

# BMJ Open Shared decision-making in advanced kidney disease: a scoping review

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## ABSTRACT

**Objectives** To provide a comprehensive overview of interventions that support shared decision-making (SDM) for treatment modality decisions in advanced kidney disease (AKD). To provide summarised information on their content, use and reported results. To provide an overview of interventions currently under development or investigation.

**Design** The JBI methodology for scoping reviews was followed. This review conforms to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist.

**Data sources** MEDLINE, Embase, Web of Science, Cochrane Library, Emcare, PsycINFO, PROSPERO and Academic Search Premier for peer-reviewed literature. Other online databases (eg, clinicaltrials.gov, OpenGrey) for grey literature.

**Eligibility for inclusion** Records in English with a study population of patients >18 years of age with an estimated glomerular filtration rate <30 mL/min/1.73 m<sup>2</sup>. Records had to be on the subject of SDM, or explicitly mention that the intervention reported on could be used to support SDM for treatment modality decisions in AKD.

**Data extraction and synthesis** Two reviewers independently screened and selected records for data extraction. Interventions were categorised as prognostic tools (PTs), educational programmes (EPs), patient decision aids (PtDAs) or multicomponent initiatives (MIs). Interventions were subsequently categorised based on the decisions they were developed to support.

**Results** One hundred forty-five interventions were identified in a total of 158 included records: 52 PTs, 51 EPs, 29 PtDAs and 13 MIs. Sixteen (n=16, 11%) were novel interventions currently under investigation. Forty-six (n=46, 35.7%) were reported to have been implemented in clinical practice. Sixty-seven (n=67, 51.9%) were evaluated for their effects on outcomes in the intended users.

**Conclusion** There is no conclusive evidence on which intervention is the most efficacious in supporting SDM for treatment modality decisions in AKD. There is a lot of variation in selected outcomes, and the body of evidence is largely based on observational research. In addition, the effects of these interventions on SDM are under-reported.

## INTRODUCTION

Over 2 million patients with kidney failure currently rely on kidney replacement therapy (KRT) to stay alive.<sup>1</sup> This number has been estimated to double by 2030,<sup>2</sup> and many

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The search queries for this scoping review were conducted without time period restrictions and generated comprehensive results covering all possible interventions that support SDM for treatment modality decisions in AKD.
- ⇒ Two reviewers independently used predeveloped charting and data-extraction tables to screen the literature, select records for inclusion and extract the relevant data.
- ⇒ The interventions identified in the included records are presented based on the decisions they were developed to support, after which information is provided on their content, format, evidence and availability.
- ⇒ Included records were not formally assessed for quality; potential risks of bias in the reported outcomes remain undetermined.
- ⇒ Interventions and/or findings from records not written in English, or records inaccessible due to subscription limitations or internet protocol address geo-blocking, are not reported.

patients with advanced kidney disease (AKD) will have to make treatment modality decisions as their kidneys deteriorate over time.

Guidelines on the management of chronic kidney disease (CKD) emphasise the importance of timely kidney failure treatment modality education and decisional support as patients progress to the more advanced stages of kidney disease.<sup>3 4</sup> Delays in the decision-making process can result in suboptimal dialysis initiation, which is associated with increased patient morbidity, mortality and healthcare costs.<sup>5</sup>

Shared decision-making (SDM) has been recognised as the preferred model to help patients with AKD understand their treatment options, and make informed decisions that align with their values and preferences.<sup>6 7</sup> SDM requires that patients and clinicians proactively engage in a collaborative decision-making process.<sup>8–10</sup> This process should be characterised by deliberation, during which patients become aware of their choice, understand all of their options

and get to consider what matters most to them. A three-step framework has been developed to help guide this decision-making process with the following conversational steps in clinical practice: (1) team talk, (2) option talk and (3) decision talk.<sup>10</sup> In addition, educational programmes (EPs) and decision support interventions such as patient decision aids (PtDAs) and prognostic tools (PTs) can be used to support deliberation and help patients and clinicians engage in SDM.<sup>10</sup> Multiple efforts have been made to foster SDM across the international healthcare community,<sup>11 12</sup> but there are still signs that patients experience a low degree of SDM,<sup>13</sup> and efforts to incentivise SDM risk being limited to the promotion of PtDAs.<sup>14 15</sup> A broader sense of awareness and knowledge of SDM is needed for it to become widely implemented,<sup>8</sup> and stakeholders should share their experiences to speed up this process.<sup>16</sup>

