Implementation and use of patient-reported outcome measures in routine nephrology care

Willik, E.M. van der

1

General introduction and thesis outline

1

General introduction and thesis outline

Healthcare is shifting towards a more person-centred approach.[1-3] More attention is paid to the patients' perspective, aiming at a personalised and holistic treatment that fits the patient's preferences and needs. Insight into patient-reported outcomes (PROs), such as health-related quality of life (HRQOL) and symptom burden, is therefore becoming increasingly important in healthcare.[4, 5] Patient-reported outcome measures (PROMs) systematically assess such outcomes and can facilitate the process of adapting to what is important to the patient.[4-7] But, how to integrate PROMs into a routine care setting and how to use PROMs to achieve this personalised and holistic treatment? This dissertation provides insight into and practical knowledge of the implementation and use of PROMs in routine nephrology care.

Chronic kidney disease

Chronic kidney disease (CKD) is a progressive condition characterized by a decreased kidney function based on a glomerular filtration rate (GFR) of less than 60 mL/min per 1.73 m², or markers of kidney damage, such as albuminuria, present for at least 3 months.[8, 9] Globally, the prevalence of CKD is estimated around 10%[10, 11], and is expected to further increase due to the aging population and the increasing number of people with diabetes and hypertension.[12] Worldwide, about 0.5% of the people has advanced CKD (GFR < 30 mL/min per 1.73 m²) and 0.1% has kidney failure (GFR < 15 mL/min per 1.73 m²).[8, 11] Patients with kidney failure have the choice to receive kidney replacement therapy (KRT) to prolong life, or comprehensive conservative care, which aims at maintaining HRQOL, optimal symptom management and slowing down disease progression.[13, 14] There are two general types of KRT, namely kidney transplantation or dialysis treatment (e.g. peritoneal dialysis or haemodialysis).[8, 14] Peritoneal dialysis treatments are every day or night and are performed from home by the patient (and any caregivers) or with help of a machine.[15] Haemodialysis treatments are usually 3 times a week for approximately 3-5 hours per dialysis session, performed at the dialysis centre or at home.[15] Patients need on average 5-7 hours to fully recover after each haemodialysis session[16, 17], underlining the invasiveness and high impact on people's life.[18] The choice for which treatment fits the patient best is generally based on availability of treatment (e.g. kidney donor and dialysis options at home or in a centre nearby), clinical characteristics (e.g. the patient's health status, medical risks and potential health benefits), and the patient's characteristics and his values, preferences and needs (e.g. what someone finds important in life).[8, 13, 18, 19]

Outcomes in patients with chronic kidney disease

CKD is a growing public health problem causing a high disease burden and healthcare costs.[12, 18, 20, 21] Advanced CKD is associated with a high cardiovascular morbidity, increased mortality and hospitalizations, and has a major impact on people's life.[9, 18, 22] Patients with advanced CKD experience numerous physical and emotional symptoms, such as fatigue, itching, muscle cramps, sleep problems, sexual problems and depressive symptoms, which have a major impact on their HRQOL.[23-26]

Nephrology care traditionally focusses on clinical measures, such as mortality, laboratory values and blood pressure. Although PROs, like HRQOL and symptom burden have been regarded as highly important by patients and healthcare professionals[27-31], these outcomes often remain unknown, undiscussed and undertreated in regular practice.[25, 32] This is partly because patients do not share everything by themselves, for instance because some topics may be difficult to talk about, or because patients assume that their symptoms cannot be treated, or are not related to their CKD or treatment for CKD.[33-35] Additionally, it may be challenging for healthcare professionals to inquire about the wide range of symptoms and needs that patients experience, for example due to time or intervention limitations.[32, 36]

Last decade, healthcare is shifting towards a more person-centred approach, including nephrology care.[1-3, 37] In addition to the traditional clinical measures, there is a stronger focus on the patient's perspective and outcomes that matter to patients.[5, 37, 38] Systematic assessment of PROs can solve the under-recognition of outcomes like HRQOL and symptom burden, and support this personalized and holistic treatment approach.[25, 39] PROs consider experienced health and should thus be assessed from the patient's perspective. PROs can be systematically assessed using PROMs.[40-42]

