Predicted Estimations of ESKD Risk Compared with 2-Year Incidence of ESKD. Clin J Am Soc Nephrol. 2019 Feb 7;14(2):206-212. doi: 10.2215/CJN.07970718. Epub 2019 Jan 10. PMID: 30630859; PMCID: PMC6390919

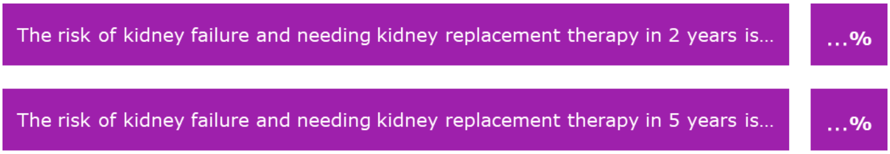
[55] Stiggelbout, AM, Pieterse, AH, De Haes, JCJM. Shared decision making: Concepts, evidence, and practice. Patient Education and Counseling, 98(10), 1172-1179. 1179. doi:10.1016/j.pec. 2015.06.022. Epub 2015 Jul 15. PMID: 26215573.

[56] Rood JA, Van Zuuren FJ, Stam F, et al. Cognitive coping style (monitoring and blunting) and the need for information, information satisfaction and shared decision making among patients with haematological malignancies. Psychooncology.

[57] Lagarde, SM., Franssen, SJ., van Werven, JR., et al. Patient preferences for the disclosure of prognosis after esophagectomy for cancer with curative intent. Annals of surgical oncology, 2008, 15(11), 3289–3298. https://doi.org/10.1245/s10434-008-0068-y

Supplement 1 – Mock-ups of two predictions of models predicting CKD progression (translated from Dutch)

Mock-up 1:



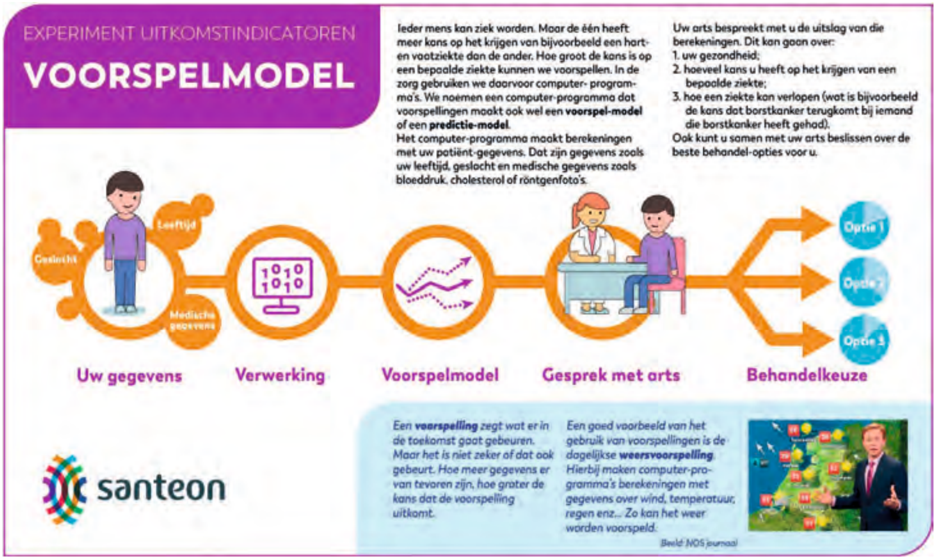
The risk of kidney failure and needing kidney replacement therapy in 2 years is… …%

The risk of kidney failure and needing kidney replacement therapy in 5 years is… …%

Mock-up 2:

You might need kidney replacement therapy because of kidney failure in … **years**

Supplement 2 – Infographic explaining a clinical prediction model (in Dutch)



EXPERIMENT UITKOMSTINDICATOREN

VOORSPELMODEL

Ieder mens kan ziek worden. Maar de één heeft meer kans op het krijgen van bijvoorbeeld een hart- en vaatziekte dan de ander. Hoe groot de kans is op een bepaalde ziekte kunnen we voorspellen. In de zorg gebruiken we daarvoor computer- programma's. We noemen een computer-programma dat voorspellingen maakt ook wel een **voorspel-model** of een **predictie-model**.
Het computer-programma maakt berekeningen met uw patiënt-gegevens. Dat zijn gegevens zoals uw leeftijd, geslacht en medische gegevens zoals bloeddruk, cholesterol of röntgenfoto's.

Uw arts bespreekt met u de uitslag van die berekeningen. Dit kan gaan over:
1. uw gezondheid;
2. hoeveel kans u heeft op het krijgen van een bepaalde ziekte;
3. hoe een ziekte kan verlopen (wat is bijvoorbeeld de kans dat borstkanker terugkomt bij iemand die borstkanker heeft gehad).

Ook kunt u samen met uw arts beslissen over de beste behandel-opties voor u.

*Een **voorspelling** zegt wat er in de toekomst gaat gebeuren. Maar het is niet zeker of dat ook gebeurt. Hoe meer gegevens er van tevoren zijn, hoe groter de kans dat de voorspelling uitkomt.*

*Een goed voorbeeld van het gebruik van voorspellingen is de dagelijkse **weersvoorspelling**. Hierbij maken computer-programma's berekeningen met gegevens over wind, temperatuur, regen enz… Zo kan het weer worden voorspeld.*

Beeld: NOS journaal

Supplement 3 – Content of the online surveys for patients and nephrologists.

Topics	Patient survey	Nephrologist survey
Introduction	Definition of a ‘prediction model’ including infographic	
Demographics	• Age • Sex • Education level[1] • Health literacy (SBSQ)[2] • Estimated remaining KF at time of survey • Coping behaviour (TMSI)[3]	• Age • Sex • Professional experience in current function (in years)
Current use of CPMs in CKD practice	• Did your nephrologist discuss predictions with you? If so: which one(s)? • Retrospectively; did you want to know these prediction(s)?	• Do you currently use CPMs? If yes: which one(s)? • If not: reasons not to use CPMs? • Do you discuss predictions without using CPMs? If yes: how do you discuss these expectations?
Preferences for predictions in CKD	• Which prediction(s) (drawn from the literature) do you want to know (and why)? • What do you consider the most important prediction (and why)? • How can CPMs be helpful to you?	• Which CPMs (drawn from literature) would you want to use in the future? • What do you consider the most important prediction (and why)? • For what purpose would you develop a new CPM if anything is possible?
Preferences for predictions about CKD progression	Mock-ups of 2 CPMs: 1) the KFRE; a two- and five-year risk prediction of progression to kidney failure (in %) 2) prediction of the time to progression in kidney failure (in years)	
	• Do you understand both predictions? • Would you want to know this information about yourself? • Which prediction do you prefer?	• Have you used the KFRE? • Would you use these predictions? • Which CPM do you prefer?
Barriers and facilitators for the adoption of CPMs in clinical practice	• Testing general attitudes (drawn from interviews) when hearing prediction models • Do you think nephrologists should use CPMs during consultations? • How/when should predictions be communicated?	• Do you agree with statements (drawn from the literature) arguing against the use of CPMS in clinical practice? • Which determinants of the MIDI[4] are most important for the successful adoption of CPMs in clinical practice? • How/when should predictions be communicated?

CPMs = clinical prediction models, CKD = chronic kidney disease, KRT = Kidney replacement therapy

1 = The International Standard Classification of Education framework was used to present patients’ educational levels [48]

2 = Set of Brief Screening Questions [49]

3 = Threatening Medical Situations [50,51]

4 = Measurement Instrument for Determinants of Innovations [52]

Supplement 4 – Identified themes and illustrative quotes from patient interviews

Identified themes and illustrative quotes from patient interviews

Themes	Summarised key points	Quotes **[prediction in %] refers to KFRE: % risk to get kidney failure after 2 and 5 years. [prediction in time to] refers to predicting amount of years until CKD progresses to kidney failure.**
1. Understanding predictions about CKD progression	No difficulties in understanding outcomes of the CPMs	P1: Let me just read… what I understand from it is that it shows what things will look like in 2 years or in 5 years. P5 Erm, yeah, I think this is especially for those who haven't had a transplant before or those where kidney replacement therapy hasn't been initiated before… because that's what this is about, isn't it – about when that time comes? P6: yes, yes. It's clear what it says. P7 ['prediction in % + 'prediction in time to']: My initial impression is that this is clear. P4 ['prediction in time to']: The latter refers to in 9 years' time. Yes, well, this patient has been aware of the fact that he has been suffering from kidney disease since 2016, so it's a good thing to be able to give someone a timeline.
	Difficulty in understanding outcomes of the CPMs	P4: ['prediction in %'] Okay, the likelihood of kidney failure and needing kidney replacement therapy in 2 years' time is 2.63% and the likelihood of kidney failure and needing kidney replacement therapy in 5 years' time. No, actually, I feel this is a vague figure. P4: Well, now I see that in 5 years' time I have a 10% chance of needing kidney replacement therapy and that this isn't even 3% in two years' time – what does that add? I don't understand it very well.
2. Preferences for predictions about CKD progression	Willingness to know predictions about CKD progression	P4: It is what it is and you do understand that it is a prediction based on the things that you have provided and the data the doctor gets from the tests. And yeah, it's just useful to know which way you're going. P5: ['prediction in %'] If you haven't experienced that before, it can be very nerve-racking. However, I can imagine that you would, for instance, want to know how you're doing and what your chances are. P6: yeah, it's about your own health, isn't it? Why wouldn't I want to know that? And you indeed realise that, goodness, in nine years' time I'll need a donor kidney or kidney dialysis or something of that nature. P7: ['prediction in %'] this is relevant to everyone, the percentages you are likely to need kidney replacement therapy in two years' or five years' time. Yeah, that's just very important. P9: ['prediction in %'I would definitely want to know, because if, at some point, I was told that, but it was already at 3.62 three years ago – for example – well, then I would have liked to know. Definitely!

Supplement 4 *(Continued)*

Themes	**Summarised key points**	**Quotes** **[prediction in %] refers to KFRE: % risk to get kidney failure after 2 and 5 years. [prediction in time to] refers to predicting amount of years until CKD progresses to kidney failure.**
	Unwillingness to know predictions about CKD progression	P8: ['prediction in time to + prediction in %'] I feel that it has some relevance. I know, yeah, maybe for some patients that may be something you'd be able to estimate, but… just considering my own case and then to think that I was on the edge and that I'm so much better now. It might not be worth all that much. I mean, yeah, no, that's a tough one. I don't know whether I would want to know that, whereas of course other people do want to know that kind of thing.
	No preferences between a 'risk of' prediction or a 'time to' prediction format	P1: ['prediction in time to + prediction in %'] It's basically the same screen as before, only it says 9 years, so it's… yeah… in more detail… the whole thing deals with multiple years. Other than that, it's actually exactly the same – so it's not a preference. P9: ['prediction in time to + prediction in %'] Erm, of course that's very different, because for one person it'll be 2 or 5 years and then a percentage; and in this case we're talking about 9 years. So those nine years, to my mind, come across as more positive than 2 or 5 years. On the other hand, I'd prefer clear information and you shouldn't sugarcoat things to be better than they actually are. If it is actually nine years then… fine. But maybe that percentage is equally fine. I'd be okay with either of them, provided I know that I can expect something in future.
	Preference for the 'time to' prediction	P8: Hmm, well, maybe a prediction saying '' in the amount of years ['prediction in time to'] may be a bit clearer than in percentages ['prediction in %']. P4: Surely, it would be more relevant to know when kidney replacement therapy is indeed necessary ['prediction in time to']. Look at the possibilities of kidney replacement therapy in 9 years' time, I mean, yeah, that's exactly the questions you're asking. P5: Ah, yeah, saying 'x amount of years', might be much better, as it's just 1 number. And, erm, look, percentages are quite abstract – it tells you your chances, erm, in terms of that you might need it in 9 years' time.
	Preference for a combination of a 'risk of' and a 'time to' prediction	P7: I would really like it if, say, this could be combined, as it were, meaning that you have the 'in 9 years' time' plus the percentages outlined alongside it. P6: maybe you could put this bar ['prediction in time to'] there and ['prediction in %'] underneath. That would give you an overall picture. That would give you the percentages and the number of years. That might be clearer for people?

Supplement 4 *(Continued)*

Themes	Summarised key points	Quotes **[prediction in %] refers to KFRE: % risk to get kidney failure after 2 and 5 years. [prediction in time to] refers to predicting amount of years until CKD progresses to kidney failure.**
3. How predictions about CKD progression can help patients	Predictions about CKD progression can help patients with their life planning	P4: ['prediction in time to'] Of course that would help, because it would help me consider the fact that, well… I guess it's not that crazy… whether I'd still want to go on another trip or whatever… what would be best: do it now and not in 9 years' time, because then I'd have to take my dialysis materials with me, or I'd need have to have had a kidney transplantation. I mean, yeah, this is… it's preparing yourself for the fact that you're going to have to take that step in 9 years' time. P5: ['prediction in time to'] Yes, yeah, at the times when you're faced with kidney failure… you do start asking 'how long have I got before?'… especially in relation to how long I've got before I need to turn my life upside down. So, erm, yeah, this would definitely help. […] yeah, I would ['prediction in % + prediction in time to'] want to know. That way you'd be able to make or cancel plans. I think that once you're confronted with kidney failure you really just want to know what the score is. P7: ['prediction in %'] Well, it might help me with regard to the expectations I have for the future and equally what I've been discussing with my doctor recently… about having children. I mean, I am very young, but the expectation is that between now and 6 years I should be having a kidney transplantation. And yeah, imagine you want to start planning starting a family, then, in my case, it would be highly relevant… in terms of, well, I should have my kidney transplant first… and if I were to know that it would roughly be… in this case it would be in about 5 years… 9.% or 80%… then I'd have rough idea of where I stand and, yeah, that's just something that's good to know.
	Predictions about CKD progression can provide patients more clarity on their disease stage	P9: well, I don't know whether it'd be helpful, but it is clear. I don't know what would be beneficial to me or how it would help me. The only thing that is clear is what stage I'm at. P7: yeah, imagine discussing this with your parents… my parents also know quite a lot about kidney failure and such, so they might know a bit more about this… and it would make more sense to them in terms of a percentage. But imagine I were talking about it to my friends and I guess it would make less sense to them… they'd find it more logical to speak in terms of 5 to 6 years – that would give them a clearer idea.
	Predictions about CKD progression can provide patients with comfort or consolation.	P5: So, the chance of kidney failure and needing kidney replacement therapy in two years' time is 2.63%… that's very reassuring to read, so yeah… I think that's very useful.
	Predictions about CKD progression can help patients focus on preserving their kidney function for as long as possible	Interviewer: And could that information ['prediction in % + prediction in time to'] help you? P6: yes, you could… the only thing you could do is discuss things with your doctor… in terms of what you could do even better P6: ['prediction in % + prediction in time to'] yeah, it's about your own health, isn't it? Why wouldn't I want to know that? And you indeed realise that, goodness, in nine years' time I'll need a donor kidney or kidney dialysis or something of that nature. Erm, yes. What can I do in the meantime to stretch out that period somewhat?

Supplement 4 *(Continued)*

Themes	Summarised key points	Quotes **[prediction in %] refers to KFRE: % risk to get kidney failure after 2 and 5 years. [prediction in time to] refers to predicting amount of years until CKD progresses to kidney failure.**
4. Potential negative effects of discussing predictions about CKD progression	Predictions about CKD progression can be very confrontational	P9: I'm also very curious to see how things are in 5 years' time. What percentage I'd have. [...] It makes me a little anxious thinking about it. I'll say quite honestly, I've never really thought about it that way before. I'm finding this a little difficult [tearing up] P9: yeah – that was a bit of a shock. If that was for me, I'd really have had a scare. I'd think I probably should go back to the Netherlands. P7: Well, what I went through myself is that it was quite a shock when the doctor suddenly told me the ['prediction in %']. It's really... I was in absolute floods of tears, so, yeah, I found the whole thing very, very confronting. P9: It just surprises me... woah! We've never talked about this before. I mean, yeah, if it's below 20, then we would have more serious conversations. But I think it's at 35, so I'm still way over the halfway mark. So yeah, I'm trying to live as healthy a life as possible and am not giving it any further thought – but when I saw the 2- and 5-year points, I just thought: woah! That's pretty intense. And those aren't even my own numbers.
	Predictions about CKD progressions can cause increase worrying and/or can be unmotivating	P8: No, of course, it'll be different for each patient. That makes sense, in terms of ... should I start worrying more or should I start slacking off? Anyway, that is more or less my opinion.
5. How to discuss predictions about CKD progression with patients	Predictions about CKD progression should be discussed with a nephrologists (especially the first time)	P7: Well, what I went through myself is that it was quite a shock when the doctor suddenly told me the ['prediction in %']. It's really... I was in absolute floods of tears, so, yeah, I found the whole thing very, very confronting. I would find it even more distressing if I were to see that on the site for the first time. P8 Yeah, look, if you're aware beforehand and know that this information will be adjusted every time... then you might be less shocked. But imagine reading 92%, then I think you would be shocked. I think it'd be better for a doctor to do that. I would only give a patient that result during a consultation – especially if the news is bad. P9: Well, look, I would want to be told by the nephrologist in any case and if I were to be able to review that information myself in the future, that would be fine. But if I had no idea whatsoever and then came across this information, I'd be scared out of my mind [...] and it's likely, and this may not even apply to me per se, but if I were to come across this information all at once, I'd want the specialist to tell me that they were keeping an eye on things and recording it in this way. P9: So, in the consultation with my nephrologist, he might say, well, this is the picture now, considering your situation, and this and that and he says it'll be 25% in 5 years' time. And then if I were to check the next time and see 21% come up and then think to myself 'oh, it's starting to fall'. But if it happened to be 27% the next time, which is equally possible, I'd think 'well, hey! I suspect that it may very well still be 25% in 5 years' time, but as long as I hear the nuts and bolts of it from my specialist first and am able to take a look at the information myself, then I wouldn't mind at all. P5: Yeah – I would like to be able to review things at home before seeing the nephrologist. You'll most likely only be given access once you've already been to see the nephrologist and already have symptoms and there have already been problems – erm, yeah, from that moment onwards I just want to have everything be clear to me.

Supplement 4 *(Continued)*

Themes	**Summarised key points**	**Quotes** **[prediction in %] refers to KFRE: % risk to get kidney failure after 2 and 5 years. [prediction in time to] refers to predicting amount of years until CKD progresses to kidney failure.**
	When discussing these predictions, it has to be clear that it is relates to an estimate	P7: ['prediction in time to'] Don't make the test definitive, meaning that in this case kidney replacement therapy would be necessary in 9 years' time, but that it is actually an estimate… that has to be made very clear.

Supplement 5 – Post-hoc analysis of coping strategies in relation to preferences regarding CPMs

Post hoc comparison using the Tukey HSD test indicated that mean monitoring score for *wanting to know* the **prediction regarding the chance of getting CVD** was significantly different than *not wanting to know* (mean difference 4.42, 95% BI (1.40-7.45) and being *neutral* (mean difference 3.50, 95%BI 1.31-5.70).

Post hoc comparison using the Tukey HSD test indicated that mean monitoring score for *wanting to know* the **prediction regarding when patients might need KRT** was significantly different than being *neutral* (mean difference 4.07, 95%BI 1.41-6.73).

Post hoc comparison using the Tukey HSD test indicated that mean monitoring score for *wanting to know* the **prediction regarding the chance of mortality before KRT** was significantly different than *not wanting to know* (mean difference 3.24, 95%BI 0.75-5.74) and being *neutral* (mean difference 2.81, 95%BI 0.52-5.09)

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

Dorinde E.M. van der Horst
Cornelia F. van Uden-Kraan
Ellen Parent
Hans J.A.J. Bart
Geeke Waverijn
Iris J.A.M. Verberk-Jonkers
Marinus A. van den Dorpel
Arwen H. Pieterse
Willem Jan W. Bos

Published in International Journal of Medical Informatics, 2022

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

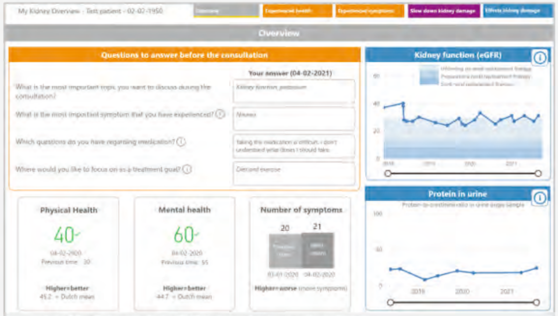
Focus groups patients

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



Questions to answer before the consultation

	Your answer (04-02-2021)
What is the most important topic you want to discuss during the consultation?	Kidney function, potassium
What is the most important symptom that you have experienced?	Nausea
Which questions do you have regarding medication?	Taking the medication is difficult. I don't understand what doses I should take.
Where would you like to focus on as a treatment goal?	Diet and exercise

Physical Health
40
04-02-2020
Previous time: 30
Higher=better
45.2 = Dutch mean

Mental health
60
04-02-2020
Previous time: 55
Higher=better
44.7 = Dutch mean

Number of symptoms
20 21
03-01-2020 04-02-2020
Higher=worse (more symptoms)

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

D.E.M. van der Horst, MD, St. Antonius Hospital, The Netherlands

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.