We previously set out to write a scoping review on interventions that can support SDM for treatment modality decisions in AKD after we showcased a lack of a comprehensive overview of these interventions in the literature.<sup>17</sup> We performed an additional preliminary search on the MEDLINE database prior to the conduct of this review and did not identify previous scoping reviews on the topic aligning to the same concept. We did identify a scoping review on the information available for clinicians counselling older patients with kidney failure,<sup>18</sup> a systematic review on PtDAs developed to support SDM between dialysis and conservative care management (CCM) pathways,<sup>19</sup> a scoping review on predialysis EPs,<sup>20</sup> a systematic review on PTs developed to predict kidney failure<sup>21</sup> and a Cochrane review on the effects of PtDAs in people facing treatment or screening decisions.<sup>22</sup>

We conducted this scoping review to provide clinicians, researchers and other stakeholders with one comprehensive, but digestible source of information on interventions that can support SDM for treatment modality decisions in AKD. An overview of interventions currently under development or investigation is also provided. We hope that this review will facilitate the future implementation of SDM in clinical practice, as well as stimulate development and research on new and effective interventions by exploring and defining knowledge gaps on the subject.

## METHODS

We followed the JBI methodology for scoping reviews<sup>23</sup> and our scoping review protocol<sup>17</sup> when we conducted this scoping review. Our objectives, research questions and methods are specified in our protocol (see online supplemental appendix 1). In addition to the protocol, we also used: (1) more detailed inclusion criteria during the screening and inclusion process and (2) the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) checklist<sup>24</sup> (see online supplemental appendix 2) when we completed the review. No other changes were made in the methodology described in our protocol.

## Objectives

In brief, our objectives were to provide:

1. a comprehensive overview of interventions that can support SDM for treatment modality decisions in AKD;
2. summarised information on their contents, use and reported results;
3. an overview of interventions currently under development or investigation.

## Inclusion criteria

We searched the peer-reviewed and grey literature for records on interventions that support SDM for treatment modality decisions in AKD. We considered any intervention in standard care that can support deliberation and/or help patients and clinicians engage in SDM (eg, EPs, PtDAs, PTs) an SDM intervention. No time period restriction was used in an effort to be as comprehensive as possible. Records were eligible for inclusion if they were written in English, and if the study population consisted of patients >18 years of age with an estimated glomerular filtration rate <30 mL/min/1.73 m<sup>2</sup>. Records had to be on the subject of SDM or explicitly mention that the reported interventions could be used to support SDM for treatment modality decisions in AKD. Records that reported on interventions that could clearly be used to support SDM without explicitly mentioning it were also included.

## Exclusion criteria

We excluded records if:

- ▶ they only reported on interventions for advance care planning;
- ▶ they only reported on interventions for the withdrawal of treatment.

## Search methodology

We performed a three-step search strategy as explained in the JBI methodology for scoping reviews<sup>23</sup> and in our review protocol<sup>17</sup> (see online supplemental appendix 1). We searched MEDLINE, Embase, Web of Science, Cochrane Library, Emcare, PsycINFO, PROSPERO and Academic Search Premier for peer-reviewed literature. We searched OpenGrey, researchgate.net, clinicaltrials.gov, europepmc.org, Google Scholar and websites of the Kidney Disease Improving Global Outcomes Association, the Renal Physicians Association, the American Society of Nephrology, the Canadian Society of Nephrology, the National Institute of Health and Care Excellence, the European Renal Association—European Dialysis and Transplant Association, the Kidney Health Australia—Caring for Australians with Renal Impairment Association and the Ottawa Hospital Research Institute for grey literature.

A research librarian generated the search queries (see online supplemental appendix 3). The results were uploaded in RefWorks V.2.0.

## Record selection and data extraction

We used previous publications, the International Patient Decision Aids Standards (IPDAS) minimum standards criteria<sup>25</sup> and the Standards for UNiversal reporting of patient Decision Aid evaluation (SUNDAE) checklist<sup>26</sup> to design charting and data-extraction tables used for record selection and data extraction. Two reviewers (NE and GNdG) independently performed the process of record selection and data extraction. Disagreements were resolved by discussion or consultation with the research team (PvdN, MvdD, WJB, AMS).

We initially screened the titles and abstracts of all identified records after which the charting table was used to register records selected for full-text analysis in Microsoft Excel V.16. We then performed full-text analysis of the selected records during which a final selection was made for data extraction. We also screened the references of this selection for additional records on the subject.

Selected records were categorised based on record type and on their scope and context as mentioned by the authors and developers. We categorised the interventions we identified in these records based on whether these interventions were PTs, EPs or PtDAs. Interventions were categorised as multicomponent initiatives (MIs) when two or more of these interventions were combined to support patients with AKD in treatment modality decisions, or implement SDM in clinical practice. We subsequently categorised the identified interventions based on the decisions they were developed to support.