Patient-reported outcome measures

PROMs are questionnaires that assess aspects of patients' perceived health, such as HRQOL and symptom burden. PROMs are reported by the patients themselves; support may be offered when filling in PROMs, as long as responses reflect the patient's perspective.[40-42]

Many different PROMs exist, using various measurement methods and characteristics. For example, PROMs are often classified as either generic or specific for a certain disease, condition or treatment.[40, 41] Generic PROMs include widely relevant health aspects and are particularly suitable for heterogeneous populations (e.g. multimorbid populations like CKD), and enable comparisons across populations and treatments.[40, 41] A specific PROM is tailored to a certain disease, condi-

tion or treatment, and is particularly suitable for comparisons within a population, as they are usually better able to detect smaller or specific changes.[40, 41] Furthermore, PROMs can be fixed (i.e. nonadaptive) or adaptive. Traditional PROMs are fixed, meaning that it contains the same questions and order for any patient at any timepoint. Adaptive PROMs are relatively novel in healthcare and make use of computerized adaptive tests (CATs), in which the next question is selected based on the answer to previous questions, adapting to the patient's ability.[43] An example of an adaptive PROM is the Patient-Reported Outcomes Measurement Information System (PROMIS).[43] Moreover, PROMs can vary for instance in the underlying measurement method, number of questions, recall period, scoring scale and method, and reference standard.[44] The features of the PROM influence the interpretation of the PROM-scores.[42] In contrast to well-known clinical measures such as blood pressure, healthcare professionals, patients and researchers are often not yet familiar with the interpretation of PROM-scores. Understanding of the PROMs and the interpretation of its PROM-scores are needed for optimal use in clinical practice.

Many different PROMs are available[41, 44-47] and which PROM is suitable for clinical practice does not only depend on the characteristics (e.g. generic or specific, measurement method and scoring) and psychometric quality (e.g. validity and reliability) of the available PROMs, but also on the population and clinical setting.[42] For example: the purpose of measuring the PRO (e.g. use during consultations), the setting (e.g. opportunity to integrate into workflow) and the homogeneity of the population (e.g. variation in experienced health or digital skills). Hence, it is important to deliberately select PROMs, so that they fit routine practice. For nephrology care, the 12-item Short-Form Health Survey (SF-12) to assess generic HRQOL was recommended by an European expert consensus group.[48] Moreover, they underlined the importance of measuring symptom burden in addition to HRQOL, but no consensus was reached on the preferred PROM to assess symptom burden.[48]

The potential of using PROMs in healthcare

PROMs have the potential to contribute to a more person-centred approach.[3, 4, 49-51] PROMs can provide insight into and a more complete picture of how the patient is really doing by incorporating the patient's perspective, complementary to traditional clinical measures. Hence, using PROMs may enhance shared decision making and facilitate personalized treatment.[6, 7, 50, 51] Moreover, literature suggests that the use of PROMs may even result in better health outcomes, for example better symptom management, less hospitalizations and better HRQOL.[5, 52] However,

the majority of existing literature is theoretical and little research has been done in nephrology care.[6, 50, 53] Therefore, research in real-world nephrology care is needed to examine these potential benefits of using PROMs.

Theoretically, the use of PROMs can contribute to clinical practice at multiple levels: at individual patient-level and at aggregated population-level. For example, individual PROM-results can support shared decision making by facilitating patient-professional communication and discussion about patients' experiences and needs.[6, 7, 50, 51] Aggregated PROM-results can inform patients (and healthcare professionals) about prognosis, treatment and factors influencing PROs.[6] In addition, aggregated PROM-results can be used to evaluate healthcare quality.[6, 54, 55] Ideally, PROMs are integrated into routine care in such a way that it provides valuable information at both the individual patient-level and the aggregated population-level.[55, 56] These different purposes must be taken into account and require a structured approach in the implementation of PROMs into routine care.