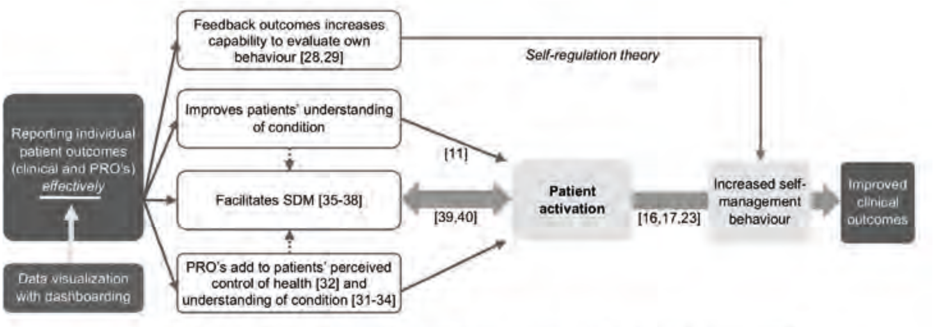


Figure 1. Conceptual model of how reporting individual patient outcomes can increase self-management behaviour and ultimately clinical outcomes. PRO's=patient-reported outcomes, SDM=Shared Decision Making

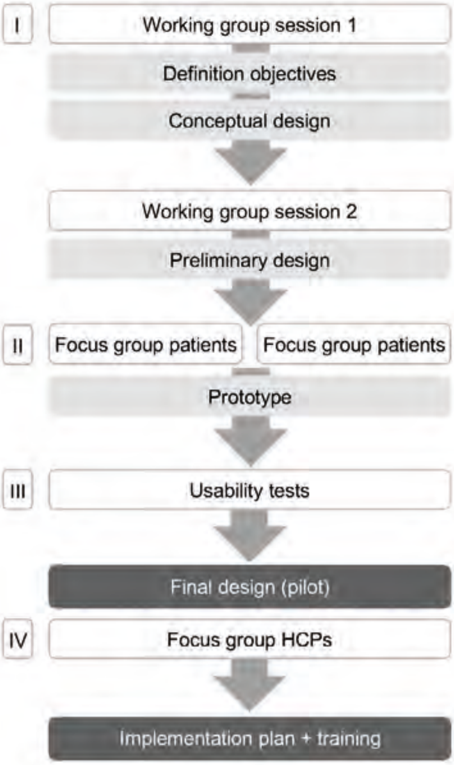
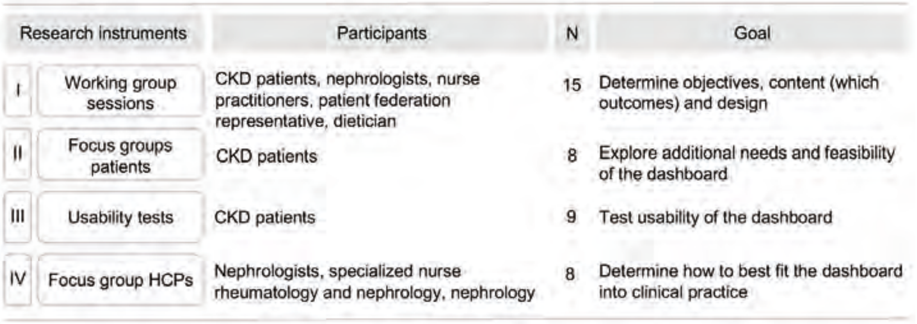


Figure 2. Overview of dashboard development, HCP=Healthcare Professional

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.

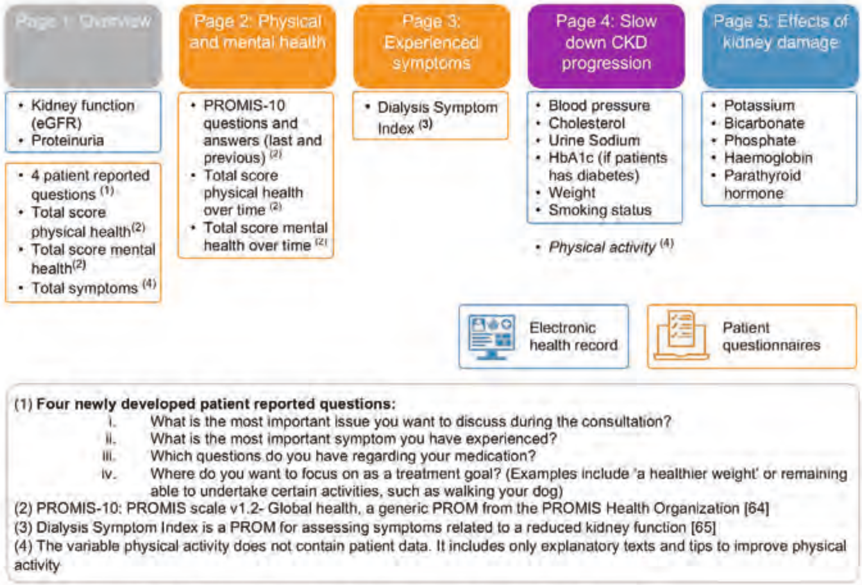
Box 1. Objectives CKD dashboard

- 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]

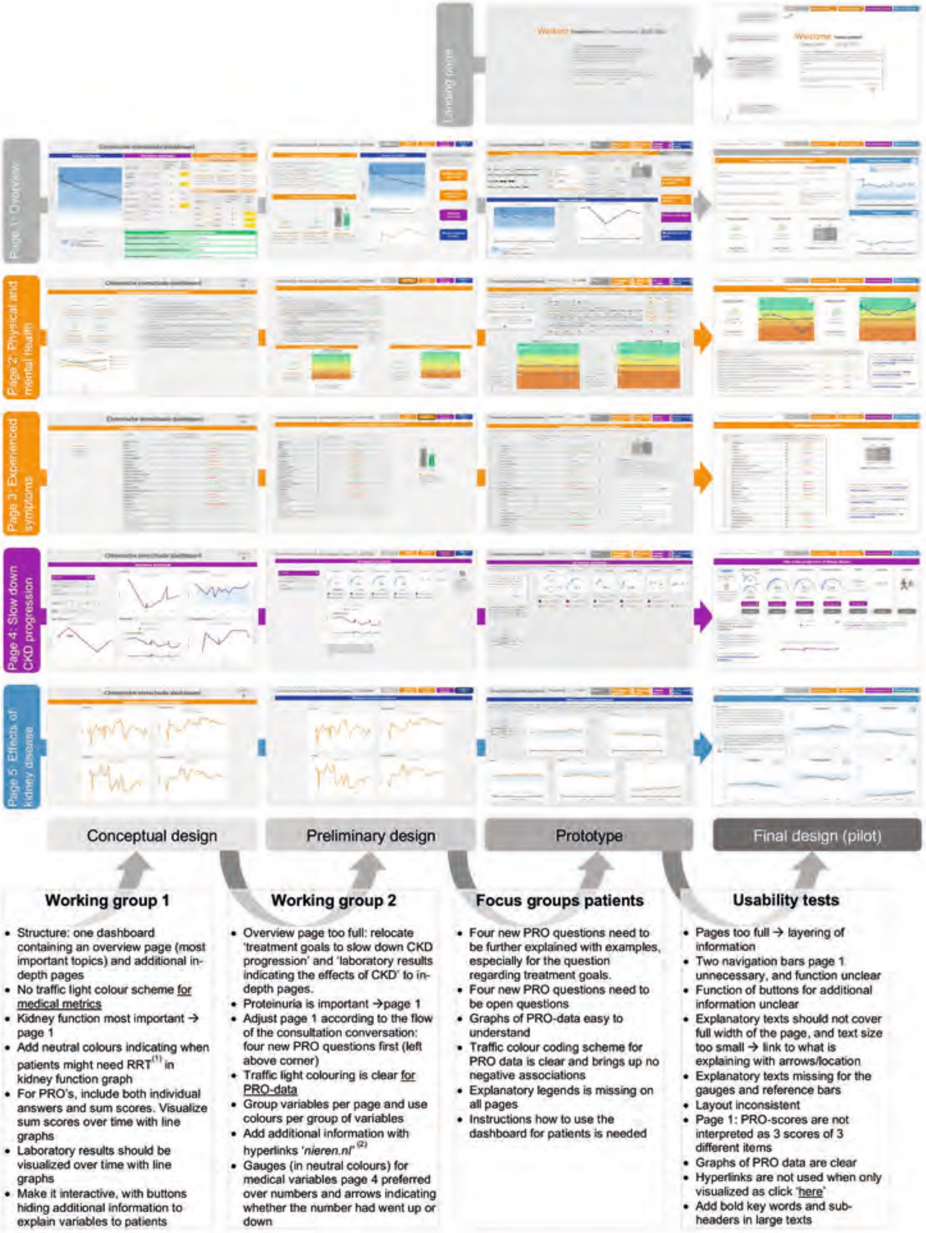
(3) Dialysis Symptom Index is a PROM for assessing symptoms related to a reduced kidney function [65]

(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

References

[1] V. Jha, G. Garcia-Garcia, K. Iseki, Z. Li, S. Naicker, B. Plattner, R. Saran, A.Y.M. Wang, C.W. Yang, Chronic kidney disease: Global dimension and perspectives, The Lancet. 382 (2013) 260–272. https://doi.org/10.1016/S0140-6736(13)60687-X.

[2] GBD Chronic Kidney Disease Collaboration, Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017, The Lancet. 395 (2020) 709–733. https://doi.org/10.1016/S0140-6736(20)30045-3.

[3] W.G. Couser, G. Remuzzi, S. Mendis, M. Tonelli, The contribution of chronic kidney disease to the global burden of major noncommunicable diseases, Kidney International. 80 (2011) 1258–1270. https://doi.org/10.1038/ki.2011.368.

[4] A.S. Levey, R. Atkins, J. Coresh, E.P. Cohen, A.J. Collins, K.U. Eckardt, M.E. Nahas, B.L. Jaber, M. Jadoul, A. Levin, N.R. Powe, J. Rossert, D.C. Wheeler, N. Lameire, G. Eknoyan, Chronic kidney disease as a global public health problem: Approaches and initiatives - A position statement from Kidney Disease Improving Global Outcomes, Kidney International. 72 (2007) 247–259. https://doi.org/10.1038/sj.ki.5002343.

[5] Kidneydisease, KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease, Official Journal of the International Society of Nephrology. 3 (2013).

[6] L.C. Plantinga, D.S. Tuot, N.R. Powe, Awareness of Chronic Kidney Disease Among Patients and Providers, Advances in Chronic Kidney Disease. 17 (2010) 225–236. https://doi.org/10.1053/j.ackd.2010.03.002.

[7] A.O. Molnar, A. Akbari, K.S. Brimble, Perceived and Objective Kidney Disease Knowledge in Patients With Advanced CKD Followed in a Multidisciplinary CKD Clinic, Canadian Journal of Kidney Health and Disease. 7 (2020). https://doi.org/10.1177/2054358120903156.

[8] J.A. Wright Nunes, K.A. Wallston, S.K. Eden, A.K. Shintani, T.A. Ikizler, K.L. Cavanaugh, Associations among perceived and objective disease knowledge and satisfaction with physician communication in patients with chronic kidney disease, Kidney International. 80 (2011) 1344–1351. https://doi.org/10.1038/ki.2011.240.

[9] J. Wright, K. Wallston, T. Elasy, T. Ikizler, KL. v Cavanaugh, Development and Results of a Kidney Disease Knowledge Survey Given to Patients With CKD, Am J Kidney Dis. 57 (2010) 387–395. https://doi.org/10.1053/j.ajkd.2010.09.018.Development.

[10] D.S. Tuot, L.C. Plantinga, What patients dont know may hurt them: Knowledge and the perception of knowledge among patients with CKD, Kidney International. 80 (2011) 1256–1257. https://doi.org/10.1038/ki.2011.269.

[11] J.H. Hibbard, J. Stockard, E.R. Mahoney, M. Tusler, Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers, Health Services Research. 39 (2004) 1005–1026. https://doi.org/10.1111/j.1475-6773.2004.00269.x.

[12] D. Nair, K.L. Cavanaugh, Measuring patient activation as part of kidney disease policy: Are we there yet?, Journal of the American Society of Nephrology. 31 (2020) 1435–1443. https://doi.org/10.1681/ASN.2019121331.

[13] T.J. Wilkinson, K. Memory, C.J. Lightfoot, J. Palmer, A.C. Smith, Determinants of patient activation and its association with cardiovascular disease risk in chronic kidney disease: A cross-sectional study, Health Expectations. (2021) 843–852. https://doi.org/10.1111/hex.13225.

[14] J.H. Hibbard, J. Greene, What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs, Health Affairs. 32 (2013) 207–214. https://doi.org/10.1377/hlthaff.2012.1061.

[15] S. Rogvi, I. Tapager, T.P. Almdal, M.L. Schiøtz, I. Willaing, Patient factors and glycaemic control - associations and explanatory power, Diabetic Medicine. 29 (2012) 382–389. https://doi.org/10.1111/j.1464-5491.2012.03703.x.

[16] D.M. Mosen, J. Schmittdiel, J. Hibbard, D. Sobel, C. Remmers, J. Bellows, Is patient activation associated with outcomes of care for adults with chronic conditions?, Journal of Ambulatory Care Management. 30 (2007) 21–29. https://doi.org/10.1097/00004479-200701000-00005.

[17] J. Greene, J.H. Hibbard, Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes, Journal of General Internal Medicine. 27 (2012) 520–526. https://doi.org/10.1007/s11606-011-1931-2.

[18] J. Greene, J.H. Hibbard, R. Sacks, V. Overton, C.D. Parrotta, When patient activation levels change, health outcomes and costs change, too, Health Affairs. 34 (2015) 431–437. https://doi.org/10.1377/hlthaff.2014.0452.

[19] N. Begum, M. Donald, I.Z. Ozolins, J. Dower, Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes, Diabetes Research and Clinical Practice. 93 (2011) 260–267. https://doi.org/10.1016/j.diabres.2011.05.031.

[20] M. Donald, R.S. Ware, I.Z. Ozolins, N. Begum, R. Crowther, C. Bain, The role of patient activation in frequent attendance at primary care: A population-based study of people with chronic disease, Patient Education and Counseling. 83 (2011) 217–221. https://doi.org/10.1016/j.pec.2010.05.031.

[21] R.L. Kinney, S.C. Lemon, S.D. Person, S.L. Pagoto, J.S. Saczynski, The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: A systematic review, Patient Education and Counseling. 98 (2015) 545–552. https://doi.org/10.1016/j.pec.2015.02.005.

[22] P. Carol Remmers, PhD; Judith Hibbard, DrPH; David M. Mosen, PhD; Morton Wagenfield, PhD; Robert E. Hoye, PhD; Ches Jones, Abstract:, Is Patient Activation Associated With Future Health Outcomes and Healthcare Utilization Among Patients With Diabetes?, J Ambulatory Care Manage. 32 (2009) 320–327. papers2://publication/uuid/5EEF2AB6-DCA3-4C94-9A7D-3C8B75574E44.

[23] J.B. Fowles, P. Terry, M. Xi, J. Hibbard, C.T. Bloom, L. Harvey, Measuring self-management of patients' and employees' health: Further validation of the Patient Activation Measure (PAM) based on its relation to employee characteristics, Patient Education and Counseling. 77 (2009) 116–122. https://doi.org/10.1016/j.pec.2009.02.018.

[24] Y. de Jong, E.M. van der Willik, J. Milders, Y. Meuleman, R.L. Morton, F.W. Dekker, M. van Diepen, Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies, BMC Nephrology. 22 (2021) 1–16. https://doi.org/10.1186/s12882-021-02489-6.

[25] M.E. Porter, What Is Value in Healthcare?, The New England Journal of Medicine. 26 (2010) 2477–2481.

[26] M. Porter, E. Teisberg, Redefining Healthcare: Creating Value-Based Competition on Results, Harvard Business School Press, Boston, 2006. https://doi.org/10.1136/bmj.333.7571.760.

[27] W.R. Verberne, Z. Das-Gupta, A.S. Allegretti, H.A.J. Bart, W. van Biesen, G. García-García, E. Gibbons, E. Parra, M.H. Hemmelder, K.J. Jager, M. Ketteler, C. Roberts, M. al Rohani, M.J. Salt, A. Stopper, T. Terkivatan, K.R. Tuttle, C.W. Yang, D.C. Wheeler, W.J.W. Bos, Development of an International Standard Set of Value-Based Outcome Measures for Patients With Chronic Kidney Disease: A Report of the International Consortium for Health Outcomes Measurement (ICHOM) CKD Working Group, American Journal of Kidney Diseases. 73 (2019) 372–384. https://doi.org/10.1053/j.ajkd.2018.10.007.

[28] H. Leventhal, D. Meyer, D. Nerenz, S. Rachman, The common sense representation of illness danger, Contributions to Medical Psychology. 2 (1980) 7–30.

[29] H. Leventhal, L. Brissette, E. Leventhal, The self-regulation of health and illness behaviour, The Self-Regulation of Health and Illness Behaviour. (2003) 42–60. https://doi.org/10.4324/9780203553220.

[30] World Health Organization, Adherence to long-term therapies - evidence for action, 2003. https://doi.org/10.1177/1049909112449068.

[31] J. Greenhalgh, K. Gooding, E. Gibbons, S. Dalkin, J. Wright, J. Valderas, N. Black, How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis, Journal of Patient-Reported Outcomes. 2 (2018). https://doi.org/10.1186/s41687-018-0061-6.

[32] J. Field, M.M. Holmes, D. Newell, <p>PROMs data: can it be used to make decisions for individual patients? A narrative review</p>, Patient Related Outcome Measures. Volume 10 (2019) 233–241. https://doi.org/10.2147/prom.s156291.

[33] D. Feldman-Stewart, M.D. Brundage, A conceptual framework for patient – provider communication : a tool in the PRO research tool box, Qual Life Res. 18 (2009) 109–114. https://doi.org/10.1007/s11136-008-9417-3.

[34] L.Y. Yang, D.S. Manhas, A.F. Howard, R.A. Olson, Patient-reported outcome use in oncology: a systematic review of the impact on patient-clinician communication, Supportive Care in Cancer. 26 (2018) 41–60. https://doi.org/10.1007/s00520-017-3865-7.

[35] O.C. Damman, M.E.A. Verbiest, S.I. Vonk, M.C. De Bruijne, M.J. Faber, Using PROMs during routine medical consultations : The perspectives of people with Parkinson' s disease and their health professionals, (2019) 939–951. https://doi.org/10.1111/hex.12899.

[36] P.B. van der Nat, The new strategic agenda for value transformation, Health Services Management Research. (2021). https://doi.org/10.1177/09514848211011739.

[37] Y. La Grouw, K. Kee, S. Ybema Hilde Taverne, L. Boonen Praktijkonderzoek iov het Zorginstituut Nederland, Samen Beslissen in de praktijk, (2019).

[38] G. Steinmann, H. Van De Bovenkamp, A. De Bont, D. Delnoij, Redefining value: a discourse analysis on value-based healthcare, BMC Health Services Research. 20 (2020) 1–13. https://doi.org/10.1186/s12913-020-05614-7.

[39] B.Y. Poon, S.M. Shortell, H.P. Rodriguez, Patient Activation as a Pathway to Shared Decision-making for Adults with Diabetes or Cardiovascular Disease, Journal of General Internal Medicine. 35 (2020) 732–742. https://doi.org/10.1007/s11606-019-05351-6.

[40] S.G. Smith, A. Pandit, S.R. Rush, M.S. Wolf, C.J. Simon, The role of patient activation in preferences for shared decision making: Results from a national survey of U.S. Adults, Journal of Health Communication. 21 (2016) 67–75. https://doi.org/10.1080/10810730.2015.1033115.