Extracted data included: primary author; developer; date of publication; country of origin; type of record; study population/target demographic; study aims; study methods; sample size; study arms; intervention; format and context of the intervention; contents of the intervention; patient participation in development; comparator; study outcomes; reports on outcomes of SDM; use of International Consortium for Health Outcomes Measurement (ICHOM)<sup>27</sup> or Standardised Outcomes in Nephrology (SONG)<sup>28</sup> outcomes; main findings; implemented in clinical practice; recruitment status; date of completion and/or publication.

## Patient and public involvement

Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

## RESULTS

Figure 1 illustrates a flow chart of the screening and inclusion process. We conducted the final search query in February 2021. We identified 1512 records and included a total of 158 records. Records were excluded because they were on another subject (n=1215, 80.3%), not available (n=127, 8.4%), not in English (n=57, 3.8%), duplicates (n=34, 2.2%), reviews (n=28, 1.9%) on the wrong population (n=27, 1.8%) or protocols for completed studies (n=24, 1.6%).

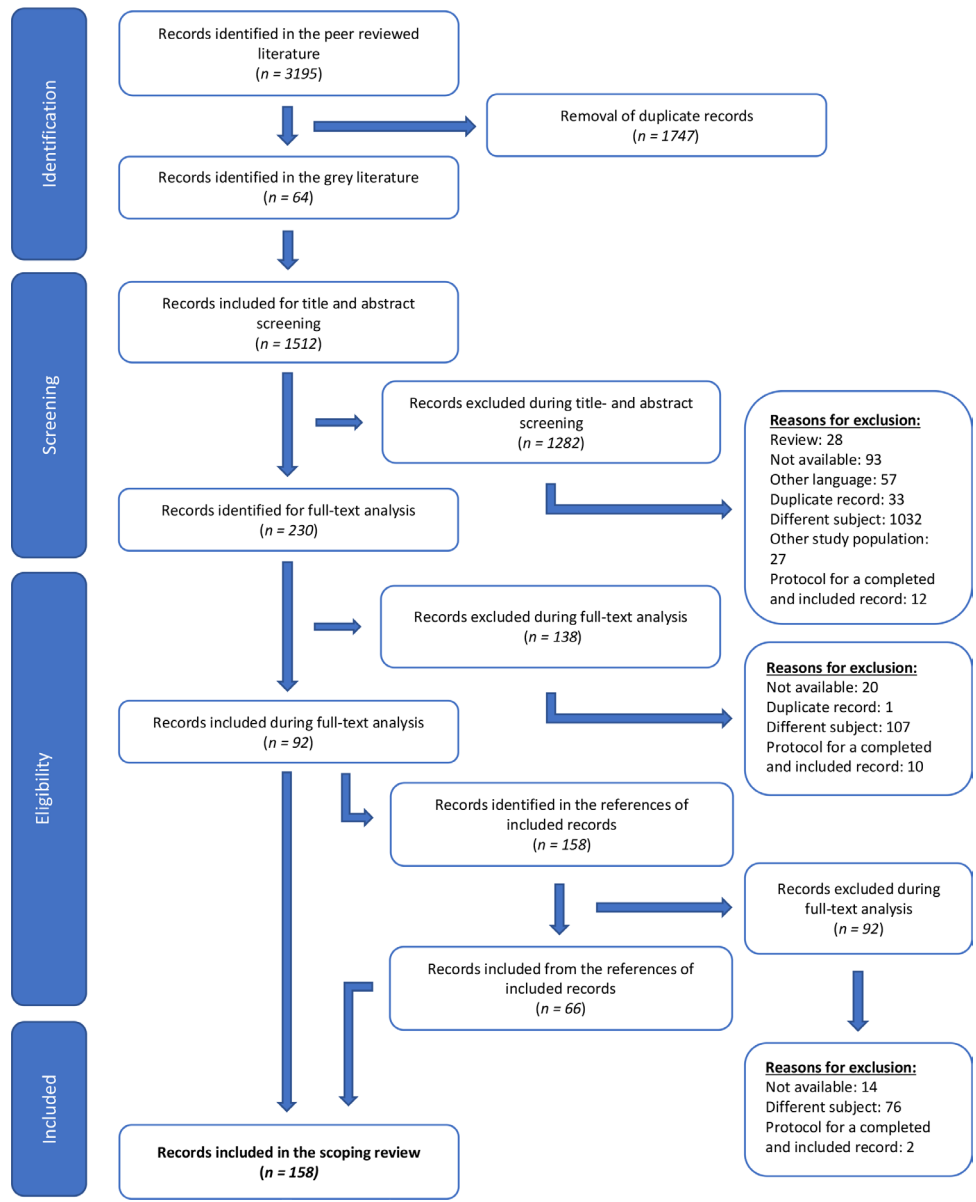
Figure 2 illustrates the included records stratified by type, scope and context. The majority of these records are observational (n=68, 43.0%) and experimental studies (n=39, 24.7%). A smaller proportion are study protocols (n=17, 10.8%), meeting abstracts (n=16, 10.1%), mixed-methods studies (n=12, 7.6%) and websites (n=6, 3.8%). Most records report on EPs (n=62, 39.2%), followed by PTs (n=42, 26.6%), PtDAs (n=37, 23.4%) and MIs (n=17, 10.8%).