Implementation of PROMs into routine nephrology care

In nephrology, the importance of PROs is widely recognized and first steps are taken to identify outcomes that matter to patients by the Standardised Outcomes in Nephrology (SONG) initiative[57] and by the International Consortium for Health Outcomes Measurement (ICHOM).[58] However, PROMs have not been widely implemented yet into routine nephrology care.[48, 59] A few examples exist and show that implementation can be challenging, for instance reaching adequate response rates, incorporation into the workflow, and struggles due to lack of knowledge on how to interpret, discuss and intervene on PROM-results.[60-63] Furthermore, literature suggests that the incorporation of PROMs requires engagement from all people involved: patients, healthcare professionals, researchers and policy makers.[61, 62, 64] Patients receiving dialysis treatment have frequent healthcare encounters and dialysis care has a strong infrastructure, which provides a good basis for reaching all people involved and implementation into the existing workflow.[65]

In the Netherlands, we establish a nationwide project to develop and implement PROMs into nephrology care (PROMs-NNL), in close collaboration with all relevant stakeholders: patients (Dutch Kidney Patients Association; NVN), healthcare professionals (Dutch Federation for Nephrology; NFN), researchers (Leiden University Medical Centre; LUMC) and the healthcare quality institute of nephrology care (Nefrovisie Foundation). PROMs will be part of the data collection in RENINE, the Dutch renal registry (www.renine.nl), to ensure nationwide support and minimal burden for healthcare centres.[48, 66] PROMs will be firstly introduced within routine dialysis care, given the relatively easy to reach population and suitable clinical set-

1

ting.[65] The PROMs-NNL project comprises the following four steps to implement PROMs into routine nephrology care in the Netherlands (Figure 1):

Step 1: determine information about which PROs is important and for what purpose.
Step 2: select the best suitable PROMs to measure these PROs, taking into account the aim and setting.
Step 3: pilot test the use of PROMs in clinical practice; are these PROMs suitable and what are feasible methods to collect and provide feedback on PROM-results?
Step 4: make adjustments based on the lessons learned and implement PROMs into routine care at national level. Implementation involves using, evaluating and adjusting iteratively to achieve optimal use of PROMs.

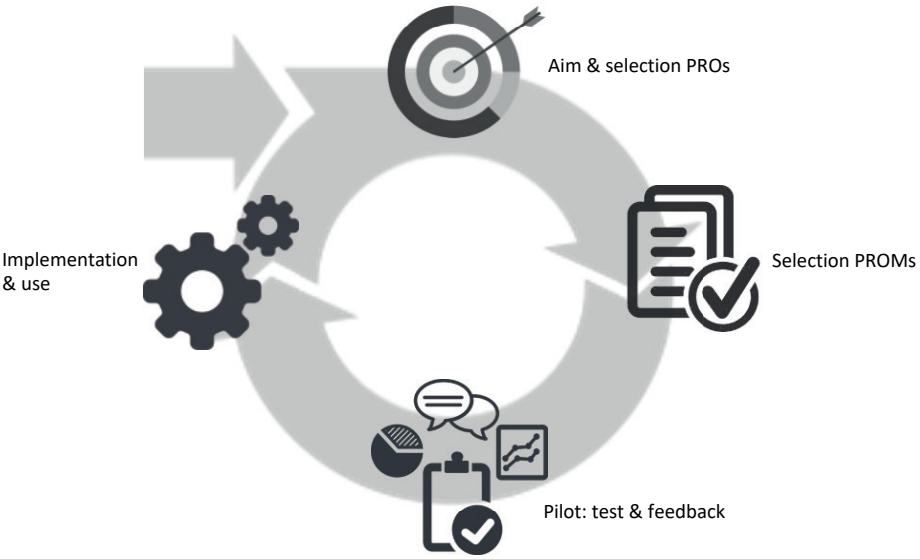

Figure 1. Steps for implementation of PROMs into routine care (PROMs-NNL study).