[41] R.P.C. Kessels, Patients' memory for medical information, J R Soc Med. 96 (2003) 219–222.

[42] S. Few, Information dashboard design, Analytics Press, 2013. https://doi.org/10.1002/9781119198048.part2.

[43] D. Dowding, R. Randell, P. Gardner, G. Fitzpatrick, P. Dykes, J. Favela, S. Hamer, Z. Whitewood-Moores, N. Hardiker, E. Borycki, L. Currie, Dashboards for improving patient care: Review of the literature, International Journal of Medical Informatics. 84 (2015) 87–100. https://doi.org/10.1016/j.ijmedinf.2014.10.001.

[44] K.I. Fischer, D. De Faoite, M. Rose, Patient-reported outcomes feedback report for knee arthroplasty patients should present selective information in a simple design - findings of a qualitative study, Journal of Patient-Reported Outcomes. 4 (2020). https://doi.org/10.1186/s41687-020-0173-7.

[45] L. V. Grossman, S.K. Feiner, E.G. Mitchell, R.M. Masterson Creber, Leveraging Patient-Reported Outcomes Using Data Visualization, Applied Clinical Informatics. 9 (2018) 565–575. https://doi.org/10.1055/s-0038-1667041.

[46] M.R. Turchioe, L. v. Grossman, A.C. Myers, D. Baik, P. Goyal, R.M. Masterson Creber, Visual analogies, not graphs, increase patients' comprehension of changes in their health status, Journal of the American Medical Informatics Association. 27 (2020) 677–689. https://doi.org/10.1093/jamia/ocz217.

[47] E.T. Bantug, T. Coles, K.C. Smith, C.F. Snyder, J. Rouette, M.D. Brundage, Graphical displays of patient-reported outcomes (PRO) for use in clinical practice: What makes a pro picture worth a thousand words?, Patient Education and Counseling. 99 (2016) 483–490. https://doi.org/10.1016/j.pec.2015.10.027.

[48] C.F. Snyder, K.C. Smith, E.T. Bantug, E.E. Tolbert, A.L. Blackford, M.D. Brundage, N.K. Aaronson, P.A. Ganz, R. Garg, F. Michael, V. Hoffman, B.B. Reeve, E. Stotsky-Himelfarb, E. Stovall, M. Zachary, What do these scores mean? Presenting patient-reported outcomes data to patients and clinicians to improve interpretability, Cancer. 123 (2017) 1848–1859. https://doi.org/10.1002/cncr.30530.

[49] A. Weel, M. Kok, D. Lopes Barreto, Better Experiences for Inflammatory Arthritis Patients Through Value-Based Patient Journey, in: N. van Weert, J. Hazelzet (Eds.), Personalized Specialty Care: Value-Based Healthcare Frontrunners from the Netherlands, Springer International Publishing, Cham, 2021: pp. 95–100. https://doi.org/10.1007/978-3-030-63746-0_13.

[50] A. Tong, P. Sainsbury, J. Craig, Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups, International Journal for Quality in Healthcare. 19 (2007) 349–357. https://doi.org/10.1093/intqhc/mzm042.

[51] J.E. Sansoni, P. Grootemaat, C. Duncan, Question Prompt Lists in health consultations : A review, Patient Education and Counseling. 98 (2015) 1454–1464. https://doi.org/10.1016/j.pec.2015.05.015.

[52] N. Gobat, P. Kinnersley, J.W. Gregory, M. Robling, What is agenda setting in the clinical encounter ? Consensus from literature review and expert consultation, Patient Education and Counseling. 98 (2015) 822–829. https://doi.org/10.1016/j.pec.2015.03.024.

[53] F. Yang, Data Visualization for Health and Risk Communication, The Handbook of Applied Communication Research. 1 (2020) 222–223. https://doi.org/10.1002/9781119399926.ch13.

[54] E.A.C. Albers, I. Fraterman, I. Walraven, E. Wilthagen, S.B. Schagen, I.M. van der Ploeg, M.W.J.M. Wouters, L. v. van de Poll-Franse, K.M. de Ligt, Visualization formats of patient-reported outcome measures in clinical practice: a systematic review about preferences and interpretation accuracy, Springer International Publishing, 2022. https://doi.org/10.1186/s41687-022-00424-3.

[55] A. Arcia, N. Suero-Tejeda, M.E. Bales, J.A. Merrill, S. Yoon, J. Woollen, S. Bakken, Sometimes more is more: Iterative participatory design of infographics for engagement of community members with varying levels of health literacy, Journal of the American Medical Informatics Association. 23 (2016) 174–183. https://doi.org/10.1093/jamia/ocv079.

[56] C. Charles, A. Gafni, E. Freeman, Implementing shared treatment decision making and treatment decision aids: A cautionary tale, Psicooncologia. 7 (2010) 243–255. https://doi.org/10.5209/rev_PSIC.2010.v7.n2.15870.

[57] Z. Mohd Don, A. Syed, Patient Decision Aids in Doctor-Patient Consultations: Treatment Decision Making on Starting Insulin, Sains Humanika. 9 (2017). https://doi.org/10.11113/sh.v9n4-2.1365.

[58] K.D. Wyatt, M.E. Branda, R.T. Anderson, L.J. Pencille, V.M. Montori, E.P. Hess, H.H. Ting, A. LeBlanc, Peering into the black box: A meta-analysis of how clinicians use decision aids during clinical encounters, Implementation Science. 9 (2014) 1–10. https://doi.org/10.1186/1748-5908-9-26.

[59] C. Rathert, J.N. Mittler, S. Banerjee, J. McDaniel, Patient-centered communication in the era of electronic health records: What does the evidence say?, Patient Education and Counseling. 100 (2017) 50–64. https://doi.org/10.1016/j.pec.2016.07.031.

[60] B.J. Powell, T.J. Waltz, M.J. Chinman, L.J. Damschroder, J.L. Smith, M.M. Matthieu, E.K. Proctor, J.A.E. Kirchner, A refined compilation of implementation strategies: Results from the Expert Recommendations for Implementing Change (ERIC) project, Implementation Science. 10 (2015) 1–14. https://doi.org/10.1186/s13012-015-0209-1.

[61] M. Boyce, J. Browne, J. Greenhalgh, The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research., BMJ Quality and Safety. 23 (2014) 508–518.

[62] D. Morgan, Focus groups, Annu Rev Sociol. 22 (1996) 129–52. https://doi.org/10.1002/9781118339893.wbeccp225.

[63] J.R. Lewis, Sample sizes for usability studies: Additional considerations, Human Factors. 36 (1994) 368–378. https://doi.org/10.1177/001872089403600215.

[64] C.B. Terwee, L.D. Roorda, H.C.W. de Vet, J. Dekker, R. Westhovens, J. van Leeuwen, D. Cella, H. Correia, B. Arnold, B. Perez, M. Boers, Dutch-Flemish translation of 17 item banks from the Patient-Reported Outcomes Measurement Information System (PROMIS), Quality of Life Research. 23 (2014) 1733–1741. https://doi.org/10.1007/s11136-013-0611-6.

[65] S.D. Weisbord, L.F. Fried, R.M. Arnold, A.J. Rotondi, M.J. Fine, D.J. Levenson, G.E. Switzer, Development of a symptom assessment instrument for chronic hemodialysis patients: The dialysis symptom index, Journal of Pain and Symptom Management. 27 (2004) 226–240. https://doi.org/10.1016/j.jpainsymman.2003.07.004.

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

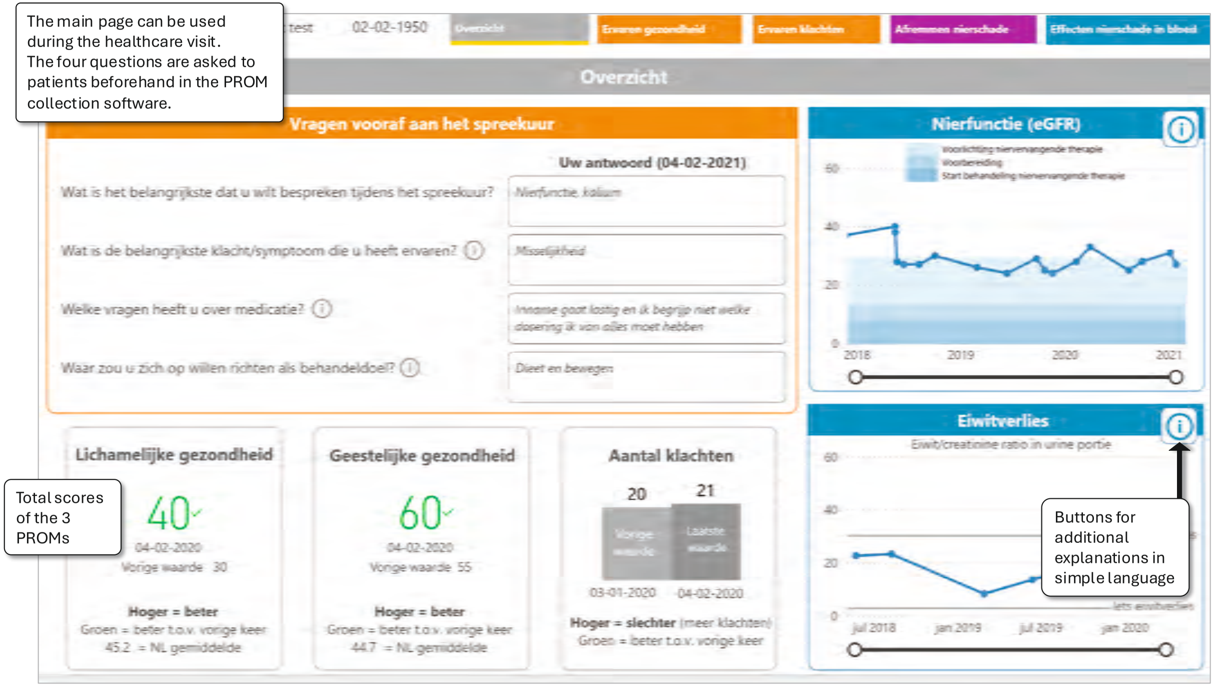
Welkom op "**Mijn nier overzicht**". Dit dashboard is bedoeld voor mensen met een matig tot ernstig afgenomen nierfunctie. Dit dashboard geeft een overzicht van hoe het met uw gezondheid en uw nieren gaat. Samen met uw zorgverleners kunt u met behulp van het dashboard bespreken hoe uw nierfunctie zo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

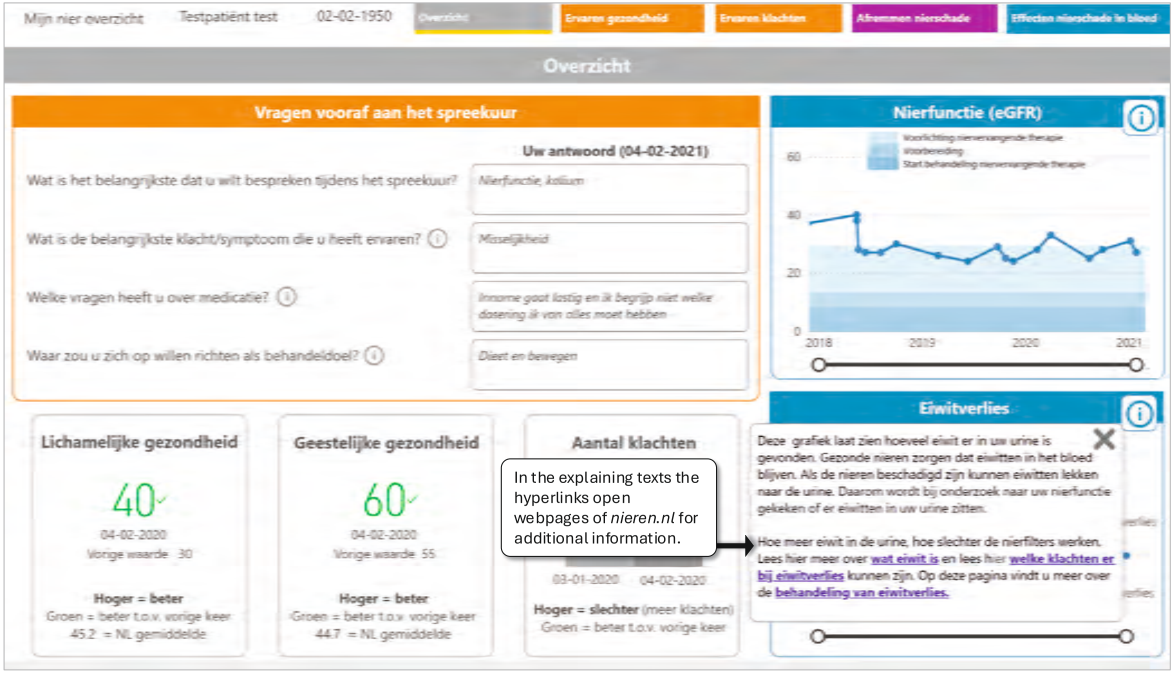
Vragen vooraf aan het spreekuur

	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 21
03-01-2020 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? ⓘ	*Innome 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

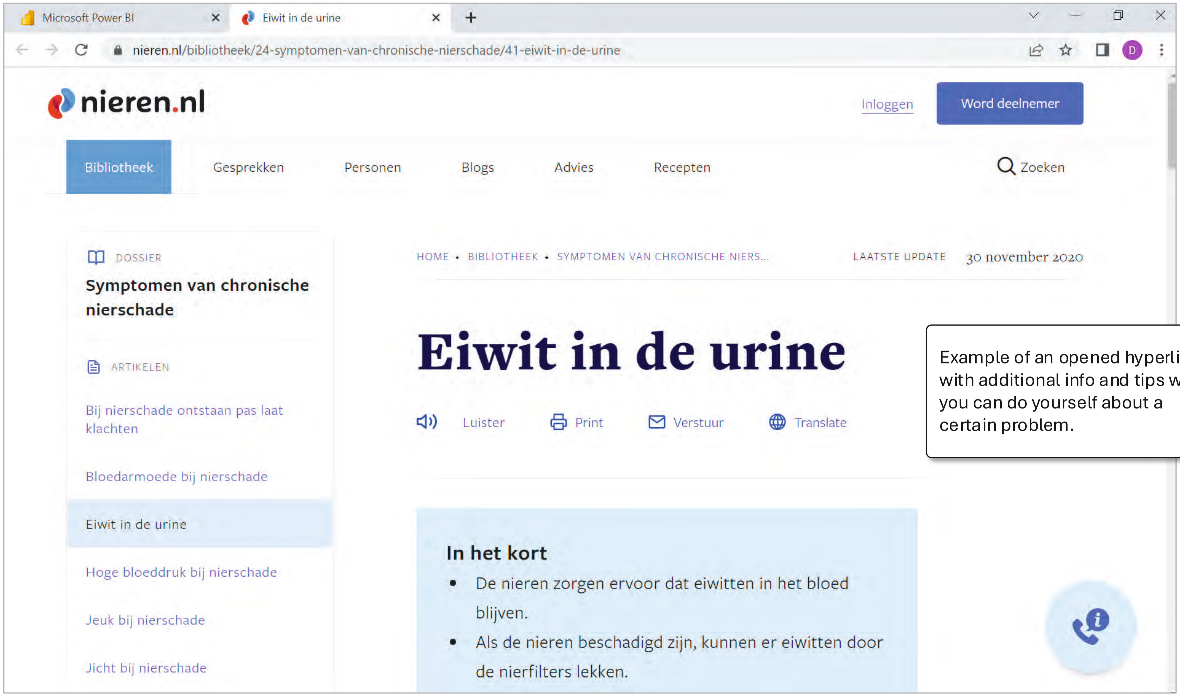
Hoger = slechter (meer klachten)

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.



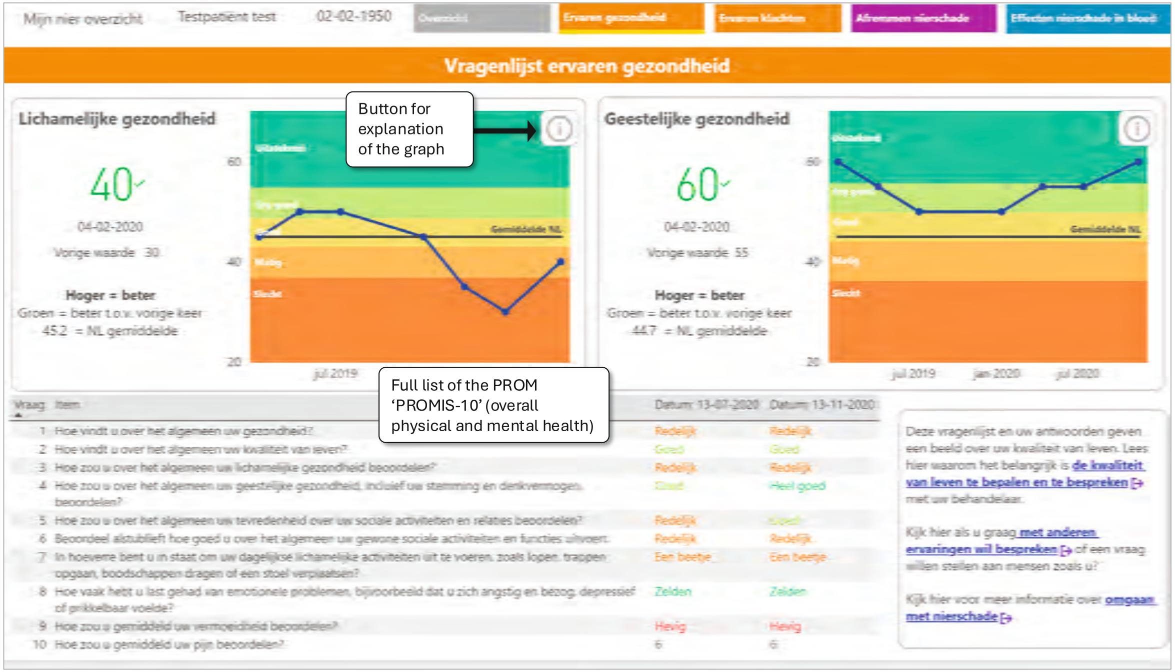
Symptomen van chronische nierschade

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.