We identified 145 interventions in the included records. Figure 3 illustrates the distribution of these interventions. The majority of these records are PTs (n=52, 35.9%) and EPs (n=51, 35.2%), followed by PtDAs (n=29, 20.0%) and MIs (n=13, 8.9%). Some of these interventions were only identified in meeting abstracts (n=14, 9.7%). A minority were novel interventions that we identified in study protocols (n=16, 11.0%). Figures 4 and 5 illustrate the implementation and evaluation rates of the identified interventions. About one-third of the interventions (n=46, 35.7%) were reported to have been implemented in clinical practice. About half of the interventions (n=67, 51.9%) were evaluated for their effects on outcomes in the intended users. PTs were the interventions with the least information on implementation status and were the least evaluated interventions, followed by PtDAs, EPs and MIs. Interventions were generally evaluated on health-related outcomes and on knowledge, decisional quality, communication and patient activation. Patients that were exposed to the interventions generally had better outcomes than patients that were not exposed to the interventions.

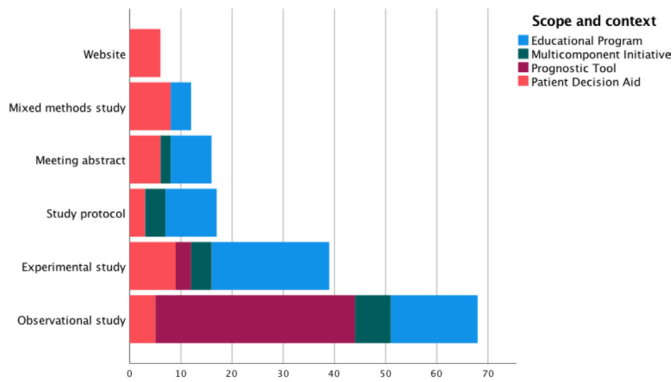
## Prognostic tools

We identified 52 PTs. All PTs were identified in peer-reviewed articles.<sup>29-59</sup>

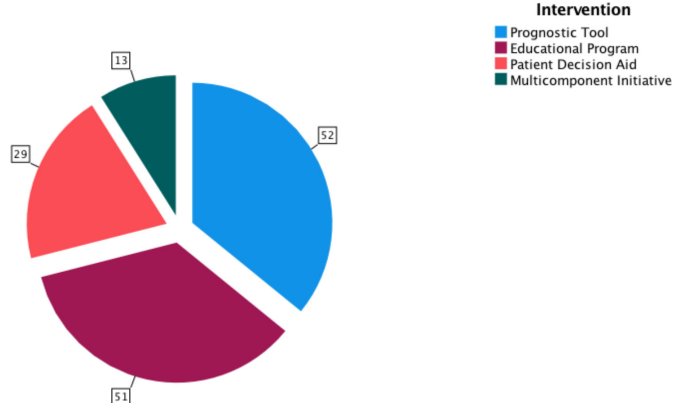
Table 1 provides an overview of the identified PTs with their characteristics and performance metrics. Table S1 in online supplemental appendix 4 provides additional details on the identified PTs (eg, sources for publicly available PTs). Nineteen PTs predict the risk of progression to kidney failure (no. 1-19) and help patients and clinicians decide whether or not patients should start with preparations for kidney failure. One PT also predicts the risk of cardiovascular disease and death (no. 19). Twenty-eight PTs predict the risk of death after starting dialysis (no. 20-47) and help patients and clinicians decide whether or not patients should choose to start dialysis. Two PTs predict the risk of death after starting CCM (no. 48, 49) and help patients and clinicians decide whether or not patients should choose to start CCM. One PT predicts the risk of death after starting dialysis or transplantation (no. 50) and helps patients and clinicians decide between dialysis and transplantation options. One PT predicts the risk of deceased donor kidney graft failure (no. 51) and helps patients and clinicians decide whether or not patients should accept a deceased donor kidney transplantation offer. One PT predicts the risk of living donor kidney graft failure (no. 52) and helps patients and