This dissertation comprises the scientific research performed in each step and aims to provide insight into and practical knowledge of the implementation and use of PROMs in routine nephrology care.

Outline of this thesis

The existing literature shows that HRQOL and symptom burden are highly prioritized by patients and healthcare professionals.[24, 27-29] Information about these PROs can contribute to a personalized treatment both at individual patient-level during consultations and at aggregated level to better inform patients and to evaluate healthcare quality.[6, 50, 54, 55] Therefore, these predetermined aims and PROs are used in the second step.

Chapter 2 describes the selection of the best suitable existing PROM to assess disease-specific symptom burden for routine assessment in nephrology care. We use a four-phase mixed methods approach, including a systematic literature search to identify existing PROMs and symptom clusters, assessment of PROMs based on predefined criteria regarding content validity, and selection based on feedback of two panels with patients and experts. In **Chapter 3**, we examine and compare psychometric properties of two recommended and commonly used generic PROMs to assess HRQOL. This study investigates the content, construct validity and test-retest reliability of seven PROMIS CATs in comparison with the SF-12 in patients with advanced CKD.

Chapter 4 describes the experiences and results of the first introduction of PROMs into Dutch routine nephrology care; the third step. We conduct a pilot study in 16 dialysis centres across the Netherlands, covering a quarter of all Dutch patients receiving dialysis treatment. We use quantitative and qualitative research methods to explore the use and collection of PROMs (e.g. PROM-scores and response rates), and the provision of feedback on PROM-results (e.g. patients' views on individual feedback) as part of routine dialysis care. Building on the findings, the PROMs infrastructure can be optimized for implementation and use of PROMs in routine dialysis care throughout the Netherlands (the fourth step).

At population level, PROM-results can be used to evaluate healthcare quality and to inform patients and professionals about the effects and course of disease or treatment. In **Chapter 5**, we explain how funnel plots can be used to compare healthcare providers on PROs to evaluate healthcare quality. This review provides insight into the use and interpretation of funnel plots by explaining the basic principles, pitfalls and considerations when applied to PROs, using examples of the first year routinely collected PROMs-data from Dutch dialysis care (i.e. RENINE/PROMs registry data). **Chapter 6** shows an example of aggregated PROM-results that can be used to inform patients and healthcare professionals. In this chapter, we use the RENINE/PROMs registry data of 2978 patients to investigate the impact of itching on HRQOL in patients receiving dialysis treatment. The effects of itching on HRQOL and interactions with sleep problems and psychological symp-

toms are examined both cross-sectionally and longitudinally over a 2-year period. For optimal use of PROMs in individual patients, knowledge on how to interpret and discuss PROM-results is needed. In **Chapter 7**, we explain the different types and characteristics of PROMs and provide guidance on how to interpret individual PROM-scores and changes in PROM-scores over time. Concepts such as minimal detectable change, minimal important change and response shift are explained and illustrated with examples from nephrology care. In **Chapter 8**, we investigate how to optimally discuss PROM-results as part of routine care. Individual semi-structured interviews are performed to gain in-depth understanding of patients' and healthcare professionals' experiences with and perspectives on discussing PROM-results in routine dialysis care.

Finally, in **Chapter 9** we summarize and discuss our results, and provide suggestions for future research and clinical implications regarding the implementation and use of PROMs in routine care.