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

Button for explanation of the graph

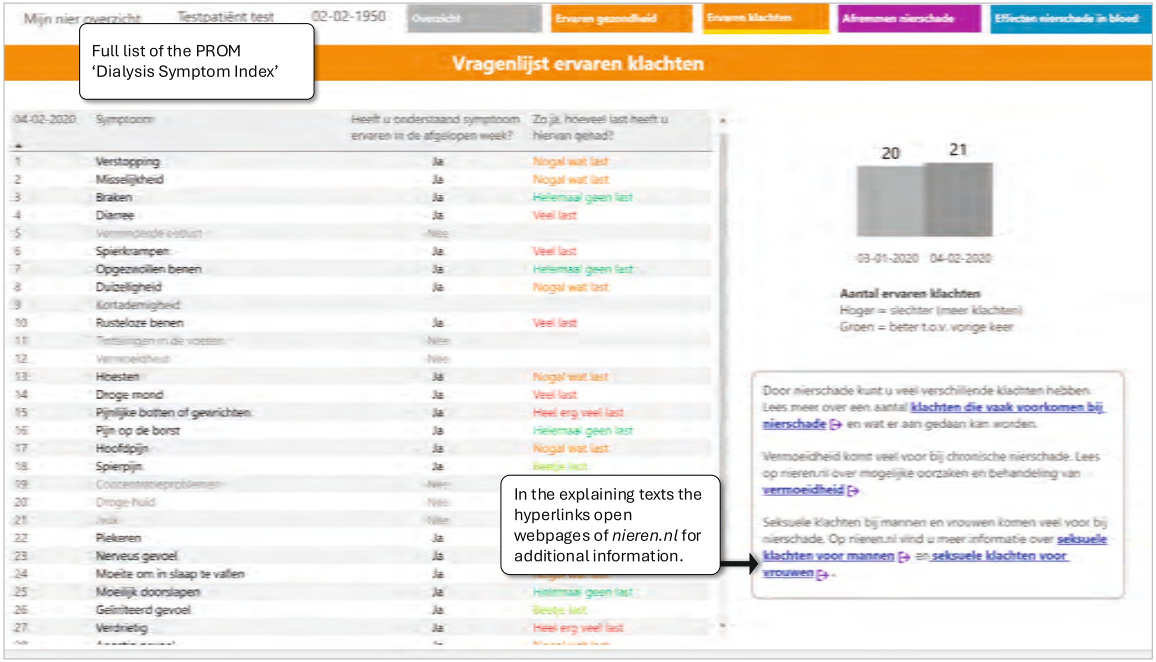
Full list of the PROM 'PROMIS-10' (overall physical and mental health)

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

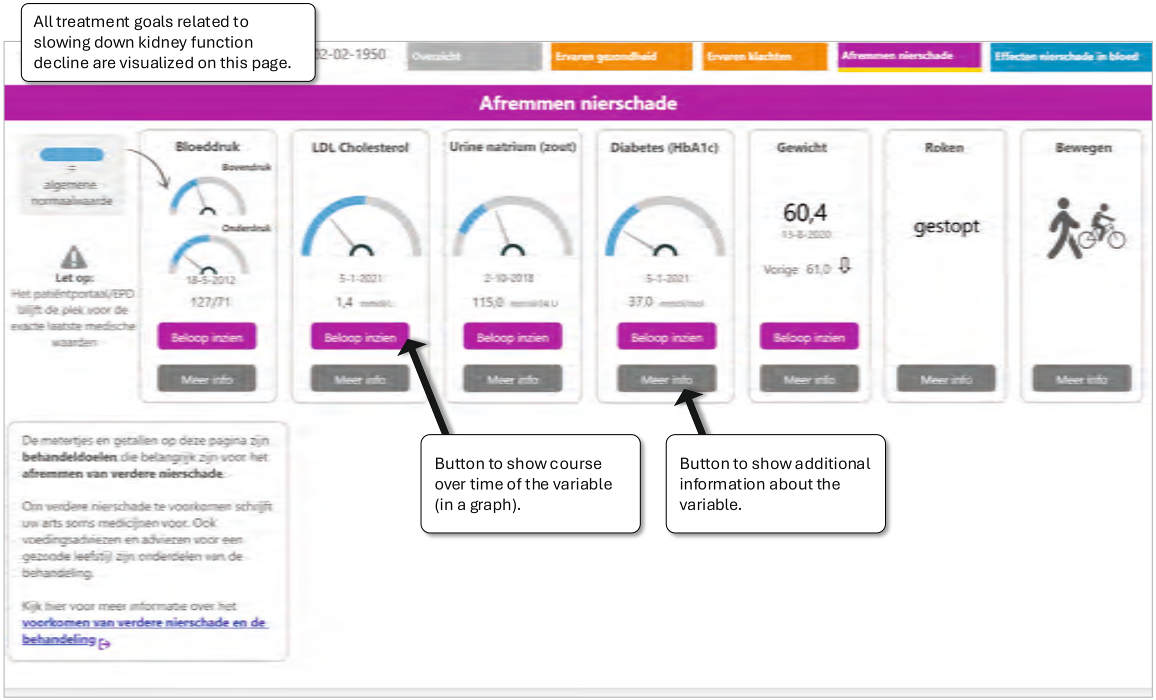
Aantal ervaren klachten
Hoger = slechter (meer klachten)
Groen = beter t.o.v. vorige keer

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**.

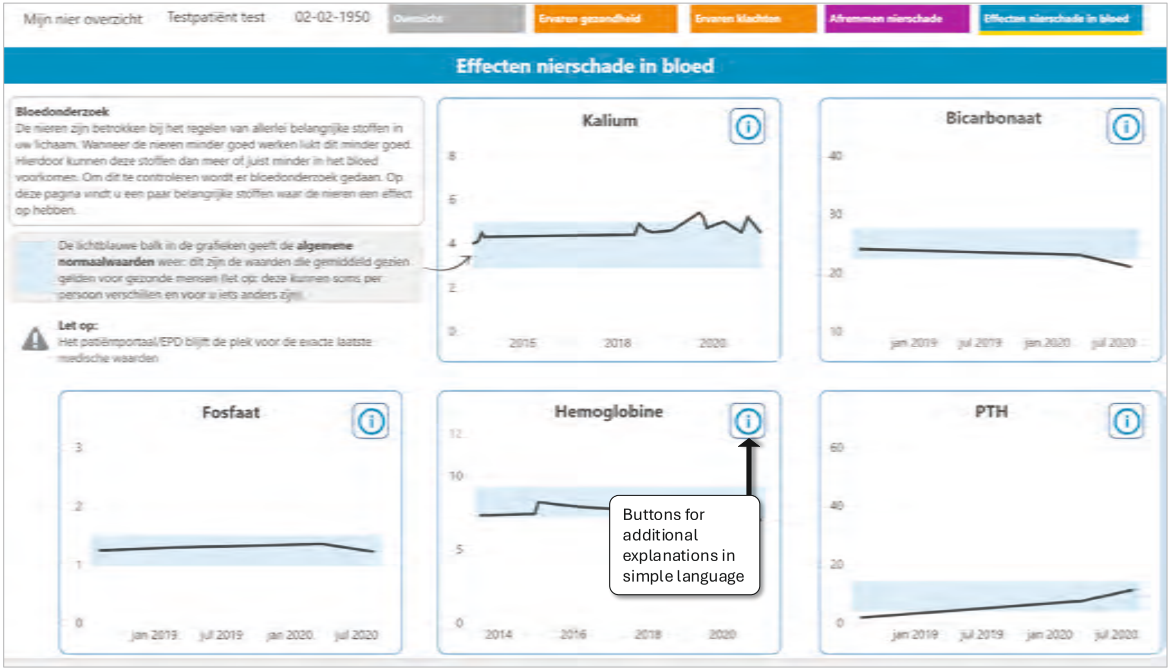
Om verdere nierschade te voorkomen schrijft uw arts soms medicijnen voor. Ook voedingsadviezen en adviezen voor een gezonde leefstijl zijn onderdelen van de behandeling.

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.



Effecten nierschade in bloed

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

Buttons for additional explanations in simple language

7

Visualizing outcome information to support the patient-clinician conversation in outpatient Chronic Kidney Disease care – an evaluation study

Dorinde. E.M. van der Horst
Cornelia F. van Uden-Kraan
Iris J.A.M. Verberk-Jonkers
Marinus A. van den Dorpel
Arwen H. Pieterse
Willem Jan W. Bos

Submitted

This chapter is currently being updated in the review process with modifications.

Abstract

Objective

Effective patient-clinician communication is crucial for patient commitment to therapy, particularly in in chronic kidney disease (CKD) to prevent further kidney function decline. This study evaluates the impact of a CKD dashboard designed to enhance information exchange during healthcare visits by visualizing clinical and patient-reported outcomes. We assessed its effects on patient activation and shared decision making (SDM).

Methods

We conducted a prospective, multiple-methods pre-post study in two Dutch teaching hospitals (January 2021–June 2022). The dashboard was implemented in the intervention hospital, while the control hospital provided usual care. Data collection included patient surveys and audio-recordings of healthcare visits at three time points: pre-implementation (T0), post-implementation (T1), and one year after implementation (T2). The primary outcome was patient activation, assessed using the Patient Activation Measure (PAM), range 0-100. Secondary outcomes included SDM, range 0-24, motivational interviewing (MI), and patient-reported experiences of care.

Results

In total, 126 patients participated. The mean PAM score at T0 was 56.6 in the intervention hospital, with no significant changes at T1 or T2, nor compared to the control hospital. Secondary outcomes showed similar results. 247 decisions were analyzed from 193 audio-recorded visits, with no significant change in median SDM scores between T0 (4.5) and T1 (6.0). The dashboard encouraged discussion of under-addressed topics, such as mental and sexual health, without neglecting other CKD-related issues. Patients expressed satisfaction with the information provided.

Conclusion

Although patient activation and SDM levels did not change, the dashboard facilitated broader discussions, contributing to actionable outcomes.

Practice implications

Beneficial effects of the dashboard are likely to increase when it is embedded in routine care and available for patients at home. Future research should focus on improving dashboard usability, ensuring accessibility, and exploring its potential in other chronic conditions.

Trial Registration

NCT05931978

1. Introduction

Patients with Chronic Kidney Disease (CKD) face numerous decisions[1], primarily centred on slowing kidney function decline. The overarching treatment goal is to delay or prevent progression to end-stage kidney disease (ESKD), at which point kidney replacement therapy (KRT) (e.g. dialysis or kidney transplantation) is needed [2], [3]. Decisions related to this treatment goal involve long-term medication use and lifestyle interventions that significantly impact patients' daily life[4]. Implementing these decisions and acquiring effective CKD management requires strong patient commitment, or 'patient activation' [5]. Patient activation is 'the level to which patients have the knowledge, skills, and confidence to manage their own health'[6]. In particular in earlier CKD phases, when much is to be gained in preventing further kidney function decline, patient activation levels are reported to be low[7], [8].

Enhancing patient involvement in CKD-related decisions may improve patient activation and treatment effectiveness. Communication approaches such as Shared Decision Making (SDM) and Motivational Interviewing (MI) can facilitate greater patient engagement. SDM is a collaborative process in which patients and clinicians work together to determine care that aligns with patient preferences and individual circumstances. It involves exchanging information about available options and exploring the patients' values and preferences[9], [10], [11], ultimately fostering commitment to treatment decisions[12]. MI, on the other hand, is a communication approach designed to elicit patients' personal motivation and commitment to change, making it particularly relevant for decisions that involve behavioural changes[13], [14].

Effective information exchange between patients and clinicians is essential for SDM and MI. The information exchange during healthcare visits includes both clinical outcomes (physiological outcomes (e.g., blood pressure measurements, kidney function and other lab results) and patient-reported outcomes (PROs). PROs measured using Patient Reported Outcome Measures (PROMs)[15], systematically assess patients' disease specific symptoms (e.g., dialysis symptom index)[16] or general quality of life (e.g., PROMIS-10 global health scale)[17]. However, current information exchange in routine CKD care remains suboptimal. Patients often report that CKD-related information is insufficient, difficult to understand or not personalized[18]. Additionally, information conveyed verbally during healthcare visits can be difficult to process and retain[19]. While PROMs facilitate the expression of patients perspectives and help clinicians address symptoms and concerns[20], they are not yet routinely integrated into CKD care.

To improve the information exchange during healthcare visits, a CKD dashboard was developed to visualize patient outcomes and support SDM and MI and ultimately patient activation levels. The dashboard presents patients' clinical outcomes, PROs and treatment goals. It was designed to be used during the patient-clinician conversation, and allows patients to review the information at home after the healthcare visit. This study aimed to evaluate the impact of the CKD dashboard on patient activation. Secondary objectives included its effects on: 1) outcomes related to patient activation (disease insight, medication adherence, patient perceived efficacy during healthcare visits), 2) patient experiences regarding the level of patient-centredness and decisional role, and 3) observed SDM- and MI levels, as well as the range of topics addressed during healthcare visits.

2. Methods

2.1 Study Design

We conducted a prospective, multiple-methods pre-post study in two large Dutch teaching hospitals from January 2021 until June 2022. The dashboard was implemented in the intervention hospital (Hospital A), while the second hospital B served as the control (**Figure 1**).

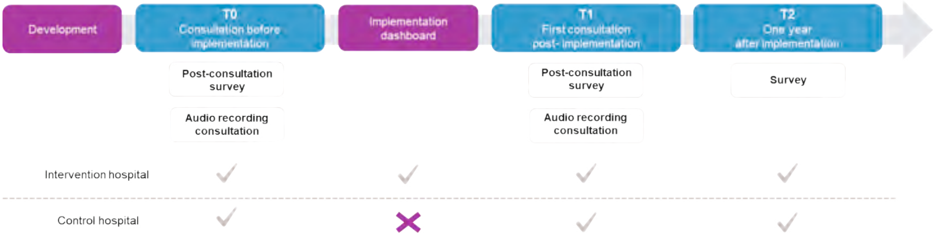


Figure 1. Study design: prospective multiple-method pre-post study

Schematic overview of the prospective study design and data collection methods. At T1, we audio-recorded the patients' first health visit after the date of implementation of the dashboard (7th May 2021) and sent them the second survey.

Data collection included patient surveys and audio recordings of healthcare visits involving clinicians (nephrologists or nurse practitioners) and patients with CKD. We conducted measurements at three consecutive time points (**Figure 1**). Each patient was sent three surveys: one day post-visit before implementation of the dashboard (T0), one day post-visit after implementation (T1) and one year after implementation (T2). Healthcare visits at T0 and T1 were audio-recorded. Patients' baseline preferred and experienced decisional role, as well as baseline observed SDM, have been published previously[1]. The Medical Research Ethics Committees United (MEC-U) approved the study protocol and confirmed that the Medical Research Involving Human Subjects Act did not apply to this study. Trial registration number: NCT05931978

2.2 Participants

Eligible participants included patients with CKD stage 3b-4 who were not yet receiving KRT, had sufficient proficiency in English or Dutch, and were not cognitively impaired. All clinicians providing outpatient CKD care in one of the two hospitals were informed about the study, with one clinician opting out due to logistical reasons. Patients were recruited by their treating clinician. To minimize selection bias, clinicians were asked to approach patients from a predetermined list based on healthcare visit dates. We obtained written informed consent from all participating patients.

Sample size calculations were based on the primary outcome (PAM) with an expected effect size of 0.4 based on earlier research[21], [22], a desired power (beta) of 0.80, a level of significance of 0.05, and a two-sided test. The required sample size was 65, accounting for an anticipated 25% dropout rate.

2.3 The intervention

The dashboard was developed in co-creation with patients and clinicians in collaboration with the Dutch Kidney Patient Federation[23]. Its theoretical foundation and development process with clinicians and patients have been published elsewhere[23]. **Figure 2** presents screenshots of the CKD dashboard, an interactive webpage visualizing individual patient clinical outcomes (retrieved from the Electronic Health Record, EHR) and PROs (collected by PROMs). The dashboard consists of multiple pages and interactive buttons, allowing clinicians and patients to access patient outcomes, track progress over time, and explore additional background information. It also includes hyperlinks to an informative website by the Dutch Kidney Patient Federation. The dashboard was designed for use during CKD healthcare visits and to be accessible to patients at home afterwards. However, at the time of the study, a real-time interactive version of the dashboard was not yet accessible at home. Instead, patients received a PDF-version containing the same information and hyperlinks. Dashboard implementation included a training for clinicians on accessing the dashboard in the EHR integrating it into patient visits. Training also provided examples of how to use the dashboard to support SDM and MI. A test version of the dashboard was made available for clinicians to explore its content. Notably, post-implementation healthcare visits in hospital A were scheduled 10 minutes longer than usual.

Figure 2. The CKD dashboard: screenshots and content

The images are screenshots of three of the five pages of the CKD dashboard, translated from Dutch and containing data of a non-existing patient. The dashboard consists of individual patient information visualized over time, including experienced health and treatment goals related to slowing down CKD progression. Data sources are the EHR and software collecting PROMS. The dashboard is built such that it reveals explanatory texts or graphs when clicking on the relevant buttons. Throughout the dashboard, hyperlinks can be found per topic, forwarding to the kidney patient association´s informative website 'nieren.nl'. HCPs can directly open the dashboard through a link in the patients' EHR.

The dashboard is aimed to be used during the conversation between patients and clinicians in the CKD health visit.

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

1. *What is the most important issue you want to discuss during the health visit?*
2. *What is the most important symptom you have experienced?*
3. *Which questions do you have regarding your medication?*
4. *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)*

(2) *PROMIS-10: a generic PROM from the PROMIS Health Organization assessing both overall mental and physical health*

(3) *Dialysis Symptom Index is a PROM for assessing symptoms related to a reduced kidney function.*

(4) *The variable physical activity does not contain patient data. It includes only explanatory texts and tips to improve physical activity.*

2.4 Patient survey

Demographic and clinical data, including age, CKD etiology, comorbidities, and duration of CKD care, were extracted from the EHR. Health literacy was assessed using the three-item set of brief screening questions (SBSQ)[24]. The primary outcome, patient activation, was measured using 13-item Patient Activation Measure (PAM), which evaluates knowledge, skills and confidence in self-management[6]. PAM scores range from 0-100 with higher scores indicate greater activation. Patient perceived self-efficacy to interact with clinicians was assessed using the 10-item Perceived Efficacy in Patient-Physician Interactions (PEPPI)[25], [26]. Disease insight was measured using three items on self-reported disease knowledge and kidney function recall. Correct recall was defined as values within a margin of error of two points in ml/min from values recorded in patients' EHR. Medication adherence was measured with the five-item Medication Adherence Report Scale (MARS)[27]. Patient experience with the healthcare visit were evaluated at baseline and at T1 with the 18-item Revised Patient Perception of Patient-Centeredness (PPPC-R)[28], and the Control Preferences Scale (CPS), assessing patients' experienced role in the decision[29]. In hospital A, patients' opinions regarding the content of the dashboard were collected using the Satisfaction with Cancer Information Profile (SCIP)-B items 1,3,4,6,7[30] with scores ranging from 5-25 (higher indicating greater satisfaction). Additionally, these patients were asked to report how helpful the dashboard was in preparing for the visit and informing them during the healthcare visit.

2.5 Audio-recordings of healthcare visits

Audio-recordings of healthcare visits were analysed to assess levels of SDM, MI, and topics addressed. Level of SDM was measured using the 4SDM coding instrument (**Supplement 1**), which assigns a 0-24 score based on observed clinician and patient SDM behaviours[9]. When multiple decisions were observed in one healthcare visit, the two most prominently discussed decisions were coded. MI-related clinician behaviour was coded when a behavioural change goal was explicitly discussed, using the Motivational Interviewing Treatment Integrity (MITI) instrument. The MITI provides global scores of relational and technical components of the MI process (scale 1-5) (**Supplement 1**). Global ratings >3.5 are considered sufficient for the relational component, and >3 for the technical component[31]. Topics addressed during visits were coded using a pre-defined list that was based on possible symptoms (according to the Dialysis Symptom Index[16]), CKD-related physiological outcomes, functional status, and quality of life. Two coders (DH and NH) coded two-thirds of the audio-recordings directly from audiotape in consensus. In case of disagreement, AP was consulted. For the final third, NH coded while DH verified. Lastly, to assess proper dashboard use, coders determined whether clinicians: 1) showed the dashboard to patients, 2) set an agenda what topics of the dashboard to discuss and whether they did this collaboratively or not, and 3) engaged in thorough discussion of patient outcomes occurred (e.g., probing further with questions).

2.6 Analysis

Data were managed using Redcap and analysed using SPSS statistics 27. Depending on distribution, data are presented as mean and standard deviation (SD) or median and interquartile range (IQR). Baseline characteristics were compared with non-parametric tests (Chi-square, Fischer's Exact, or Mann Whitney U tests). We used non-parametric tests to compare absolute scores on the primary outcome between time points and between hospitals. In case of missing data on one or two items of the PAM, data were imputed based on the mean for that patient.

3. Results

3.1 Participants´ characteristics

Sixty-five patients were included in each hospital. For different reasons, four patients left the study before the first measurement (N=126; see flow charts in **Supplement 2**). **Table 1** shows the patients' and clinicians' characteristics. Patients' median age was 71 and 74 years in hospital A and B, respectively.

Table 1. Participant characteristics.