**Figure 1** Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) flow chart of screening and inclusion process.

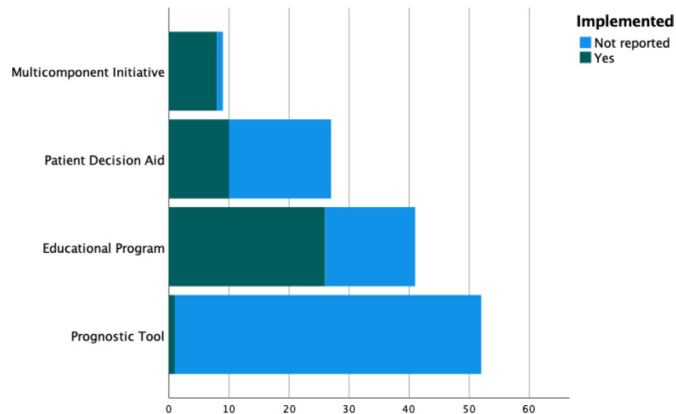


**Figure 2** Included records stratified by record type, scope and context.



**Figure 3** Distribution of the different types of interventions.





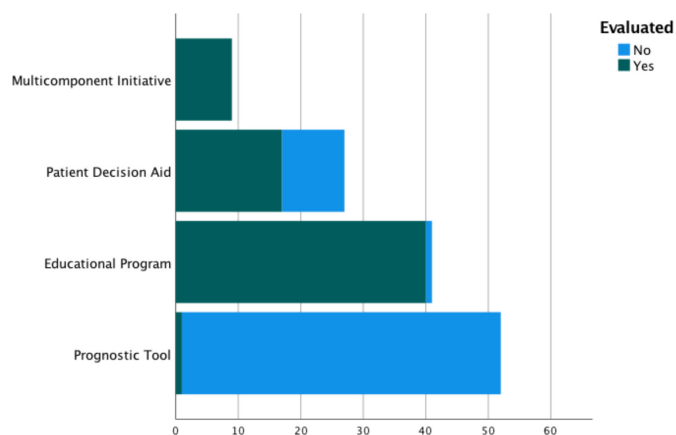
**Figure 4** Stacked bar count of the interventions stratified by implementation status. \*Interventions currently under investigation (n=16, 11.0%) are not shown here.

clinicians decide whether or not patients should accept a living donor kidney transplantation (LDKT) offer.

A relatively large proportion (n=19, 36.5%) of the identified PTs were developed to be used in elderly patients with AKD (no. 4, 25, 26, 28–31, 33, 34, 40–49). The remaining PTs can be used in the general population of patients with AKD.

The majority of PTs (n=32, 61.5%) are publicly available as formulas (no. 2–5, 7–19, 22, 24, 35–39, 46–52), eight of which (no. 2, 3, 19, 38, 39, 50–52) can be used on interactive websites. One of these PTs (no. 50) has been designed as a PtDA. Point-based scoring systems (no. 1, 20, 21, 25–34, 45) and nomograms (no. 44) were also used, although less frequently (n=14, 26.9%, n=1, 1.9%). A minority of PTs (n=6, 11.5%) are not publicly available (no. 6, 23, 40–43) and depend on computer software to be used.

Not all PTs were completely validated (assessed for performance) during development. About a quarter (n=11, 21.2%) were not evaluated on calibration outcomes (no. 22, 23, 26, 30, 34, 40–43, 51, 52), and some (n=2, 3.8%) were not validated at all (no. 20, 21). Most of them (n=37, 71.2%) were developed and validated



**Figure 5** Stacked bar count of the interventions stratified by evaluation status. \*Interventions currently under investigation (n=16, 11.0%) are not shown here.

with the same cohort of patients (no. 1, 6, 7, 9–18, 22–26, 28–33, 40–52). A quarter (n=13, 25.0%) were developed and validated with different patient cohorts (no. 2–5, 8, 19, 27, 34–39). The discriminatory power of the PTs was generally acceptable, one-fourth (n=13, 25.0%) had C-statistics below 0.7 on all, or a subset of, predictions (no. 9, 28–30, 34, 39, 41, 43, 46, 48, 50–52). The remaining PTs had better C-statistics.

Table 2 provides an overview of the PTs (no. 2–5, 19, 20, 25, 26, 30, 33, 51, 52) that were externally validated in independent external validation studies.<sup>31 32 46 55 60–69</sup>

Table S2 in online supplemental appendix 4 provides additional details on these external validation studies. One PT (no. 2) was externally validated in six different studies,<sup>32 60–63 67</sup> two other PTs (no. 3, 25) were externally validated in three<sup>31 62 67</sup> and four different studies,<sup>46 55 64 66</sup> respectively. The other nine (no. 4, 5, 19, 20, 26, 30, 33, 51, 52) were externally validated less frequently.