References

1. World Health Organization. Regional Office for the Western P. People-centred health care: technical papers: International Symposium on People-Centred Health Care: Reorienting Health Systems in the 21st Century, The Tokyo International Forum, 25 November 2007. WHO Regional Office for the Western Pacific, Manila: 2008; 2008

2. Porter ME. What is value in health care? *N Engl J Med* 2010;363(26):2477-81

3. Feldthusen C, Forsgren E, Wallström S, et al. Centredness in health care: A systematic overview of reviews. *Health Expect* 2022;25(3):885-901

4. Lewis S. Realizing the PROMise of PROMs. *Healthc Pap* 2011;11(4):20-3; discussion 55-8

5. McLaren S, Jhamb M, Unruh M. Using Patient-Reported Measures to Improve Outcomes in Kidney Disease. *Blood Purif* 2021;50(4-5):649-54

6. Schick-Makaroff K, Levay A, Thompson S, et al. An Evidence-Based Theory About PRO Use in Kidney Care: A Realist Synthesis. *The Patient - Patient-Centered Outcomes Research* 2022;15(1):21-38

7. Noonan VK, Lyddiatt A, Ware P, et al. Montreal Accord on Patient-Reported Outcomes (PROs) use series - Paper 3: patient-reported outcomes can facilitate shared decision-making and guide self-management. *J Clin Epidemiol* 2017;89:125-35

8. KDIGO. 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 (Supl. 1):1-150

9. Webster AC, Nagler EV, Morton RL, Masson P. Chronic Kidney Disease. *The Lancet* 2017;389(10075):1238-52

10. Bikbov B, Purcell CA, Levey AS, et al. Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet* 2020;395(10225):709-33

11. Hill NR, Fatoba ST, Oke JL, et al. Global Prevalence of Chronic Kidney Disease – A Systematic Review and Meta-Analysis. *PLOS ONE* 2016;11(7):e0158765

12. Jager KJ, Fraser SDS. The ascending rank of chronic kidney disease in the global burden of disease study. *Nephrol Dial Transplant* 2017;32(suppl_2):ii121-ii8

13. Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int* 2015;88(3):447-59

14. K/DOQI. Clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis* 2002;39(2 Suppl 1):S1-266

15. Abrahams AC, van Jaarsveld BC. [Dialysis in end-stage kidney disease]. *Ned Tijdschr Geneeskd* 2020;164

16. Lindsay RM, Heidenheim PA, Nesrallah G, Garg AX, Suri R. Minutes to Recovery after a Hemodialysis Session: A Simple Health-Related Quality of Life Question That Is Reliable, Valid, and Sensitive to Change. *Clinical Journal of the American Society of Nephrology* 2006;1(5):952-9

17. Elsayed MM, Zeid MM, Hamza OMR, Elkholy NM. Dialysis recovery time: associated factors and its association with quality of life of hemodialysis patients. *BMC Nephrolo-*

gy 2022;23(1):298

18. Bello AK, Okpechi IG, Osman MA, et al. Epidemiology of haemodialysis outcomes. *Nat Rev Nephrol* 2022;18(6):378-95

19. Verberne WR, Dijkers J, Kelder JC, et al. Value-based evaluation of dialysis versus conservative care in older patients with advanced chronic kidney disease: a cohort study. *BMC Nephrol* 2018;19(1):205

20. Couser WG, Remuzzi G, Mendis S, Tonelli M. The contribution of chronic kidney disease to the global burden of major noncommunicable diseases. *Kidney International* 2011;80(12):1258-70

21. van Oosten MJM, Logtenberg SJJ, Leegte MJH, et al. Age-related difference in health care use and costs of patients with chronic kidney disease and matched controls: analysis of Dutch health care claims data. *Nephrol Dial Transplant* 2020;35(12):2138-46

22. Go AS, Chertow GM, Fan D, McCulloch CE, Hsu CY. Chronic kidney disease and the risks of death, cardiovascular events, and hospitalization. *N Engl J Med* 2004;351(13):1296-305

23. Almutary H, Bonner A, Douglas C. Symptom burden in chronic kidney disease: a review of recent literature. *J Ren Care* 2013;39(3):140-50

24. Fletcher BR, Damery S, Aiyegbusi OL, et al. Symptom burden and health-related quality of life in chronic kidney disease: A global systematic review and meta-analysis. *PLoS Med* 2022;19(4):e1003954