Patient characteristics (N=126)	*Hospital A (intervention)*	*Hospital B (control)*	*P-value*
Sex (male), n (%) [1]	36 (59.0%)	40 (61.5%)	0.77
Age, median years (IQR) [1]	71.0 (61.0-76.5)	74.0 (63.5-79.0)	0.25
Number of years since first visit nephrologist, median (IQR) [1]	6.00 (2.5-8.5)	6.00 (3.0-10.0)	1.0
SBSQ score, median (IQR)	4.67 (4.0-5.0)	4.33 (4.0-5.0)	0.75
Education level, n (%)			0.08
Low (ISCED [2] levels 0-2)	27 (46.6%)	25 (41.0%)	
Medium (ISCED levels 3-4)	22 (37.9%)	16 (26.2%)	
High (ISCED levels 5-8)	9 (15.5%)	20 (32.8%)	
Aetiology of CKD [1]			
Hypertension/vascular disease	23 (37.7%)	32 (49.2%)	0.19
Diabetes (with or without vascular disease)	15 (24.6%)	6 (9.2%)	0.02
Glomerulonephritis	6 (9.8%)	10 (15.4%)	0.35
Unknown	3 (4.9%)	6 (9.2%)	0.49
Polycystic kidney disease	2 (3.3%)	4 (6.2%)	0.68

Table 1. *(Continued)*

Patient characteristics (N=126)	*Hospital A (intervention)*	*Hospital B (control)*	*P-value*
Obstructive kidney disease	4 (6.6%)	3 (4.6%)	0.71
Prerenal (heart failure)	1 (1.6%)	1 (1.5%)	1.0
Other[3]	7 (11.5%)	3 (4.6%)	0.20
Comorbidities[1,4], n (%)			
Myocardial infarction	15 (24.6%)	16 (24.6%)	1.0
Diabetes with chronic complication	22 (36.1%)	7 (10.8%)	< 0.001
Peripheral vascular disease	9 (14.8%)	18 (27.7%)	0.08
Any malignancy without metastasis	12 (19.7%)	14 (21.5%)	0.80
Rheumatic disease	13 (21.3%)	7 (10.8%)	0.11
Chronic pulmonary disease	8 (13.1%)	7 (10.8%)	0.69
Diabetes without chronic complication	2 (3.3%)	9 (13.8%)	0.04
Cerebrovascular disease	4 (6.6%)	6 (9.2%)	0.75
Congestive heart failure	5 (8.2%)	5 (7.7%)	1.0
Leukaemia	3 (4.9%)	1 (1.5%)	0.35
Metastatic solid tumour	3 (4.9%)	0	0.11
Peptic Ulcer disease	1 (1.6%)	1 (1.5%)	1.0
Clinician characteristics (n=14)			
Age, median years (IQR)	49 (18.3)		
Sex (male), n (%)	8 (57.1%)		
Function			
Nephrologist	13 (92.8%)		
Nurse practitioner	1 (7.1%)		
Years of experience in current position			
0-5 years	2 (14.3%)		
6-10 years	4 (28.6%)		
11-15 years	3 (21.4%)		
>15 years	5 (35.7%)		

IQR = Interquartile range, SBSQ = Set of Brief Screening Questions (self-report health literacy measure), CKD=Chronic Kidney Disease

[1] *Extracted from electronic health records*

[2] *ISCED = International Standard Classification of Education framework*

[3] *Other = monokidney, repeated urinary infections, prerenal (heart failure), nephrotoxic medication, nephroptosis, myeloma cast nephropathy, acute tubular necrosis (due to sepsis)*

Table 2. Patient Activation Measure and related outcomes

	Hospital A (intervention)						Hospital B (control)					
	n	T0	n	T1	n	T2	n	T0	n	T1	n	T2
Primary outcome												
PAM, *M*	57	**56.6**	56	**56.6**	46	**56.2**	64	**58.8**	58	**57.4**	55	**57.0**
(SD)		(8.8)		(15.2)		(11.3)		(11.8)		(12.9)		(12.9)
Δ time points				ΔT0-T1 = 0		ΔT0-T2 = -0.4				ΔT0-T1 = -1.4		ΔT0-T2 = -1.8
95% CI p-value				-4.0-2.9, 0.75		-4.0-2.2, 0.56				-2.1-4.8, 0.45		-0.8-4.3, 0.18
Δ hospitals in ΔT0-T1 =1.86, 95% CI =-3.0-6.7		*P*=0.447										
Δ hospitals in ΔT0-T2 = 2.67, 95% CI = -1.3-6.7		*P*=0.187										
Secondary outcomes												
PEPPI, *Md*	58	**40.0**	54	**40.0**	39	**40.0**	64	**40.0**	59	**40.0**	52	**40.0**
(IQR)		(38.8-40.0)		(36.8-41.0)		(33.0-40.0)		(40.0-43.8)		(40.0-44.0)		(40.0-41.0)
Medication adherence, *Md*	54	**24.0**	53	**24.0**	45	**24.0**	64	**24.0**	57	**25.0**	55	**24.0**
(IQR)		(22.8-25.0)		(23.0-25.0)		(23.0-25.0)		(23.0-25.0)		(22.5-25.0)		(23.0-25.0)
Disease insight, *M*	57	**10.8**	54	**11.0**	46	**10.8**	62	**11.5**	58	**11.6**	54	**11.3**
(SD)		(2.7)		(2.8)		(2.6)		(2.2)		(2.3)		(2.3)
Patient centeredness, *M*	51	**59.0**	48	**59.0**	37	**58.0**	58	**61.5**	53	**62.0**	44	**61.0**
(SD)		(50.0-66.0)		(51.3-67.0)		(46.0-61.5)		(53.0-68.3)		(55.0-68.0)		(53.8-65.0)

M=mean, SD=standard deviation, 95% CI=95% confidence interval, Md=Median, IQR=Interquartile range.

PAM, Patient Activation Measure, range 0-100

PEPPI, Perceived Efficacy in Patient-Physician Interactions, range total score, 10-50

Medication adherence measured with MARS, Medication Adherence Report Scale, range total score, 5-25

Disease insight, range total score, 3-15

Patient-centredness measured with Revised Patient Perception of Patient Centredness, range total score, 18-72

3.2 Effect of the dashboard on patient activation and related outcomes

The mean PAM-scores in both hospitals ranged from 56.6-58.8. No significant differences were found between T0 and T1 or T2 at either hospital (**Table 2**). Outcomes related to patient activation showed no or minimal differences between the different time points at both hospitals (**Table 2**). At both hospitals, most patients correctly recalled their kidney function at T0. A small improvement was observed over time at both hospitals; in hospital A, 33/40 correctly recalled their eGFR at T0 and 27/34 at T1. In hospital B, 34/45 correctly recalled their eGFR at T0 and 33/42 at T1.

3.3 Effect of the dashboard on patient-centeredness and experienced decisional role

In hospital A, 93 healthcare visits were in-person, 17 by telephone and 10 by video-conference. In hospital B, 49 healthcare visits were in-person, 71 by telephone and seven by video-conference. Patient perceived patient-centeredness of the healthcare visits at both hospitals was moderate to high, ranging from 58.0-62.0 and did not significantly change over time (**Table 2**). Patients' experiences of who decided varied between a shared role for patient and clinician, and the clinician mostly or fully deciding (**Figure 3**). In hospital A, experienced decisional role did not change after the dashboard was implemented. In hospital B, decisions were experienced more often as shared at T1 than at T0.

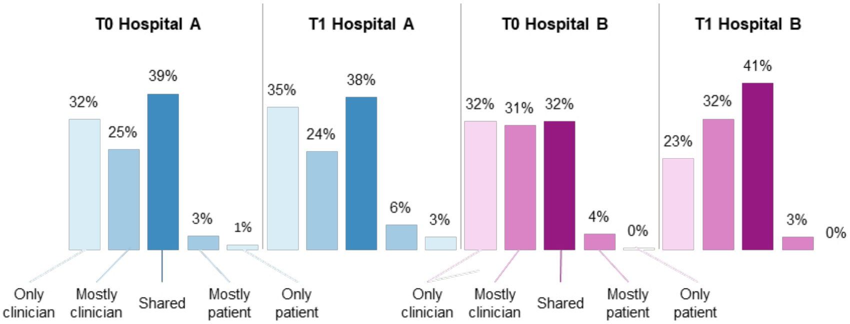


Figure 3. Patients' experienced decisional role as percentage of total number of patient-reported decisions.

Decisional roles: ***only clinician****=the clinician makes the decision alone,* ***mostly clinician****=the clinician makes the decision after seriously considering the patient's opinion,* ***shared****=patient and clinician make the decision together,* ***mostly patient****=the patient makes the decision after seriously considering the clinician's opinion,* ***only patient****=the patient makes the decision alone[29].*

3.4 Effect of the dashboard on SDM, MI and topics addressed during healthcare visits

In total, 193 healthcare visits were successfully recorded. In hospital A at T0 (n=40) the mean duration was 12:06 minutes (range, 01:55-31:10), and at T1 (n=49) 14:59 minutes (range, 04:30 – 42:59). In hospital B the mean duration was 11:03 minutes (range, 02:34-22:19) at T0 (n=53), and 11:25 minutes (range, 02:54-31:16) at T1 (n=51).

3.4.1 SDM

In total (both hospitals), at T0, 118 decisions were coded for level of SDM, and at T1 129. Most decisions were about medication (n=136), planning (n=38), diagnostic tests (n=25), or care transitions such as referrals (n=21). At T0, the median SDM score in both hospitals was low: 4.5 (IQR, 2.0-9.0, hospital A) and 3.5 (IQR, 1.8-7.0, hospital B). At T1, SDM scores were slightly but not significantly higher (+1.5 points in hospital A, *P*=0.915; +3.75 points in hospital B, *P*=0.191). At both time points, SDM scores did not differ significantly between the hospitals (T0, *P*=0.51; T1, *P*=0.31).

3.4.2 Motivational Interviewing

A discussion regarding behavioral change occurred in 15/93 visits at T0 and 12/100 visits at T1. Overall, mean relational and technical global MI scores were low at both hospitals (**Table 3**). At hospital A, the scores were lower at T1 compared to T0; this was not observed at hospital B.

3.4.3 Topics of conversation

Clinical outcomes and topics regarding mental health and lifestyle were more frequently addressed at hospital A after dashboard implementation. Most symptoms were also more frequently discussed at T1, particularly sexual problems, muscle cramps, joint pain, diarrhea, pain, and tiredness. To illustrate, mental problems were addressed with 5 and 10 patients at T0 and T1 respectively; sexual problems with 0 and 4 patients at T0 and T1 respectively. At hospital B, particularly topics regarding physiological measurements and lifestyle were less frequently addressed at T1 compared to T0. **Supplement 3** shows the full list of topics addressed during visits at each hospital.

3.5 How the dashboard was used

The observers identified in 42 of the 49 healthcare visits post implementation that the dashboard was discussed. In 14 visits, the clinician set up an agenda of topics from the dashboard to discuss at the beginning of the visit, and in six out of these 14 visits they did so together with the patient.

In 26/42 visits, the dashboard was used as intended; the dashboard was shown to patients and clarification of the information visualized in the dashboard was provided. Additionally, the patient outcomes were thoroughly discussed instead of merely reported (i.e., by asking the patient additional questions or leaving room for patients to add topics or questions). In 11/42 healthcare visits, the patient's outcomes in the dashboard were briefly reported, but not discussed thoroughly. In 4/42 healthcare visits, the dashboard was shown and its potential use explained in a general way; outcomes for the patient were not addressed. Observations showed that clinicians used the dashboard to: present the different (laboratory) CKD-related outcomes (n=23 visits), communicate the current stage of CKD (n=14), decide or draw attention that a decision is needed (n=12), explain treatment goals (n=8), and/or advice what patients can do themselves to slow down CKD progression (n=3). In 20 visits, actions were observed as a result of discussing the dashboard, including: stopping or changing medication because of side-effects; providing lifestyle advice, in particular losing weight and quit smoking; and discussing possible referral for mental health issues or symptoms not directly related to CKD.

3.6 Patients' experiences with the dashboard

Thirty-three of the 42 patients observed to have discussed the dashboard, reported to have discussed it. Fifteen patients reported that they were able to access the dashboard at home at least once. Mean SCIP-B score was 20 (SD=3.9) (**Figure 4A**). **Figure 4B** presents how helpful the patients considered the dashboard. Most patients agreed that the dashboard helps to: 1) think of questions you want to ask (preparation), 2) find important information about your kidney disease, and 3) get an overview of your disease trajectory.

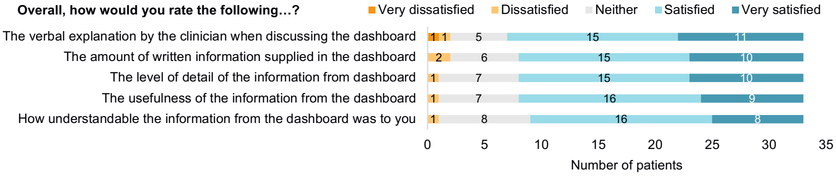


Figure 4 A. Patient satisfaction with the information provided in the dashboard (SCIP-B)

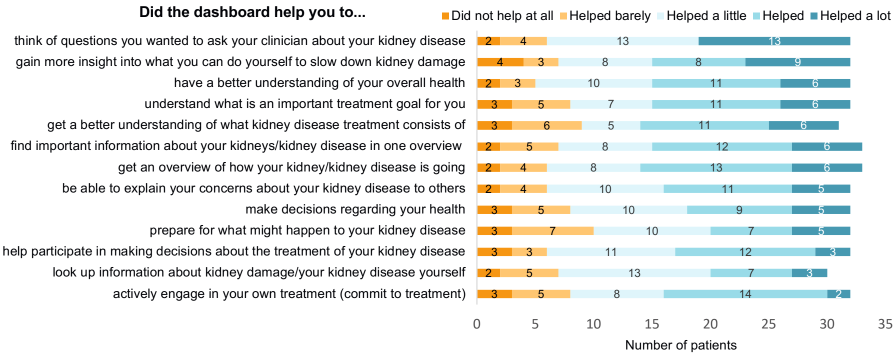


Figure 4 B. Statements* regarding how helpful patients considered the dashboard

** The statements were based on the goals the dashboard should achieve, as formulated by the patients and clinicians members of the working group that developed the dashboard.*

4. Discussion and conclusions

4.1 Discussion

We assessed the impact of a CKD dashboard, designed to enhance the information exchange during healthcare visits by visualizing both clinical and patient-reported outcomes. Patient activation levels and related secondary outcomes showed no significant changes following dashboard implementation, nor did they differ between the intervention and control hospital. Consistent with previous research[7], [8], patient activation levels were low to moderate in both hospitals. Patients' perceived decisional roles and the experienced patient-centeredness of healthcare visits remained largely unchanged post-implementation, with the latter being consistently rated as high. Levels of SDM- and MI were low and did not improve after the dashboard had become available. The persistently low SDM levels suggest a limited familiarity with SDM in common CKD decisions, indicating a need for further improvement.

However, the dashboard influenced the range of topics discussed during healthcare visits. Topics that are often under-addressed in routine care, such as mental health and sexual health concerns, were more frequently discussed in healthcare visits when the dashboard was used. Notably, the increased discussion of these topics did not reduce attention given to other CKD-related concerns; instead, nearly all topics were addressed more frequently in dashboard-supported conversations. Patients responded positively to the dashboard, with the majority expressing satisfaction with the information provided and acknowledging its potential benefits, such as improving their understanding of CKD and enhancing their preparation for healthcare visits through PROM completion.

Several factors may explain the absence of a clear effect on patient activation and related outcomes. First, data collection occurred shortly after implementation due to logistical reasons and time constraints. At T1, the dashboard had been used for the first time, and at T2, most clinicians still had used it infrequently. Adopting a new approach to healthcare visits requires time and practice, and the dashboard was not always used as intended. Audio recordings revealed that when used correctly, the dashboard facilitated in-depth discussions, often leading to actions such as setting a treatment goal together (e.g., smoking cessation) or making treatment decisions (e.g., modifying medication plans based on side effects). Second, due to technical constraints and privacy legislation issues, patients could not easily access the dashboard from home, contrary to initial plans. Both patient and clinician feedback suggested that home access would significantly enhance the dashboard's impact, aligning with prior findings[23]. Third, levels of patient-centeredness and medication adherence were already high at baseline, potentially creating a 'ceiling-effect' for these outcomes and limiting room for measurable improvement.

Despite the lack of a significant effect on patient activation, the dashboard influenced the content of healthcare discussions. Similar to studies regarding the effect of PRO's, the dashboard facilitated conversations abouts sensitive topics[20]. Although challenging to quantify, this effect may be meaningful for individual patients. For example, sexual dysfunction - highly prevalent (around 70%) among CKD patients[32] but often overlooked. In the present study, sexual dysfunction was mentioned in the dashboard and when discussed during healthcare visits, it led to treatment modifications, such as adjustment in blood pressure medication.

This study uniquely combined implementation and evaluation, assessing a range of outcomes through both self-reported and observational methods. The inclusion of a control hospital allowed us to account for potential learning effects in survey responses. However, several limitations must be acknowledged. First, while clinicians were instructed to recruit patients from a predefined list to minimize selection bias, they still had a large role in the selection process. Second, some patients had difficulty recalling whether the dashboard had been discussed during their visits implying recall bias. Second, the sample size was smaller than aimed for, due to a larger dropout than expected in the intervention hospital. Third, reflexivity issues need to be mentioned. WB and MD, both participating clinicians in one of the two hospitals, were also part of the research team. Their recorded healthcare visits may not resemble the general population of clinicians less familiar with SDM. Further, SDM trainings had been provided in the months prior to the start of the study at both hospitals focusing on the KRT decision (not on routine CKD care decisions as subject in this study). Fourth, although patients co-developed the dashboard with clinicians and the research team[23], they were not actively involved in conducting the study. Lastly, a number of healthcare visits were conducted by telephone due to COVID-19 restrictions. However, a sensitivity analysis comparing in-person versus mediated (video or telephone) visits did not show significant differences in patient activation or related outcomes.

4.2 Practice implications

Visualizing outcomes by using a dashboard can optimize CKD healthcare visits. To fully integrate the dashboard into CKD care, practical barriers—such as IT security concerns limiting home access—must be addressed. Future studies may assess the dashboard's long-term impact following complete implementation. More importantly, qualitative evaluations of clinician and patient user experiences of the dashboard are needed for refining the dashboard. These evaluations should also explore strategies to enhance accessibility for patients with low literacy or language barriers. Ultimately, the CKD dashboard can be used as a format for other chronic conditions as well.

4.3 Conclusion

We found no evidence that implementing a CKD dashboard improved patient activation or enhanced SDM- or MI-levels during healthcare visits. However, the dashboard positively influenced information exchange, with patients appreciating the information provided. Audio-recorded healthcare visits showed that the dashboard introduced changes in the topics addressed, which created value for individual patients when their treatment was adjusted accordingly. Visually presenting individual outcomes using the dashboard may shed more light on patient problems and preferences, which may be otherwise left undiscussed. The CKD dashboard could have a larger impact if optimally embedded in the kidney care trajectory and when patients can (easily) access it from home.

References

[1] D. E. M. van der Horst *et al.*, "Shared Decision Making in Healthcare Visits for CKD: Patients' Decisional Role Preferences and Experiences," *Am. J. Kidney Dis.*, vol. 82, no. 6, pp. 677–686, 2023, doi: 10.1053/j.ajkd.2023.04.012.

[2] W. G. Couser, G. Remuzzi, S. Mendis, and M. Tonelli, "The contribution of chronic kidney disease to the global burden of major noncommunicable diseases," *Kidney Int.*, vol. 80, no. 12, pp. 1258–1270, 2011, doi: 10.1038/ki.2011.368.

[3] A. S. Levey *et al.*, "Chronic kidney disease as a global public health problem: Approaches and initiatives - A position statement from Kidney Disease Improving Global Outcomes," *Kidney Int.*, vol. 72, no. 3, pp. 247–259, 2007, doi: 10.1038/sj.ki.5002343.

[4] Kidneydisease, "KDIGO 2013 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease," *Off. J. Int. Soc. Nephrol.*, vol. 3, no. 1, 2013, [Online]. Available: https://kdigo.org/wp-content/uploads/2017/02/KDIGO_2012_CKD_GL.pdf.

[5] A. Bonner, K. Havas, C. Douglas, T. Thepha, P. Bennett, and R. Clark, "Self-management programmes in stages 1-4 chronic kidney disease: A literature review," *J. Ren. Care*, vol. 40, no. 3, pp. 194–204, 2014, doi: 10.1111/jorc.12058.

[6] J. H. Hibbard, J. Stockard, E. R. Mahoney, and M. Tusler, "Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers," *Health Serv. Res.*, vol. 39, no. 4 I, pp. 1005–1026, 2004, doi: 10.1111/j.1475-6773.2004.00269.x.

[7] D. Nair and K. L. Cavanaugh, "Measuring patient activation as part of kidney disease policy: Are we there yet?," *J. Am. Soc. Nephrol.*, vol. 31, no. 7, pp. 1435–1443, 2020, doi: 10.1681/ASN.2019121331.

[8] T. J. Wilkinson, K. Memory, C. J. Lightfoot, J. Palmer, and A. C. Smith, "Determinants of patient activation and its association with cardiovascular disease risk in chronic kidney disease: A cross-sectional study," *Heal. Expect.*, no. January, pp. 843–852, 2021, doi: 10.1111/hex.13225.

[9] A. M. Stiggelbout, A. H. Pieterse, and J. C. J. M. De Haes, "Shared decision making: Concepts, evidence, and practice," *Patient Educ. Couns.*, vol. 98, no. 10, pp. 1172–1179, 2015, doi: 10.1016/j.pec.2015.06.022.