The majority of the PTs (n=10, 83.3%) were externally validated in different patient populations (no. 2, 3, 4, 5, 19, 20, 25, 26, 30, 33) than the ones they were developed for. Three PTs had poor discriminatory power in these patient populations (no. 2, 30, 33), with C-statistics between 0.5 and 0.6.<sup>63 66</sup> Performance metrics were generally comparable between developmental and external validation studies when similar patient populations were used (see tables 1 and 2). Only one PT (no. 50) was reported to have been implemented in clinical practice. This PT was designed as a PtDA<sup>57</sup> and is in that regard the only PT that has been evaluated for its effects on outcomes in the intended users.<sup>70</sup>

### Educational programmes

We identified 41 EPs (excluding ten currently under investigation). Thirty-five were identified in peer-reviewed articles.<sup>71–104</sup> Six were identified in meeting abstracts found in the grey literature.<sup>105–110</sup>

Table 3 provides an overview of the identified EPs and their characteristics. Table S3 in online supplemental appendix 4 provides additional details on the identified EPs (eg, sources for publicly available EPs). One EP was developed to promote peritoneal dialysis (PD) and helps patients choose whether to start with PD or not (no. 1). Eleven EPs help patients choose between dialysis options (no. 2–11), with two promoting a particular treatment modality (no. 5, 11). Ten help patients choose between dialysis and transplantation options (no. 12–21), with two promoting a particular treatment modality (no. 13, 14). Seven EPs were developed to promote LDKT (no. 2–28) and help patients decide whether to pursue LDKT or not. Two EPs help patients choose between dialysis and CCM options (no. 29, 30). Seven help patients choose between transplantation, dialysis and CCM options (no. 31–37), one of which promotes home therapy modalities (no. 37). Four EPs help patients choose between transplantation options (no. 38–41).

**Table 1** Overview of the identified PTs, their characteristics and performance metrics

PT	Prediction*	Format	Population†	Validation	Discrimination‡	Calibrations§	External validation	Implemented	Evaluated
Start preparation for kidney failure?									
No. 1: Johnson prognostic score	5-year risk of kidney failure	Point-based scoring system	Patients with CKD stage 3-4	Bootstrapping	C-statistic=0.89	Calibration plot and Hosmer-Lemeshow test ( $p>0.99$ )	No	Not reported	No
No. 2: 4-variable kidney failure risk equation	1. 1-year risk of kidney failure 2. 3-year risk of kidney failure 3. 5-year risk of kidney failure	1. Formula 2. Interactive website	Patients with CKD stage 3-5	External sample	1. C-statistic 1-year risk of kidney failure=0.85 2. C-statistic 3-year risk of kidney failure=0.83 3. C-statistic 5-year risk of kidney failure=0.83	Calibration plot and Nam and D'Agostino statistic 3-year risk of kidney failure (32)	Yes	Not reported	No
No. 3: 8-variable kidney failure risk equation	1. 1-year risk of kidney failure 2. 3-year risk of kidney failure 3. 5-year risk of kidney failure	1. Formula 2. Interactive website	Patients with an eGFR <30mL/min/1.73 m <sup>2</sup>	1. Bootstrapping 2. External sample	1. C-statistic 1-year risk of kidney failure=0.86 2. C-statistic 3-year risk of kidney failure=0.84 3. C-statistic 5-year risk of kidney failure=0.84	Calibration plot and Nam and D'Agostino statistic 3-year risk of kidney failure (19)	Yes	Not reported	No
No. 4: Drawz prognostic model	1-year risk of kidney failure	Formula	Patients >65 years of age with an eGFR <30mL/min/1.73 m <sup>2</sup>	1. Bootstrapping 2. External sample	1. C-statistic bootstrapping=0.85 2. C-statistic external sample=0.82	Calibration plot	Yes	Not reported	No
No. 5: Marks prognostic model	5-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	External sample	C-statistic=0.94	Calibration plot and Hosmer-Lemeshow statistic (4.6)	Yes	Not reported	No
No. 6: Norouzi prognostic model	1. eGFR after 6 months 2. eGFR after 12 months 3. eGFR after 18 months	Computer software package	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	Comparison of performance in training and testing datasets	1. Mean absolute error after 6 months=4.76 2. Mean absolute error after 12 months=5.50 3. Mean absolute error after 18 months=5.95	1. Calibration plot eGFR after 6 months 2. Calibration plot eGFR after 12 months 3. Calibration plot eGFR after 18 months	No	Not reported	No
No. 7: Tangri dynamic prognostic model	Time to kidney failure (dynamic)	Formula	Patients with CKD stage 3-5	1. Bootstrapping 2. Cross-validation	C-statistic=0.91	Calibration plot and Hosmer-Lemeshow statistic (<20)	No	Not reported	No
No. 8: Schroeder prognostic model	5-year risk of kidney failure	Formula	Patients with CKD stage 3-4	1. Bootstrapping 2. External sample	C-statistic=0.95	Calibration plot	No	Not reported	No
No. 9: 2-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	1. Bootstrapping 2. Split sample	1. C-statistic bootstrapping=0.56 2. C-statistic split sample=0.56	1. Nam and D'Agostino statistic bootstrapping (5.40) 2. Nam and D'Agostino statistic split sample (7.48)	No	Not reported	No
No. 10: 3-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	1. C-statistic bootstrapping=0.84 2. C-statistic split sample=0.83	1. C-statistic bootstrapping=0.84 2. C-statistic split sample=0.83	1. Nam and D'Agostino statistic bootstrapping (16.9) 2. Nam and D'Agostino statistic split sample (16)	No	Not reported	No
No. 11: 4-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with CKD stage 3-5	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.87	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.87	1. Nam and D'Agostino statistic bootstrapping (8.54) 2. Nam and D'Agostino statistic split sample (6.03)	No	Not reported	No
No. 12: 5-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with CKD stage 3-4	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.86	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.86	1. Nam and D'Agostino statistic bootstrapping (8.45) 2. Nam and D'Agostino statistic split sample (6.61)	No	Not reported	No
No. 13: 6-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.86	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.86	1. Nam and D'Agostino statistic bootstrapping (8.79) 2. Nam and D'Agostino statistic split sample (5.41)	No	Not reported	No
No. 14: 7-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.86	1. C-statistic bootstrapping=0.87 2. C-statistic split sample=0.86	1. Nam and D'Agostino statistic bootstrapping (7.88) 2. Nam and D'Agostino statistic split sample (6.63)	No	Not reported	No
No. 15: 8-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	1. C-statistic bootstrapping=0.88 2. C-statistic split sample=0.87	1. C-statistic bootstrapping=0.88 2. C-statistic split sample=0.87	1. Nam and D'Agostino statistic bootstrapping (7.12) 2. Nam and D'Agostino statistic split sample (4.61)	No	Not reported	No
No. 16: 9-variable CKD-JAC clinical prediction model	3-year risk of kidney failure	Formula	Patients with an eGFR <60mL/min/1.73 m <sup>2</sup>	1. C-statistic bootstrapping=0.88 2. C-statistic split sample=0.87	1. C-statistic bootstrapping=0.88 2. C-statistic split sample=0.87	1. Nam and D'Agostino statistic bootstrapping (6.54) 2. Nam and D'Agostino statistic split sample (4.20)	No	Not reported	No