25. Raj R, Ahuja KD, Frandsen M, Jose M. Symptoms and their recognition in adult haemodialysis patients: Interactions with quality of life. *Nephrology (Carlton)* 2017;22(3):228-33

26. Murtagh FE, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. *Adv Chronic Kidney Dis* 2007;14(1):82-99

27. Manns B, Hemmelgarn B, Lillie E, et al. Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol* 2014;9(10):1813-21

28. Urquhart-Secord R, Craig JC, Hemmelgarn B, et al. Patient and Caregiver Priorities for Outcomes in Hemodialysis: An International Nominal Group Technique Study. *Am J Kidney Dis* 2016;68(3):444-54

29. 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

30. Tommel J, Evers AWM, van Hamersvelt HW, et al. "What matters to you?": The relevance of patient priorities in dialysis care for assessment and clinical practice. *Semin Dial* 2022

31. González AM, Gutman T, Lopez-Vargas P, et al. Patient and Caregiver Priorities for Outcomes in CKD: A Multinational Nominal Group Technique Study. *Am J Kidney Dis* 2020;76(5):679-89

32. Weisbord SD, Fried LF, Mor MK, et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007;2(5):960-7

33. Pugh-Clarke K, Read SC, Sim J. Symptom experience in non-dialysis-dependent chronic kidney disease: A qualitative descriptive study. *J Ren Care* 2017;43(4):197-208

34. Aresi G, Rayner HC, Hassan L, et al. Reasons for Underreporting of Uremic Pruritus in People With Chronic Kidney Disease: A Qualitative Study. *J Pain Symptom Manage* 2019;58(4):578-86.e2

35. Flythe JE, Dorough A, Narendra JH, Forfang D, Hartwell L, Abdel-Rahman E. Perspectives on symptom experiences and symptom reporting among individuals on hemodialysis. *Nephrol Dial Transplant* 2018;33(10):1842-52

36. Feldman R, Berman N, Reid MC, et al. Improving symptom management in hemodialysis patients: identifying barriers and future directions. *J Palliat Med* 2013;16(12):1528-33

37. Kalantar-Zadeh K, Li PK, Tantisattamo E, et al. Living well with kidney disease by patient and care partner empowerment: kidney health for everyone everywhere. *Transpl Int* 2021;34(3):391-7

38. Al Sayah F, Lahtinen M, Bonsel GJ, Ohinmaa A, Johnson JA. A multi-level approach for the use of routinely collected patient-reported outcome measures (PROMs) data in healthcare systems. *Journal of Patient-Reported Outcomes* 2021;5(2):98

39. Kalantar-Zadeh K, Lockwood MB, Rhee CM, et al. Patient-centred approaches for the management of unpleasant symptoms in kidney disease. *Nat Rev Nephrol* 2022;18(3):185-98

40. Weldring T, Smith SM. Patient-Reported Outcomes (PROs) and Patient-Reported Outcome Measures (PROMs). *Health Serv Insights* 2013;6:61-8

41. Tang E, Bansal A, Novak M, Mucsi I. Patient-Reported Outcomes in Patients with Chronic Kidney Disease and Kidney Transplant-Part 1. *Front Med (Lausanne)* 2017;4:254

42. De Vet HC, Terwee CB, Mokkink LB, Knol DL. Measurement in medicine: a practical guide. Cambridge university press: 2011;

43. Cella D, Riley W, Stone A, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *J Clin Epidemiol* 2010;63(11):1179-94

44. Flythe JE, Karlsson N, Sundgren A, et al. Development of a preliminary conceptual model of the patient experience of chronic kidney disease: a targeted literature review and analysis. *BMC Nephrol* 2021;22(1):233

45. Aiyegbusi OL, Kyte D, Cockwell P, et al. Measurement properties of patient-reported outcome measures (PROMs) used in adult patients with chronic kidney disease: A systematic review. *PLoS One* 2017;12(6):e0179733