[10] H. Bomhof-Roordink, F. R. Gärtner, A. M. Stiggelbout, and A. H. Pieterse, "Key components of shared decision making models: A systematic review," *BMJ Open*, vol. 9, no. 12. BMJ Publishing Group, Dec. 17, 2019, doi: 10.1136/bmjopen-2019-031763.

[11] G. Elwyn *et al.*, "A three-talk model for shared decision making: Multistage consultation process," *BMJ*, vol. 359, 2017, doi: 10.1136/bmj.j4891.

[12] D. E. M. van der Horst, M. M. Garvelink, W. J. W. Bos, A. M. Stiggelbout, and A. H. Pieterse, "For which decisions is Shared Decision Making considered appropriate? – a systematic review," *Patient Educ. Couns.*, no. September, 2022, doi: 10.1016/j.pec.2022.09.015.

[13] W. Miller and S. Rollnick, *Motivational interviewing: Helping people change.*, Third. The Guilford Press, 2013.

[14] G. Elwyn, C. Dehlendorf, R. M. Epstein, K. Marrin, J. White, and D. L. Frosch, "Shared decision making and motivational interviewing: Achieving patient-centered care across the spectrum of healthcare problems," *Ann. Fam. Med.*, vol. 12, no. 3, pp. 270–275, 2014, doi: 10.1370/afm.1615.

[15] N. Anderson *et al.*, "Electronic patient-reported outcomes in chronic kidney disease," *Nat. Rev. Nephrol.*, vol. 18, no. 12, pp. 739–740, 2022, doi: 10.1038/s41581-022-00619-3.

[16] S. D. Weisbord *et al.*, "Development of a symptom assessment instrument for chronic hemodialysis patients: The dialysis symptom index," *J. Pain Symptom Manage.*, vol. 27, no. 3, pp. 226–240, 2004, doi: 10.1016/j.jpainsymman.2003.07.004.

[17] C. B. Terwee *et al.*, "Dutch-Flemish translation of 17 item banks from the Patient-Reported Outcomes Measurement Information System (PROMIS)," *Qual. Life Res.*, vol. 23, no. 6, pp. 1733–1741, 2014, doi: 10.1007/s11136-013-0611-6.

[18] Y. de Jong *et al.*, "Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies," *BMC Nephrol.*, vol. 22, no. 1, pp. 1–16, 2021, doi: 10.1186/s12882-021-02489-6.

[19] R. P. C. Kessels, "Patients' memory for medical information," *J. R. Soc. Med.*, vol. 96, pp. 219–222, 2003.

[20] J. Greenhalgh *et al.*, "How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis," *J. Patient-Reported Outcomes*, vol. 2, no. 1, 2018, doi: 10.1186/s41687-018-0061-6.

[21] A. S. Schuit *et al.*, "Efficacy and cost-utility of the eHealth application 'Oncokompas', supporting patients with incurable cancer in finding optimal palliative care, tailored to their quality of life and personal preferences: A study protocol of a randomized controlled trial," *BMC Palliat. Care*, vol. 18, no. 1, pp. 1–11, 2019, doi: 10.1186/s12904-019-0468-8.

[22] A. van der Hout *et al.*, "Role of eHealth application Oncokompas in supporting self-management of symptoms and health-related quality of life in cancer survivors: a randomised, controlled trial," *Lancet Oncol.*, vol. 21, no. 1, pp. 80–94, 2020, doi: 10.1016/S1470-2045(19)30675-8.

[23] D. E. M. van der Horst *et al.*, "Optimizing the use of patients' individual outcome information – Development and usability tests of a Chronic Kidney Disease dashboard," *Int. J. Med. Inform.*, vol. 166, no. February, p. 104838, 2022, doi: 10.1016/j.ijmedinf.2022.104838.

[24] L. D. Chew, K. A. Bradley, and E. J. Boyko, "Brief Questions to Identify Patients With Inadequate Health Literacy," *Fam. Med.*, pp. 588–594, 2004, [Online]. Available: https://fammedarchives.blob.core.windows.net/imagesandpdfs/fmhub/fm2004/September/Lisa588.pdf.

[25] R. C. Maly, J. C. Frank, G. N. Marshall, M. R. DiMatteo, and D. B. Reuben, "Perceived Efficacy in Patient-Physician Interactions (PEPPI): Validation of an instrument in older persons," *J. Am. Geriatr. Soc.*, vol. 46, no. 7, pp. 889–894, 1998, doi: 10.1111/j.1532-5415.1998.tb02725.x.

[26] J. Rademakers, J. Nijman, L. Van Der Hoek, M. Heijmans, and M. Rijken, "Measuring patient activation in the Netherlands: Translation and validation of the American short form Patient Activation Measure (PAM13)," *BMC Public Health*, vol. 12, no. 1, p. 1, 2012, doi: 10.1186/1471-2458-12-577.

[27] A. H. Y. Chan, R. Horne, M. Hankins, and C. Chisari, "The Medication Adherence Report Scale: A measurement tool for eliciting patients' reports of nonadherence," *Br. J. Clin. Pharmacol.*, vol. 86, no. 7, pp. 1281–1288, 2019, doi: 10.1111/bcp.14193.

[28] B. L. Ryan, J. B. Brown, P. F. Tremblay, and M. Stewart, "Measuring Patients' Perceptions of Healthcare Encounters: Examining the Factor Structure of the Revised Patient Perception of Patient-Centeredness (PPPC-R) Questionnaire," *J. Patient-Centered Res. Rev.*, vol. 6, no. 3, pp. 192–202, 2019, doi: 10.17294/2330-0698.1696.

[29] L. Degner, J. Sloan, and P. Venkatesh, "The Control Preferences Scale," *Can. J. Nurs. Res.*, vol. 29, no. 3, pp. 21–43, 1997.

[30] M. C. Hankins and C. D. Llewellyn, "Is the Satisfaction with Cancer Information Profile (SCIP) valid for tailoring information for patients with head and neck cancer?," *BMC Cancer*, vol. 8, pp. 1–7, 2008, doi: 10.1186/1471-2407-8-164.

[31] T. B. Moyers, J. K. Manuel, and D. Ernst, “Personal communication: (Motivational interviewing treatment integrity coding manual 4.2.1),” *Unpubl. Man.*, no. June, pp. 1–40, 2014, [Online]. Available: https://casaa.unm.edu/download/miti4_2.pdf.

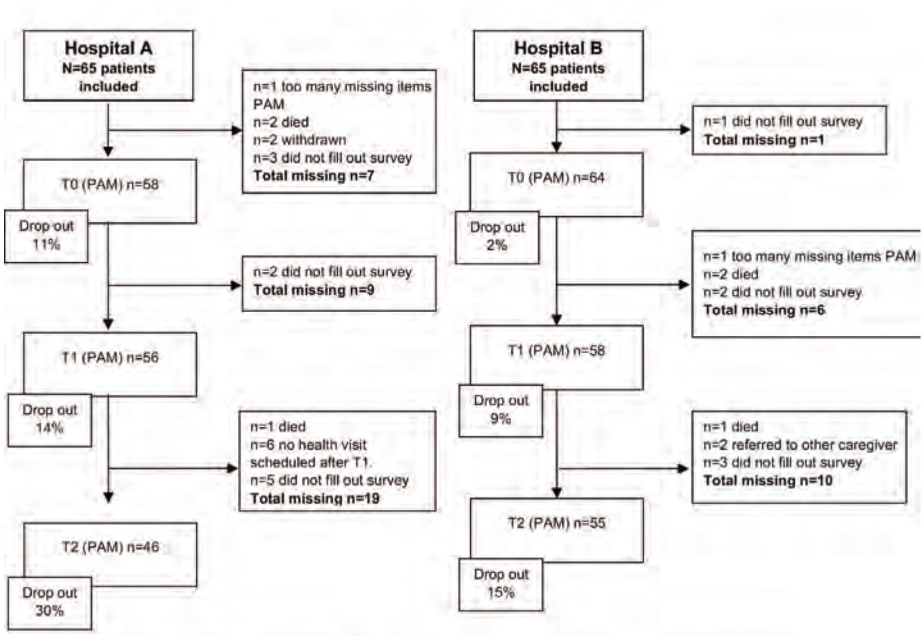
[32] S. D. Navaneethan *et al.*, “Prevalence and correlates of self-reported sexual dysfunction in CKD: A meta-analysis of observational studies,” *Am. J. Kidney Dis.*, vol. 56, no. 4, pp. 670–685, 2010, doi: 10.1053/j.ajkd.2010.06.016.

Supplement 1 – coding items 4SDM and MITI

Steps 4SDM	Items 4 SDM	Did this behavior occur?	Who initiated the behavior?
Step 1: Setting agenda	1. It is stated (or re-affirmed) that a decision about management or treatment needs to be made.	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
	2. It is stated (or re-affirmed) that the decision depends on the values and preferences of the patient.	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
Step 2: Informing about options	3. The available management or treatment options are stated (or re-affirmed).	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
	4. The pros and cons of each option are stated or re-affirmed.	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
Step 3: Exploring	5. The patient states the outcomes that are important to him/her (values).	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
	6. The patient states how s(h)e appraises the (characteristics of) the management or treatment options.	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
Step 4: Making or deferring a decision in agreement	7. The patient expresses or confirms his/her preference or the (provisional) lack of a preference	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician
	8. The moment of making (or deferring) the decision is explicit and decision making occurs in agreement	0 No 1 Minimally 2 Sufficient 3 Good	☐ Patient (or companion) ☐ Clinician

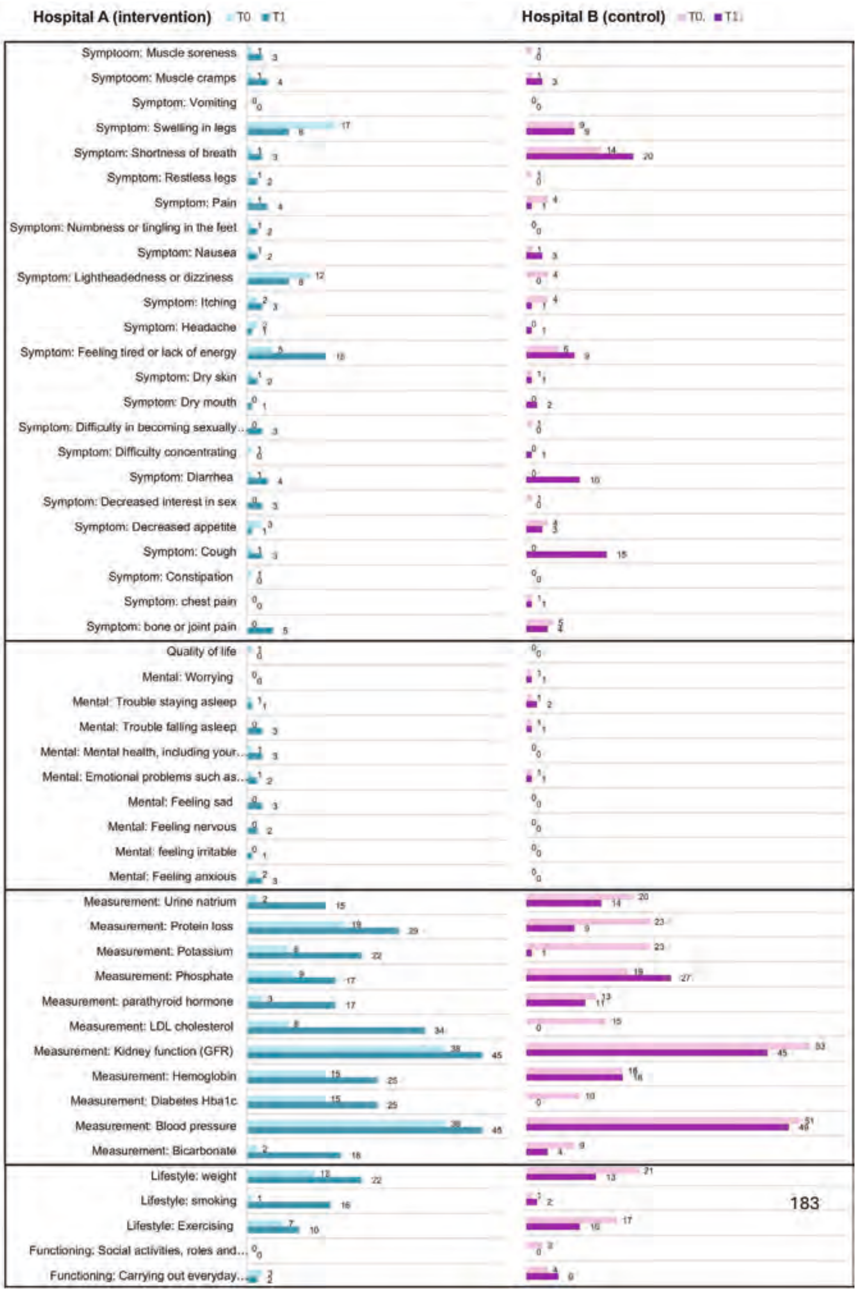
Items Motivational Interviewing Treatment Integrity- global scores	
Cultivating change talk	1 Clinician shows no explicit attention to, or preference for, the client's language in favor of changing.
	2 Clinician sporadically attends to client language in favor of change – frequently misses opportunities to encourage change talk.
	3 Clinician often attends to the client's language in favor of change, but misses some opportunities to encourage change talk.
	4 Clinician consistently attends to the client's language about change and makes efforts to encourage it.
	5 Clinician shows a marked and consistent effort to increase the depth, strength, or momentum of the client's language in favor of change.
Softening sustain talk	1 Clinician consistently responds to the client's language in a manner that facilitates the frequency or depth of arguments in favor of the status quo.
	2 Clinician usually chooses to explore, focus on, or respond to the client's language in favor of the status quo
	3 Clinician gives preference to the client's language in favor of the status quo, but may show some instances of shifting the focus away from sustain talk.
	4 Clinician typically avoids an emphasis on client language favoring the status quo.
	5 Clinician shows a marked and consistent effort to decrease the depth, strength, or momentum of the clients language in favor of the status quo.
Partnership	1 Clinician actively assumes the expert role for the majority of the interaction with the client. Collaboration or partnership is absent.
	2 Clinician superficially responds to opportunities to collaborate
	3 Clinician incorporates client's contributions but does so in a lukewarm or erratic fashion.
	4 Clinician fosters collaboration and power sharing so that client's contributions impact the session in ways that they otherwise would not
	5 Clinician actively fosters and encourages power sharing in the interaction in such a way that client's contributions substantially influence the nature of the session.
Empathy	1 Clinician gives little or no attention to the client's perspective.
	2 Clinician makes sporadic efforts to explore the client's perspective. Clinician's understanding may be inaccurate or may detract from the client's true meaning.
	3 Clinician is actively trying to understand the client's perspective, with modest success.
	4 Clinician makes active and repeated efforts to understand the client's point of view. Shows evidence of accurate understanding of the client's worldview, although mostly limited to explicit content.
	5 Clinician shows evidence of deep understanding of client's point of view, not just for what has been explicitly stated but what the client means but has not yet said.
Calculation global scores: Global scores are assigned on a five-point Likert scale: minimum=1, maximum=5. Relational global score is calculated as (partnership + empathy) / 2 Technical global score is calculated as (cultivating change talk + softening sustain talk) / 2	

Supplement 2 – Flow chart of patients who filled out the PAM (primary outcome).



Hospital A = intervention hospital, Hospital B=control hospital. PAM= Patient Activation Measure, T0=pre-implementation measurements, T1=post-implementation measurements. T2= one year after implementation.

Supplement 3 – Topics addressed during health visits, based on audio-recordings



8

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'*.

References

[1] GBD Chronic Kidney Disease Collaboration, “Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017,” *Lancet*, vol. 395, no. 10225, pp. 709–733, 2020, doi: 10.1016/S0140-6736(20)30045-3.

[2] W. G. Couser, G. Remuzzi, S. Mendis, and M. Tonelli, “The contribution of chronic kidney disease to the global burden of major noncommunicable diseases,” *Kidney Int.*, vol. 80, no. 12, pp. 1258–1270, 2011, doi: 10.1038/ki.2011.368.

[3] Y. de Jong *et al.*, “Person centred care provision and care planning in chronic kidney disease: which outcomes matter? A systematic review and thematic synthesis of qualitative studies,” *BMC Nephrol.*, vol. 22, no. 1, pp. 1–16, 2021, doi: 10.1186/s12882-021-02489-6.

[4] D. Nair and K. L. Cavanaugh, “Measuring patient activation as part of kidney disease policy: Are we there yet?,” *J. Am. Soc. Nephrol.*, vol. 31, no. 7, pp. 1435–1443, 2020, doi: 10.1681/ASN.2019121331.

[5] T. J. Wilkinson, K. Memory, C. J. Lightfoot, J. Palmer, and A. C. Smith, “Determinants of patient activation and its association with cardiovascular disease risk in chronic kidney disease: A cross-sectional study,” *Heal. Expect.*, no. January, pp. 843–852, 2021, doi: 10.1111/hex.13225.

[6] W. J. W. Bos, M. ten Dam, T. Hoekstra, H. Prinsen, N. van Uden, and C. Voorend, “Showcase nefrologie - samen voor betere nierzorg. Ontwikkeling en toepassing van kwaliteitsinstrumenten bij chronische nierschade.,” 2024. [Online]. Available: https://projecten.zonmw.nl/nl/project/showcase-nefrologie.

[7] H. J. Westerink *et al.*, “Evaluating patient participation in value-based healthcare: Current state and lessons learned,” *Heal. Expect.*, vol. 27, no. 1, 2024, doi: 10.1111/hex.13945.

[8] R. P. C. Kessels, “Patients’ memory for medical information,” *J. R. Soc. Med.*, vol. 96, pp. 219–222, 2003.

[9] S. M. Keij *et al.*, “How are patient-related characteristics associated with shared decision-making about treatment? A scoping review of quantitative studies,” *BMJ Open*, vol. 12, no. 5, 2022, doi: 10.1136/bmjopen-2021-057293.

[10] I. G. Hargraves *et al.*, “Patient Education and Counseling Purposeful SDM : A problem-based approach to caring for patients with shared decision making,” *Patient Educ. Couns.*, vol. 102, no. 10, pp. 1786–1792, 2019, doi: 10.1016/j.pec.2019.07.020.

[11] A. M. Stiggelbout, A. H. Pieterse, and J. C. J. M. De Haes, “Shared decision making: Concepts, evidence, and practice,” *Patient Educ. Couns.*, vol. 98, no. 10, pp. 1172–1179, 2015, doi: 10.1016/j.pec.2015.06.022.

[12] H. van Veenendaal, G. Chernova, C. M. Bouman, F. S. va. Etten – Jamaludin, S. van Dieren, and D. T. Ubbink, “Shared decision-making and the duration of medical consultations: A systematic review and meta-analysis,” *Patient Educ. Couns.*, vol. 107, no. July 2022, p. 107561, 2023, doi: 10.1016/j.pec.2022.11.003.

[13] P. Hahlweg *et al.*, “Cancer patients’ preferred and perceived level of involvement in treatment decision-making: an epidemiological study,” *Acta Oncol. (Madr).*, vol. 59, no. 8, pp. 967–974, 2020, doi: 10.1080/0284186X.2020.1762926.

[14] E. M. Driever, A. M. Stiggelbout, and P. L. P. Brand, “Shared Decision-making in Different Types of Decisions in Medical Specialist Consultations,” *J. Gen. Intern. Med.*, vol. 37, no. 12, pp. 2966–2972, 2022, doi: 10.1007/s11606-021-07221-6.

[15] O. c. Damman, L. Murugesu, V. de Groot, and B. A. de Jong, “‘So Let’s Go On Like This?’—Shared Decision-Making and the Use of Outcome Information in Routine Care Management for People With Multiple Sclerosis,” *Heal. Expect.*, vol. 27, 2024.

[16] D. E. Lupu, M. M. Sanchez, and N. Gedney, “It Shouldn’t Be a Battle: Customizing Shared Decision Making to Meet Patients’ Preferences,” *Am. J. Kidney Dis.*, vol. 82, no. 6, pp. 650–652, 2023, doi: 10.1053/j.ajkd.2023.07.007.

[17] A. H. Pieterse, P. Gulbrandsen, E. H. Ofstad, and J. Menichetti, “What does shared decision making ask from doctors? Uncovering suppressed qualities that could improve person-centered care,” *Patient Educ. Couns.*, vol. 114, no. May, p. 107801, 2023, doi: 10.1016/j.pec.2023.107801.