Continued

Table 1 Continued

PT	Prediction*	Format	Population†	Validation	Discrimination‡	Calibrations§	External validation	Implemented	Evaluated
No. 17: 10-variable CRD-JAC clinical prediction model	3-year risk of kidney failure	Formula			1. C-statistic bootstrapping=0.88 2. C-statistic split sample=0.87	1. Nam and D'Agostino statistic bootstrapping (5.77) 2. Nam and D'Agostino statistic split sample (3.27)	No	Not reported	No
No. 18: 11-variable CRD-JAC clinical prediction model	3-year risk of kidney failure	Formula			1. C-statistic bootstrapping=0.88 2. C-statistic split sample=0.87	1. Nam and D'Agostino statistic bootstrapping (6.92) 2. Nam and D'Agostino statistic split sample (4.38)	No	Not reported	No
No. 19: CKD-PC risk	1. 2-year risk of kidney failure 2. 4-year risk of kidney failure 3. 2-year risk of cardiovascular disease 4. 4-year risk of cardiovascular disease 5. Death within 2 years 6. Death within 4 years	1. Formula 2. Interactive website	Patients with an eGFR <30 mL/min/1.73 m <sup>2</sup>	External sample	C-statistic 2-year risk of kidney failure=0.81	Calibration plot 2-year risk of kidney failure	No	Not reported	No
Start with dialysis or not?									
No. 20: Foley prognostic score	Death within 6 months of dialysis initiation	Point-based scoring system	Patients on dialysis	No	No	No	Yes	Not reported	No
No. 21: Barret prognostic score	Death within 6 months of dialysis initiation	Point-based scoring system	Patients on dialysis (PD/HD)	No	No	No	No	Not reported	No
No. 22: Geiddes multivariate prognostic model	1. Death within 1 year of KRT initiation 2. Death within 5 years of KRT initiation	Formula	Patients on KRT	Split sample	1. PPV 1 year=80.4% 2. NPV 1 year=47% 3. PPV 5 years=77% 4. NPV 5 years=74%	No	No	Not reported	No
No. 23: Geiddes self-learning rule-based model	1. Death within 1 year of KRT initiation 2. Death within 5 years of KRT initiation	Computer software package			1. PPV 1 year=84.2% 2. NPV 1 year=32% 3. PPV 5 years=63.1% 4. NPV 5 years=74.2%	No	No	Not reported	No
No. 24: Mauri prognostic model	Death within 1 year of HD initiation	Formula	Patients on HD	Split sample	C-statistic=0.78	Calibration plot and Hosmer-Lemeshow test (p=0.49)	No	Not reported	No
No. 25: 6-month REIN score	Death within 6 months of dialysis initiation	Point-based scoring system	Patients >75 years of age on dialysis	Split sample	C-statistic=0.70	Calibration plot and Hosmer-Lemeshow test (p=0.93)	Yes	Not reported	No
No. 26: 3-month REIN score	Death within 3 months of dialysis initiation	Point-based scoring system	Patients >75 years of age on dialysis	Split sample	C-statistic=0.75	No	Yes	Not reported	No
No. 27: Duseux prognostic score	Death within 3 years of dialysis initiation	Point-based scoring system	Patients with an eGFR <60 mL/min/1.73 m <sup>2</sup>	External sample	C-statistic=0.71	Calibration plot and Hosmer-Lemeshow test (p=0.23)	No	Not reported	No
No. 28: Weiss prognostic score (age 65-79 years)	1. Death within 6 months after dialysis initiation 2. Death within 2 years after dialysis initiation	Point-based scoring system	Patients >70 years of age on dialysis (PD/HD)	Bootstrapping	1. C-statistic 6-month mortality=0.68 2. C-statistic 2-year mortality=0.68	1. Calibration plot and Hosmer-Lemeshow test 6-month mortality (p=0.14) 2. Calibration plot and Hosmer-Lemeshow test 2-year mortality (p=0.14)	No	Not reported	No