46. Flythe JE, Powell JD, Poulton CJ, et al. Patient-Reported Outcome Instruments for Physical Symptoms Among Patients Receiving Maintenance Dialysis: A Systematic Review. *Am J Kidney Dis* 2015;66(6):1033-46

47. Nair D, Wilson FP. Patient-Reported Outcome Measures for Adults With Kidney Disease: Current Measures, Ongoing Initiatives, and Future Opportunities for Incorporation Into Patient-Centered Kidney Care. *Am J Kidney Dis* 2019;74(6):791-802

48. Breckenridge K, Bekker HL, Gibbons E, et al. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant* 2015;30(10):1605-14

49. Carfora L, Foley CM, Hagi-Diakou P, et al. Patients' experiences and perspectives of patient-reported outcome measures in clinical care: A systematic review and qualitative

meta-synthesis. *PLoS One* 2022;17(4):e0267030

50. Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. *J Patient Rep Outcomes* 2018;2:42

51. Etkind SN, Daveson BA, Kwok W, et al. Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference? A systematic review. *J Pain Symptom Manage* 2015;49(3):611-24

52. Basch E, Deal AM, Kris MG, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol* 2016;34(6):557-65

53. Johnson JA, Al Sayah F, Buzinski R, et al. A cluster randomized controlled trial for the Evaluation of routinely Measured PATient reported outcomes in HemodialYsis care (EMPATHY): a study protocol. *BMC Health Serv Res* 2020;20(1):731

54. Greenhalgh J, Dalkin S, Gibbons E, et al. How do aggregated patient-reported outcome measures data stimulate health care improvement? A realist synthesis. *J Health Serv Res Policy* 2018;23(1):57-65

55. Van Der Wees PJ, Nijhuis-Van Der Sanden MW, Ayanian JZ, Black N, Westert GP, Schneider EC. Integrating the use of patient-reported outcomes for both clinical practice and performance measurement: views of experts from 3 countries. *Milbank Q* 2014;92(4):754-75

56. Bingham CO, 3rd, Noonan VK, Auger C, Feldman DE, Ahmed S, Bartlett SJ. Montreal Accord on Patient-Reported Outcomes (PROs) use series - Paper 4: patient-reported outcomes can inform clinical decision making in chronic care. *J Clin Epidemiol* 2017;89:136-41

57. Standardised Outcomes in Nephrology (SONG). https://songinitiative.org/

58. International Consortium for Health Outcomes Measurement (ICHOM). https://www.ichom.org/

59. Anderson N, Kyte D, McMullan C, et al. Electronic patient-reported outcomes in chronic kidney disease. *Nat Rev Nephrol* 2022;18(12):739-40

60. Nimmo A, Bell S, Brunton C, et al. Collection and determinants of patient reported outcome measures in haemodialysis patients in Scotland. *Qjm* 2018;111(1):15-21

61. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. *J Patient Rep Outcomes* 2018;2:46

62. Boyce MB, Browne JP, Greenhalgh J. 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 Qual Saf* 2014;23(6):508-18

63. Anderson NE, McMullan C, Calvert M, et al. Using patient-reported outcome measures during the management of patients with end-stage kidney disease requiring treatment with haemodialysis (PROM-HD): a qualitative study. *BMJ Open* 2021;11(8):e052629

64. Apel C, Hornig C, Maddux FW, Ketchersid T, Yeung J, Guinsburg A. Informed decision-making in delivery of dialysis: combining clinical outcomes with sustainability. *Clin Kidney J* 2021;14(Suppl 4):i98-i113

65. Flythe JE, Narendra JH, Hilliard T, et al. Cultivating a Research-Ready Dialysis Community. *J Am Soc Nephrol* 2019;30(3):375-80

66. van der Veer SN, Couchoud C, Morton RL. The role of kidney registries in expediting large-scale collection of patient-reported outcome measures for people with chronic kidney disease. *Clinical Kidney Journal* 2021;14(6):1495-503