[18] M. Kunneman *et al.*, “Humanistic communication in the evaluation of shared decision making: A systematic review,” *Patient Educ. Couns.*, vol. 102, no. 3, pp. 452–466, 2019, doi: 10.1016/j.pec.2018.11.003.

[19] H. J. Westerink *et al.*, “The use of outcome data in patient consultations from the healthcare professionals’ and patients’ perspectives: A mixed methods study,” *Patient Educ. Couns.*, vol. 118, no. March 2023, 2024, doi: 10.1016/j.pec.2023.108043.

[20] I. Ramsay, M. Peters, and N. Corsini, *Consumer health information needs and preferences: A rapid evidence review*, vol. 100, no. 9. 2017.

[21] C. D. Chu *et al.*, “Utility of the Kidney Failure Risk Equation and Estimated GFR for Estimating Time to Kidney Failure in Advanced CKD,” *Am. J. Kidney Dis.*, vol. 82, no. 4, pp. 386-394.e1, 2023, doi: 10.1053/j.ajkd.2023.03.014.

[22] N. Engels *et al.*, “Development of an online patient decision aid for kidney failure treatment modality decisions,” *BMC Nephrol.*, vol. 23, no. 1, pp. 1–16, 2022, doi: 10.1186/s12882-022-02853-0.

[23] J. W. Ankersmid, C. H. C. Drossaert, Y. E. A. van Riet, L. J. A. Strobbe, and S. Siesling, “Needs and preferences of breast cancer survivors regarding outcome-based shared decision-making about personalised post-treatment surveillance,” *J. Cancer Surviv.*, no. 0123456789, 2022, doi: 10.1007/s11764-022-01178-z.

[24] L. J. Trevena *et al.*, “Presenting quantitative information about decision outcomes: A risk communication primer for patient decision aid developers,” *BMC Med. Inform. Decis. Mak.*, vol. 13, no. SUPPL. 2, p. S7, 2013, doi: 10.1186/1472-6947-13-S2-S7.

[25] R. D. Vromans, M. C. Van Eenbergen, G. Geleijnse, S. Pauws, L. V. Van De Poll-Franse, and E. J. Krahmer, “Exploring cancer survivor needs and preferences for communicating personalized cancer statistics from registry data: Qualitative multimethod study,” *JMIR Cancer*, vol. 7, no. 4, 2021, doi: 10.2196/25659.

[26] K. Schick-Makaroff *et al.*, “An Evidence-Based Theory About PRO Use in Kidney Care: A Realist Synthesis,” *Patient*, vol. 15, no. 1, pp. 21–38, 2022, doi: 10.1007/s40271-021-00530-2.

[27] J. Greenhalgh *et al.*, “How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis,” *J. Patient-Reported Outcomes*, vol. 2, no. 1, 2018, doi: 10.1186/s41687-018-0061-6.

[28] E. M. Van Der Willik *et al.*, “Discussing results of patient-reported outcome measures (PROMs) between patients and healthcare professionals in routine dialysis care: a qualitative study,” *BMJ Open*, vol. 12, no. 11, pp. 4–6, 2022, doi: 10.1136/bmjopen-2022-067044.

[29] M. G. Katz, T. A. Jacobson, E. Veledar, and S. Kripalani, “Patient literacy and question-asking behavior during the medical encounter: A mixed-methods analysis,” *J. Gen. Intern. Med.*, vol. 22, no. 6, pp. 782–786, 2007, doi: 10.1007/s11606-007-0184-6.

[30] K. J. McCaffery *et al.*, “Addressing health literacy in patient decision aids,” *BMC Med. Inform. Decis. Mak.*, vol. 13, no. SUPPL. 2, 2013, doi: 10.1186/1472-6947-13-S2-S10.

[31] J. Noordman, L. Van Vliet, M. Kaunang, M. Van Den Muijsenbergh, G. Boland, and S. Van Dulmen, "Towards appropriate information provision for and decision-making with patients with limited health literacy in hospital-based palliative care in Western countries: A scoping review into available communication strategies and tools for healthcare provider," *BMC Palliat. Care*, vol. 18, no. 1, pp. 1–10, 2019, doi: 10.1186/s12904-019-0421-x.

[32] F. Koster, D. Lopes Barreto, S. C. Nair, M. R. Kok, and A. E. A. M. Weel-Koenders, "Defining the care delivery value chain and mapping the patient journey in rheumatoid arthritis," *Rheumatol. Int.*, vol. 43, no. 4, pp. 743–750, 2023, doi: 10.1007/s00296-022-05215-z.

[33] D. E. M. van der Horst, "Combining two different worlds: cooperations between startups and hospitals - An analysis of the cooperation between startups and hospitals with a Resource Dependency Theory perspective," Erasmus School of Health Policy & Management, 2018.

[34] C. May *et al.*, "Understanding the implementation of complex interventions in health care: The normalization process model," *BMC Health Serv. Res.*, vol. 7, pp. 1–7, 2007, doi: 10.1186/1472-6963-7-148.

[35] D. Coghlan, *Doing action research in your own organization*, Fifth. Sage publications, 2019.

[36] Santeon, "Routekaart Samen Beslissen," 2022. https://issuu.com/santeon/docs/boekje_routekaart_def_online_6776ff06375f6d.

[37] Ministry of Health Welfare and Sports, "Integraal Zorgakkoord (IZA)," 2022. [Online]. Available: https://www.lhv.nl/opkomen-voor-belangen/integraal-zorgakkoord/%0Ahttps://www.rijksoverheid.nl/documenten/rapporten/2022/09/16/integraal-zorgakkoord-samen-werken-aan-gezonde-zorg.

[38] Vastgesteld in Kernteam namens BO-Kwaliteit, "Eindrapport aandoeningswerkgroep Chronische Nierschade - Programma Uitkomstgerichte Zorg – Lijn 1 'Meer inzicht in uitkomsten,'" 2023.

[39] Linnean, "Dashboard chronische nierschade faciliteert Samen Beslissen - Dorinde v/d Horst & Ellen Parent," *13-09-2021*, 2021. https://linnean.nl/uit+de+praktijk/praktijkvoorbeelden/2035849.aspx.

List of abbreviations

Summary in Dutch

About the author

PhD portfolio

List of publications

Acknowledgements in Dutch

List of abbreviations

4SDM – 4-step SDM instrument (coding scheme)
BC – Breast cancer
CKD – Chronic Kidney Disease
CPM – Clinical Prediction Models
CPS – Control Preferences Scale
CVD – Cardiovascular Disease
DSI – Dialysis Symptom Index
eGFR – Estimated Glomerular Filtration Rate
ESKD – End Stage Kidney Disease
HCP – Healthcare Professional
ISCED – International Standard Classification of Education
IQR – Interquartile Range
KFRE – Kidney Failure Risk Equation
KRT – Kidney Replacement Therapy
MARS – Medication Adherence Report Scale
Md – Median
MI – Motivational Interviewing
MITI – Motivational Interviewing Treatment Integrity (coding scheme)
PAM – Patient Activation Measure
PEPPI – Perceived Efficacy in Patient-Physician Interactions
PRO – Patient Reported Outcome
PROM – Patient Reported Outcome Measures
SBSQ – Set of Brief Screening Questions
SD – Standard Deviation

Summary in Dutch

Inleiding

Chronische nierschade is een progressieve ziekte waarbij de nierfunctie van patiënten in de loop van de tijd de tijd achteruitgaat. Het belangrijkste behandeldoel bij chronische nierschade is het afremmen van de daling van de nierfunctie. Nierfalen, het moment dat een patiënt dialyse of een niertransplantatie nodig heeft, wil je voorkomen of zo lang mogelijk uitstellen. Patiënten worden doorgaans op de polikliniek behandeld door een nefroloog, waarbij ze geregeld langskomen om het beloop van de ziekte en de behandelingen te bespreken. Bij zo'n bezoek aan de nefroloog worden allerlei keuzes gemaakt die gerelateerd zijn aan het afremmen van nierschade, zoals keuzes over: leefstijlinterventies (bijv. stoppen met roken, afvallen, verminderde zoutinname); behandelingen met medicatie (bijv. medicatie tegen hoge bloeddruk of te hoog cholesterol); plannen van zorg (bijv. wanneer zal de volgende afspraak plaatsvinden en is deze fysiek of per telefoon?). *Samen beslissen* bij keuzes als deze vergroot de kans dat patiënten adequaat worden geïnformeerd en dat zij therapietrouw zijn. Bij samen beslissen gaan patiënt en behandelaar een *proces* door van verschillende stappen, waarin wensen en voorkeuren van de patiënt besproken worden om gezamenlijk tot een besluit te komen die het beste past bij de patiënt. De vier stappen van samen beslissen zijn: 1) agenderen dat er een keuze gemaakt moet worden; 2) informeren over de opties; 3) voorkeuren van de patiënt bespreken; 4) een besluit nemen. Samen beslissen kan ook *'patiëntactivatie'* versterken. 'Patiëntactivatie' is de mate waarin patiënten kennis, vertrouwen en vaardigheden hebben om hun gezondheid te managen. Bij specifieke 'grote' beslissingen, zoals de keuze omtrent niervervangende therapie, is al veel onderzoek gedaan naar samen beslissen. Echter, bij meer routinematige, 'kleinere' beslissingen weten we nog niet goed wat de plek is van samen beslissen.

Samen beslissen kan in de praktijk worden ondersteund met het gebruik van uitkomstinformatie. Uitkomstinformatie gaat over de resultaten van de zorg. Het geeft inzicht in wat zorg oplevert voor de patiënt. Er worden vier vormen van uitkomstinformatie onderscheiden: 1) klinische informatie zoals laboratorium uitslagen; 2) patiënt-gerapporteerde informatie, ook wel 'patient reported outcomes measures', PROMS (vragenlijsten die patiënten invullen over bijvoorbeeld hun symptomen of ervaren gezondheid); 3) voorspelmodellen waarmee een prognose over het beloop van de ziekte kan worden gegeven; 4) modellen waarin een patiënt kan worden vergeleken met een groep patiënten met dezelfde karakteristieken. Om uitkomstinformatie beter te kunnen gebruiken in de spreekkamer onderzoeken we hoe patiënten en artsen aankijken tegen het gebruik van deze verschillende vormen van uitkomstinformatie.

Uitkomstinformatie visueel weergeven tijdens het gesprek in de spreekkamer, zoals met een dashboard, kan bijdragen aan het effectief bespreken van uitkomstinformatie en zo helpen bij het adequaat informeren van patiënten. Een dergelijk dashboard kan bijdragen aan samen beslissen in de spreekkamer en mogelijk patiëntactivatie versterken. Voor patiënten met nierschade en hun behandelaars hebben we een dashboard ontwikkeld en geïmplementeerd en de effecten op samen beslissen en patiëntactivatie gemeten.

De drie doelstellingen van dit proefschrift zijn:

1. Bepalen in welke mate samen beslissen van toepassing is bij 'routine' medische beslissingen en nagaan hoe beslissingen in de huidige praktijk gemaakt worden in de spreekkamer bij chronische nierschade.
2. Exploreren hoe patiënten en behandelaars aankijken tegen het bespreken van verschillende vormen van uitkomstinformatie in de spreekkamer.
3. Een dashboard ontwikkelen voor chronische nierschade als nieuwe manier om uitkomstinformatie te visualiseren en de effecten evalueren op samen beslissen en mate van patiënt activatie.

Het proefschrift is ingedeeld in 3 gedeeltes, aansluitend op de 3 doelstellingen.

Deel 1 – Samen beslissen bij chronische nierschade - het verbreden van de reikwijdte.

In **hoofdstuk 2** delen we onze resultaten van een literatuurreview waarin we zijn nagegaan wanneer samen beslissen van toepassing is volgens de auteurs van de artikelen geïncludeerd in de review. We hebben specifiek gekeken welke karakteristieken van beslissingen worden benoemd die maken dat samen beslissen aan de orde lijkt. In de 92 geïncludeerde artikelen identificeerden we de volgende karakteristieken van beslissingen waarvoor samen beslissen van toepassing lijkt: voorkeursgevoelige beslissingen, beslissingen met meerdere opties, beslissingen waarbij er sprake is van 'equipoise' (gelijk wegende opties), beslissingen met grote impact en beslissingen waarbij patiënt betrokkenheid noodzakelijk is voor het uitvoeren van de beslissing. Bij vier beslissingskenmerken was het ambigu of samen beslissen wel of niet van toepassing is, namelijk beslissingen met: één beste optie, weinig/lage impact, een afweging tussen individueel effect en maatschappelijk voordeel en korte tijd om de beslissing te nemen. Tot slot beschreven auteurs ook beslissingskenmerken waarbij samen beslissen als niet passend werd beschouwd: geen gelijk wegende opties, verzoek van patiënt om een behandeling in strijd met het oordeel van de arts, onmiddellijk levensreddend handelen is noodzakelijk en potentiële bedreiging van de openbare veiligheid. Uit het literatuuroverzicht bleek dat niet alleen in grote voorkeursgevoelige beslissingen samen beslissen van toepassing lijkt, maar dat ook in kleinere beslissingen, bij uitstek daar waar patiënt betrokkenheid nodig is voor het implementeren van de keuze en zelfs bij beslissingen met één optie, samen beslissen aan de orde lijkt. Er zijn enkele uitzonderingen waarbij samen beslissen niet van toepassing lijkt, zoals in medische noodsituaties. We adviseren dan ook om in de praktijk bij elke beslissing (ook 'kleinere beslissingen)' samen beslissen na te streven in plaats van samen beslissen alleen te reserveren voor 'grote' voorkeursgevoelige beslissingen.

In **hoofdstuk 3** hebben we gekeken hoe samen beslissen wordt toegepast tijdens bezoeken van patiënten met nierschade aan de polikliniek. In deze studie werd met vragenlijsten na de spreekkamergesprekken aan patiënten gevraagd welke beslissingen waren besproken, wie deze beslissingen volgens hen had genomen en wat hun voorkeur is over wie dergelijke beslissingen neemt. Daarnaast maakten we geluidopnames van deze spreekkamergesprekken om te analyseren in welke mate samen beslissen werd toegepast in de gesprekken volgens onafhankelijke observatoren. In de 122 vragenlijsten werden 357 beslissingen door patiënten gerapporteerd. Dit waren het vaakst beslissingen over: planning (bijvoorbeeld van het volgende bezoek); aanpassingen in medicatie; veranderingen in leefstijl; behandeldoelen; en diagnostische testen. De voorkeur van patiënten voor hun rol in het nemen van deze beslissingen varieerde. Patiënten wilden de beslissing samen met de behandelaar nemen (32%), of dat de behandelaar de beslissing grotendeels (35%) of helemaal (28%) zou nemen. In veel beslissingen (151/357) kwam de voorkeur van de patiënt niet overeen met hoe ze de beslissing hebben ervaren. De beslissing was dan of wel 'te veel samen' of wel 'te weinig samen' beide in ongeveer gelijke mate. Er werden 93 spreekkamergesprekken opgenomen en geanalyseerd, waarin 118 beslissingen werden gescoord op de mate van samen beslissen. De mate van samen beslissen was laag volgens de observatoren. Dit strookte niet altijd met de ervaring van de patiënten, die beslissingen waar de observator weinig samen beslissen had gescoord soms hadden ervaren als een beslissing die zij samen met de behandelaar hadden genomen en andersom. Het is belangrijk hierbij te realiseren dat in deze studie patiënten werden gevraagd wat hun voorkeur was betreffende het nemen van de beslissing. Dit is niet hetzelfde als het totale *proces* van samen beslissen. Een beslissing kan nog steeds middels samen beslissen zijn genomen, ook als de behandelaar uiteindelijk de keuze maakt. Voorwaarde hiervoor is dat daarvoor de vier stappen van samen beslissen wel zijn doorlopen. Daarnaast observeerden we dat de vier theoretische stappen van samen beslissen van belang zijn voor succesvol samen beslissen, maar dat ook andere communicatieve vaardigheden, zoals stiltes laten vallen en ruimte bieden voor patiënten om zaken in te brengen, belangrijk zijn.

Deel 2: Het bespreken van uitkomstinformatie in de speekkamer - huidige praktijk en voorkeuren.

Met 22 duo-interviews, interviews met een patiënt en hun behandelaar tegelijk, hebben we in **hoofdstuk 4** gekeken hoe behandelaars (artsen of verpleegkundig specialisten) en patiënten tegen het gebruik van de vier verschillende vormen van uitkomstinformatie in de spreekkamer aankijken. Deze studie werd uitgevoerd bij patiënten met chronische nierschade of borstkanker om verschillende perspectieven te kunnen exploreren. De interviews toonden aan dat onder patiënten en behandelaars onderling veel individuele variatie bestaat in hoe ze naar de verschillende vormen van uitkomstinformatie kijken. Over het algemeen vonden zowel patiënten als hun behandelaars klinische uitkomsten belangrijk, maar verschilden vooral patiënten hoe zeer zij de focus legden op getallen. Tijdens de duo-interviews konden de deelnemers direct op elkaar reageren en zo bleek dat een aantal aannames van patiënten en behandelaars niet te kloppen. Er waren bijvoorbeeld patiënten die zich niet bewust waren dat bepaalde informatie over hun leven en functioneren belangrijk was voor de behandelaar. Andersom waren behandelaren niet altijd goed in het inschatten of patiënten bepaalde informatie (met name over toekomstig ziektebeloop) wel of niet wilden horen. Het doen van duo-interviews bleek een geschikte methode om dergelijke (verkeerde) aannames over elkaar boven water te krijgen. De gevonden individuele variatie in behoefte aan uitkomstinformatie en soms verkeerde aannames van patiënten en behandelaars over elkaar benadrukt het belang van een open dialoog. Het expliciet nagaan van aannames en vragen stellen vanuit intrinsieke nieuwsgierigheid zou daarbij leidend moeten zijn voor het bespreken van uitkomstinformatie in de spreekkamer.

We hebben één vorm van uitkomstinformatie in **hoofdstuk 5** verder onder de loep genomen: het gebruik van voorspelmodellen. Een voorspelmodel doet een voorspelling over het beloop van ziekte, vaak in getallen of percentages, op basis van een rekenkundig model. Dit hoofdstuk bracht het huidige gebruik en de voorkeuren van zowel patiënten als behandelaars ten aanzien van voorspelmodellen bij chronische nierschade in kaart. In totaal hebben 126 patiënten en 50 nefrologen uit heel Nederland hierover een vragenlijst ingevuld. Alhoewel veel patiënten aangaven dat er wel eens een voorspelling over de snelheid van nierschade progressie was besproken, werd hier niet vaak een rekenmodel voor gebruikt. Overeenkomstig met onze resultaten in **hoofdstuk 4**, gaven veel patiënten aan de informatie van voorspelmodellen nuttig te vinden, maar sommige patiënten wilden liever geen berekende voorspellingen in getallen of percentages over hun ziektebeloop horen. Voor het bouwen van dashboards, keuzehulpen of andere hulpmiddelen raden wij dan ook aan voorspelmodellen *optioneel* zichtbaar te maken. Een goede toelichting in een gesprek met de behandelaar werd ook in onze studies in hoofdstuk 4 en 5 benoemd als een belangrijke voorwaarde voor het gebruiken van voorspelmodellen.

Deel drie: Een nieuwe manier om uitkomstinformatie in de spreekkamer te gebruiken – het nierschade dashboard.

Hoofdstuk 6 beschrijft het proces van co-ontwikkeling van het nierschade dashboard met patiënten, artsen, verpleegkundig specialisten en diëtisten. In dit hoofdstuk introduceerden we een conceptueel raamwerk over hoe het rapporteren van uitkomstinformatie (zowel klinische informatie als PROMs) door middel van datavisualisatie samen beslissen kan faciliteren en patiënt activatie kan versterken. Om dit in de praktijk toe te passen hebben we het nierschade dashboard ontwikkeld. Werkgroepen, focusgroepen en gebruikersonderzoeken waren onderdeel van het iteratieve ontwikkelproces. Belangrijke bevindingen hierin waren dat het dashboard niet het gesprek in de spreekkamer moet vervangen en dat bij het bespreken van het dashboard het belangrijk is dat patiënt en behandelaar eerst afstemmen welke onderwerpen in het dashboard zij zullen bespreken. Uiteindelijk is een nierschade dashboard ontwikkeld dat bestaat uit individuele klinische gegevens (zoals nierfunctie en bloeddruk) en PROMs. Het dashboard is opgebouwd uit verschillende onderdelen (bladen) met één hoofdblad. Op dit hoofdblad staat onder andere de nierfunctie over de tijd weergegeven en vier vragen. Deze vragen beantwoorden patiënten voorafgaand aan het spreekkamer gesprek. De vragen gaan onder andere over wat patiënten het belangrijkste vinden om te bespreken met de behandelaar en wat voor hen de belangrijkste symptomen op dat moment zijn. Het dashboard bevat ook uitleg over verschillende termen, zoals 'kalium' of 'hemoglobine' en behandeldoelen zoals 'bloeddruk regulatie'. Deze aanvullende informatie is te raadplegen via een "lees meer" knop en bevat ook verwijzingen naar de informatieve website van de Nierpatiënten Vereniging Nederland: nieren.nl. Het doel is het dashboard te bespreken in de spreekkamer en dat patiënten het thuis naderhand ook kunnen openen om besproken informatie nog eens na te lezen en meer informatie te bekijken waar gewenst.

Het ontwikkelde nierschade dashboard is vervolgens geëvalueerd met een studie in twee ziekenhuizen. De resultaten van deze studie zijn beschreven in **hoofdstuk 7**. In deze studie keken we of er voor en na de implementatie van het dashboard verschillen waren in de mate van patiëntactivatie (met gestandaardiseerde patiëntvragenlijsten) en de mate van samen beslissen (gecodeerd aan de hand van geluidopnames van spreekkamergesprekken). Er werden geen significante verschillen in patiëntactivatie en mate van samen beslissen gevonden voor en na de implementatie van het dashboard. Het is echter goed te beseffen dat de metingen relatief kort na de implementatie plaatsvonden, waarbij het dashboard nog geen routine onderdeel was van poliklinische zorg in de praktijk. Bovendien was het dashboard nog niet beschikbaar voor patiënten thuis om na het bezoek te kunnen inzien. Zowel volgens patiënten als behandelaars ligt daar de grote meerwaarde. In de geluidopnames van de spreekkamergesprekken (in totaal 193) was de mate van samen beslissen laag; de mediane score was 4.5 voor implementatie en 6.0 na implementatie op een schaal van 0-24, waarbij een hogere score meer samen beslissen aangeeft. In de geluidopnames werd wel gezien dat wanneer het dashboard werd besproken, meer verschillende gespreksonderwerpen aan bod kwamen, waaronder vaak onderbelichte onderwerpen zoals mentale gezondheid en seksuele disfunctie, wat vaak een bijwerking is van voorgeschreven medicatie. Het viel op dat wanneer deze onderwerpen werden besproken en de stappen van samen beslissen grotendeels werden doorlopen, dit vaak leidde tot aanpassing van de behandeling op de situatie en wensen van de patiënt; op deze manier voegde de beschikbaarheid van het dashboard waarde toe voor het individu.

Conclusies

In dit proefschrift verbreden we de reikwijdte van wanneer samen beslissen van toepassing is. Bij chronische nierschade is samen beslissen niet alleen relevant bij de beslissing over nierfunctie vervangende therapie maar ook bij ‘kleinere’, meer routinematige beslissingen in de periode voorafgaand aan nierfalen. In theorie kan samen beslissen adequate informatievoorziening helpen waarborgen en de mate van activatie van patiënten en hun betrokkenheid bij hun eigen behandelingen versterken; iets wat bij uitstek bij chronische nierschade van belang is. In de praktijk worden de vier stappen van samen beslissen bij ‘kleinere beslissingen’ echter nog weinig toegepast bij chronische nierschade. Er zijn wel goede praktijkvoorbeelden in de opnames van gesprekken in de spreekkamer gevonden die ondersteunen dat wanneer de stappen worden doorlopen, behandelingen op de patiënt en hun omstandigheden en voorkeuren worden aangepast.

Om samen beslissen te ondersteunen en patiëntactivatie bij chronische nierschade te vergroten hebben we een dashboard gemaakt dat gebruikt kan worden tijdens het gesprek in de spreekkamer. Het dashboard visualiseert verschillende gegevens van patiënten (o.a. laboratorium waardes en PROMS, inclusief ervaren symptomen) over de tijd. Het geeft een overzicht van het ziekteproces, bevat uitleg over medische termen en benadrukt wat de behandeldoelen zijn voor het afremmen van nierschade. Significant aantoonbare effecten van het dashboard op samen beslissen en de mate van patiëntactivatie hebben we in dit proefschrift niet aan kunnen tonen. Het bespreken van het dashboard leidde wel tot verandering in gespreksonderwerpen, waarbij doorgaans onderbelichte onderwerpen meer aan bod kwamen. In gesprekken waarin het dashboard werd besproken op een manier zoals beoogd, hoorden we in onze opnames terug dat behandelingen beter werden afgestemd op de voorkeuren van patiënten; zo lijkt het gebruik van het dashboard waarde te creëren voor patiënten. Van belang bij het bespreken van een dergelijk dashboard en van uitkomstinformatie in het algemeen, is dat patiënt en behandelaar aan het begin van het bezoek afstemmen wat zij beiden willen bespreken. Dit waarborgt dat onderwerpen die het meest belangrijk worden gevonden aan bod komen binnen de gegeven tijd van het bezoek. Daarnaast biedt het de kans de kans om aannames over welke informatie belangrijk wordt bevonden te toetsen. Dit laatste is van belang omdat we in dit proefschrift vonden dat er veel individuele variatie bestaat in welke uitkomstinformatie belangrijk wordt geacht te bespreken. Ook vonden we dat patiënten en behandelaars niet altijd goed inschatten welke informatie de ander wenst te bespreken. Nieuwsgierigheid als kompas en het toetsen van aannames over de ander zal bijdragen aan effectievere communicatie in de spreekkamer.

Vervolgstappen in onderzoek

Het implementeren en evalueren van een innovatie blijkt lastig met traditionele academische methoden, zoals een klinisch onderzoek (trial) met een pre-postdesign. Een langere periode is vaak nodig om verschillen aan te kunnen tonen, aangezien implementatie tijd en aanpassingen aan de praktijk vergt. Daarnaast is het vaststellen van een primaire kwantitatieve uitkomstmaat die overeenkomt met het vaststellen van waarde voor patiënten en de geleverde zorg complex. Kwalitatieve evaluaties bieden meer diepgang in waarom een innovatie goed of minder goed werkt. Kwalitatief onderzoek kan ook meer inzicht bieden in hoe de innovatie verder te verbeteren. *Actieonderzoek* kan een passend alternatief zijn voor meer traditionele onderzoeksmethodes voor het evalueren en bestuderen van innovaties vergelijkbaar aan het nierschade-dashboard. In actieonderzoek ligt de focus op kort-cyclisch evalueren om zo de innovatie iteratief te verbeteren. Vanuit de ervaringen uit dit proefschrift zouden wij dan ook aanbevelen actieonderzoek te verrichten om de link met de dagelijkse praktijk te versterken en te waarborgen dat de innovaties als een dashboard verder worden ontwikkeld.

Vervolgstappen in de praktijk

Bevindingen uit dit proefschrift over samen beslissen zijn verwerkt in trainingen ter bevordering van samen beslissen in verschillende Santeon ziekenhuizen en in het platform '*Samen de zorg vernieuwen*', ontwikkeld door de Santeon ziekenhuizen (https://samendezorgvernieuwen.nl/personaliseren/). Het doel van dit platform is om professionals in de zorg op weg te helpen bij het vernieuwen van zorg, aan de hand van een praktisch stappenplan voor het personaliseren, standaardiseren en digitaliseren van zorg. Het stappenplan 'personaliseren van zorg' kan worden ingezet om iedere patiënt de best passende zorg te leveren, specifiek gericht op belangrijke momenten in het zorgpad op samen beslissen, waarbij gebruik gemaakt wordt van uitkomstinformatie. Met behulp van het stappenplan worden zorginstellingen geholpen bij het stapsgewijs komen tot optimale, gepersonaliseerde zorg aan de hand van informatie, tools en praktijkvoorbeelden. Het stappenplan is ontwikkeld door Santeon in samenwerking met het programma Uitkomstgerichte zorg II, van het ministerie van Volksgezondheid, welzijn en sport.

De landelijke werkgroep binnen het Uitkomstgerichte Zorg I programma van de overheid heeft de resultaten over samen beslissen bij chronische nierschade gebruikt bij de keuze van uitkomsten bij chronische nierschade die zijn opgenomen in de landelijke set van gestandaardiseerde uitkomsten. De set van uitkomsten is verbreed op grond van onze bevindingen en richten zich nu ook mede op de vele 'kleinere' beslissingen bij chronische nierschade.

Het nierschade dashboard wordt momenteel verder ontwikkeld binnen Santeon in het '*Zorg bij jou*' programma, waarin de medische uitkomsten en PROMS voor patiënten makkelijker inzichtelijk gemaakt worden. Daar worden ook thuismetingen aan toegevoegd.

About the author

Dorinde was born on the 19th of August in 1993 in Leiden, the Netherlands. She grew up with her two older brothers Arno and Sander and her parents Robin and Irene. In 2011 she graduated cum laude from secondary school 'Stedelijk Gymnasium' in Leiden. Subsequently she started medical training at the University of Utrecht in 2011. During her studies, she did multiple internships abroad including in Vietnam and Madagascar. In her last year of her Master in Medicine, in 2018, she was driven to improve her understanding of the healthcare system, including the governance perspective. That year she completed a master of Healthcare Management at the Erasmus School of Health Policy and Management. For her thesis on innovation in healthcare – collaborations between hospitals and startups, she was awarded the 'best thesis of the year'. In that same year, she worked as a consultant at De Kleine Consultant (DKC), a non-profit student consultancy firm providing socially engaged companies with strategic advice and was a member of the Medical Business Masterclass Board of the Medical Business Foundation. She received her medical degree in 2019 and started working as a resident not in specialist training (ANIOS) in Internal Medicine at St. Antonius Hospital, Nieuwegein. Here, she met prof. Willem Jan Bos (LUMC and st. Antonius Hospital), with whom she shared the interest in looking at healthcare through a macroscopic lens and searching for ways to innovate it. Their discussions regarding healthcare during clinical rounds eventually led to this PhD thesis. Other supervisors of the PhD project were Nelly van Uden (Santeon) and Arwen Pieterse (LUMC). During her PhD, Dorinde attended the Harvard Seminar on Value-Based Healthcare and she joined the working group on data visualization and dashboarding of the nationwide Linnean Initiative. In 2021 she became an ambassador of value-based healthcare in the program 'Uitkomstgerichte zorg' of the Ministry of Health, wellbeing and sports. In 2023 she started to work as a resident not in specialist training (ANIOS) at Tergooi Medical Center in Hilversum in Internal Medicine, Pulmonology and Cardiology. The same year she started in University Medical Center Utrecht, where she is currently resident in training (AIOS) in Pulmonology.

PhD portfolio

Courses

2020, Time management, taking control of and optimizing your time and life, Leiden University
2020, Basic Methods and Reasoning in Biostatistics, Leiden University
2020, Responsible Research, Leiden University
2020, Leiden University Onboarding Programme Inform & Connect, Leiden University
2021, Harvard Intensive Seminar, Value-Based Healthcare, Harvard Business School
2021, Data visualization, Data Vision Lab
2021, Redcap course, data management, St. Antonius Hospital, Nieuwegein
2021, Training for ambassadors of ‘Uitkomstgerichte zorg’ – Ministry of Health, wellbeing and sports
2022, Academic Writing, Babel Utrecht
2022, Storytelling, Leiden University

Conferences

2023, Keynote presentation ‘Wetenschapsavond’ (science evening), St. Antonius Hospital Nieuwegein.
2023, Oral presentations (2), ‘Nefrologie dagen’ (nephrology days), Veldhoven.
2023, Oral presentation, International Conference on Communication in Healthcare, Glasgow, UK
2023, Oral presentation Innovation lab Congress Value Based Healthcare ‘Uitkomstgerichte zorg’, The Hague
2022, Oral presentation, International Shared Decision Making conference, Kolden, Denmark
2021, Oral presentation, Shared Decision Making of the NVZ (Dutch association of hospitals) conference, Nieuwegein
2021, Oral presentation (online), ‘Wetenschapsmaand’ (Science month) NVN (Dutch Kidney Patient Federation)
2021, Oral presentation (online), International Consortium for Health Outcomes Measurements

Teaching activities

2022,	Training healthcare professionals in two hospitals in dashboard use, including use of Patient-Reported Outcome Measures and shared decision making.
2022,	Master thesis supervisor, Master Health Sciences- Health Policy, VU University Amsterdam.

List of publications

In this thesis

van der Horst DEM, Garvelink MM, Bos WJW, Stiggelbout AM, Pieterse AH. For which decisions is Shared Decision Making considered appropriate? - A systematic review.
Patient Education and Counseling. 2023;106:3-16. doi:10.1016/j.pec.2022.09.015

van der Horst DEM, Hofstra N, van Uden-Kraan CF, Stiggelbout AM, van den Dorpel MA, Pieterse AH, Bos WJW. Shared Decision Making in Health Care Visits for CKD: Patients' Decisional Role Preferences and Experiences.
American Journal of Kidney Disease. 2023;82(6):677-686. doi:10.1053/j.ajkd.2023.04.012

van der Horst DEM, Engelhardt EG, Hackert M, van der Wees PJ, Bos WJW, van Uden-Kraan CF. Clinicians' and patients' perspectives on discussing outcomes during healthcare visits - Qualitative study with dyadic interviews.
Patient Education and Counseling. 2025;139. doi:10.1016/j.pec.2025.109229

van der Horst DEM*, Engels N*, Hendrikx J, van den Dorpel MA, Pieterse AH, Stiggelbout AM, van Uden-Kraan CF, Bos WJW. Predicting outcomes in chronic kidney disease: needs and preferences of patients and nephrologists.
BMC Nephrology. 2023;24(1):66. doi:10.1186/s12882-023-03115-3
** shared first author*

van der Horst DEM, van Uden-Kraan CF, Parent E, Bart JAJ, Waverijn G, Verberk-Jonkers IJAM, van den Dorpel MA, Pieterse AH, Bos WJW. Optimizing the use of patients' individual outcome information - Development and usability tests of a Chronic Kidney Disease dashboard.
International Journal of Medical Informatics. 2022;166:104838. doi:10.1016/j.ijmedinf.2022.104838

van der Horst DEM, van Uden-Kraan CF, Stiggelbout AM, Verberk-Jonkers IJAM, van den Dorpel MA, Pieterse AH, Bos WJW. Visualizing outcome information to support the patient - clinician conversation in outpatient Chronic Kidney Disease care - an evaluation study.
Submitted

Other publications

Cleypool CGJ, Schurink B., **van der Horst DEM**, Bleys RLAW (2020). Sympathetic nerve tissue in milky spots of the human greater omentum.
Journal of anatomy, *236*(1), 156–164. https://doi.org/10.1111/joa.13077

Acknowledgements

'High risk, high reward', zo omschreef promotor Willem Jan Bos dit promotietraject aan mij nog voordat ik begonnen was. Inmiddels kan ik met zekerheid bevestigen dat het voor mij een 'high reward' was om dit promotietraject te mogen doen. De kansen en mogelijkheden die deze promotie bood om vanaf scratch nieuwe projecten op te kunnen zetten vond ik enorm leerzaam en ontzettend leuk. De samenwerkingen met anderen stonden hierin voor mij centraal en maakten dat ik zoveel heb geleerd en met veel plezier terugkijk op de afgelopen tijd.

Willem Jan bos, ik wil je ontzettend bedanken voor de kans die jij mij hebt aangereikt toen we van gedachten wisselden over de zorg in jouw spreekkamer in het Antonius. Dat de spreekkamer ook precies de setting van dit proefschrift werd was vast een voorbode. Ik heb me door jou altijd enorm gesteund gevoeld en uitgedaagd om de projecten naar een hoger niveau te tillen.

Arwen Pieterse, van jouw oneindige kennis in het veld van samen beslissen in combinatie met jouw analytische blik heb ik enorm veel geleerd. De uren (dagen? weken?) tot in de letter analyseren van de artikelen voor de review vond ik heel waardevol. Daarbij mag jouw taalkundige blik en de gezelligheid op congressen niet ongenoemd blijven.

Nelly van Uden, ik kan niet genoeg benadrukken hoe belangrijk jouw begeleiding is geweest. Zowel academisch als bij de praktische kant van de projecten heb jij mij enorm geholpen; je hebt mij wegwijs gemaakt in het zorglandschap van verschillende instanties, commissies, partners en ziekenhuizen en jouw feedback was altijd zeer waardevol.

Ellen Parent, ik wil jou graag bedanken voor jouw enorme inzet bij het ontwikkelen en implementeren van de PROMs en het dashboard. Tevens Rene van den Dorpel en Iris Verberk bedankt voor jullie toewijding in het implementeren en tevens Geeke van Waverijn voor haar technische kennis (en gezelligheid).

Daarnaast wil ik graag alle patiënten en zorgverleners bedanken die ofwel input hebben gegeven aan de opzet van de studies of de ontwikkeling van het chronische nierschade dashboard. In het bijzonder Hans Bart en Wanda Konijn die de samenwerking met Nierpatienten Vereniging Nederland mogelijk maakten. Ook wil ik de deelnemende patiënten en zorgverleners die hebben meegedaan aan de studies bedanken. Het mogen meeluisteren naar gesprekken in de spreekkamer middels de geluidsopnames was bijzonder en enorm waardevol. Ook wil ik graag Petra Veen, Juliette Rahman-Berg en Jose Verstijnen bedanken voor hun inzet in het verzamelen van deze opnames.

Beste collega's van Santeon, in het bijzonder Noel, Jet A. en Janine, dank voor jullie gezelligheid op kantoor en tijdens de congressen. Ik heb veel gehad aan jullie geleerde lessen binnen het 'Experiment Uitkomstindicatoren'. Ook andere collega's binnen Santeon en het Antonius Ziekenhuis bedankt voor de leerzame samenwerkingen, waaronder Mirjam, Ellen E. en Mariska.

Beste LUMC collega's, Anne Stiggelbout, jouw scherpe blik heeft onder andere de review mooi aangescherpt. Ook Martha, Marleen, Esther, Thomas en Roukaya, dank voor de mooie discussies over medische beslisvorming!

Huidige collega's bij de longziekten in Utrecht, dank voor jullie gezelligheid binnen en buiten het ziekenhuis tijdens de laatste jaren van mijn proefschrift!

John Noy, bedankt voor jouw koekjes en goede muziek tijdens onze schildersessies en het meedenken in de vormgeving.

Ook wil ik mijn lieve vrienden bedanken, die voor mijn klaar staan als het nodig is en waarmee ik zoveel plezier beleef! Lieve paranimfen Arina en Nicole, jullie zijn twee ijzersterke vrouwen en ik ben trots dat jullie naast mij staan tijdens de verdediging. Maar ook, in willekeurige volgorde, Veronique, Fenna, Jesler, Marleen, Suzanne, Jeroen, Noor, Iris, Alexander, Steffie, Justin, Tom en mijn hockeyteam, jullie zijn mij zeer dierbaar.

Ten slotte, aan mijn lieve familie, tijdens de duur van dit proefschrift is het voor jullie niet altijd gemakkelijk geweest. We hebben afscheid moeten nemen van mijn lieve en krachtige opa Bote, een voorbeeld voor mij in de zorg, als huisarts en later directeur van het Havenziekenhuis; opa Hans, de drukke onderhandelaar en grappigste man die ik ken; mijn lieve oma Trudy, nuchter, vogelkenner en iemand aan wie ik alles kon vertellen; en haar dochter, mijn tante, Eugenie, een vrouw van oprechtheid en vrolijkheid.

Lieve vader en moeder, jullie zijn er onvoorwaardelijk voor mij en dat betekent enorm veel voor me. Van jullie beiden en jullie verschillende perspectieven heb ik veel mogen leren. Dank voor de kansen die ik heb gekregen om te kunnen doen wat ik wil en mijzelf te ontwikkelen. Ik ben jullie eeuwig dankbaar.

Lieve Sander en Arno, lieve broers, sinds ik mij kan herinneren kan ik ook op jullie terugvallen. Dat laat mij heel sterk voelen. Zoals jullie zelf al weleens riepen: dit is ook een beetje jullie proefschrift! Lieve Mark, vriend van Sander, en Fleur, vrouw van Arno, ook jullie wil ik bedanken voor jullie steun en warmte.

Ten slotte, lieve Gideon, jouw zorgzaamheid, begrip en flexibiliteit waren enorm steunend in de laatste jaren van mijn promotie. Je bent een warm, slim en prachtig mens, dank voor jouw steun!