No. 29: Weiss prognostic score (age >80 years)	1. Death within 6 months after dialysis initiation 2. Death within 2 years after dialysis initiation	Point-based scoring system	Patients >67 years of age on dialysis	Split sample	1. C-statistic 6-month mortality=0.69 2. C-statistic 2-year mortality=0.69	1. Calibration plot and Hosmer-Lemeshow test 6-month mortality (p=0.07) 2. Calibration plot and Hosmer-Lemeshow test 2-year mortality (p=0.74)	No	Not reported	No
No. 30: 7-variable Thamer prognostic score	1. Death within 3 months after dialysis initiation 2. Death within 6 months after dialysis initiation	Point-based scoring system	Patients >67 years of age on dialysis	Split sample	1. C-statistic 3-month mortality=0.69 2. C-statistic 6-month mortality=n.a.	No	Yes	Not reported	No
No. 31: 14-variable Thamer prognostic score	1. Death within 3 months after dialysis initiation 2. Death within 6 months after dialysis initiation	Point-based scoring system			1. C-statistic 3-month mortality=0.71 2. C-statistic 6-month mortality=0.71	1. Calibration plot 3-month mortality 2. Calibration plot 6-month mortality	Yes	Not reported	No
No. 32: Doi prognostic score	Death within 1 year of HD initiation	Point-based scoring system	Patients on HD	Bootstrapping	C-statistic=0.83	Calibration plot	No	Not reported	No
No. 33: Wick prognostic score	Death within 6 months of dialysis initiation	Point-based scoring system	Patients >65 years of age on dialysis (PD/HD)	Cross-validation	C-statistic=0.72	Calibration plot and Hosmer-Lemeshow test (p=0.20)	Yes	Not reported	No

Continued

**Table 1** Continued

PT	Prediction*	Format	Population†	Validation	Discrimination‡	Calibration§	External validation	Implemented	Evaluated
No. 34: Chen prognostic score	Death within 5 years of dialysis initiation	Point-based scoring system	Patients >70 years of age on dialysis (PD/HD)	1. Split sample 2. External sample	1. C-statistic split sample=0.71 2. C-statistic external sample=0.60	No	No	Not reported	No
No. 35: Haapio prognostic model	Death within 1 year of dialysis initiation	Formula	Patients on dialysis (PD/HD)	External sample	C-statistic=0.76	Calibration plot and Hosmer-Lemeshow test (p=0.041)	No	Not reported	No
No. 36: Haapio prognostic model	Death within 2 years of dialysis initiation	Formula			C-statistic=0.74	Calibration plot and Hosmer-Lemeshow test (p=0.015)	No	Not reported	No
No. 37: Schmidt prognostic model	Death within 1 year	Formula	Patients with CKD stage 4–5	External sample	C-statistic=0.74	Calibration plot and Hosmer-Lemeshow test (p=0.46)	No	Not reported	No
No. 38: Dialysis score (for patients with eGFR <15 mL/min/1.73 m <sup>2</sup> )	Death within 1 year of dialysis initiation	1. Formula 2. Interactive website	Patients on dialysis	1. Split sample 2. External sample	1. C-statistic split sample validation=0.71 2. C-statistic external sample (men)=0.77 3. C-statistic external sample (women)=0.74	1. Calibration plot split sample 2. Calibration plot external sample	No	Not reported	No
No. 39: dialysis score (for patients with eGFR ≥15 mL/min/1.73 m <sup>2</sup> )	Death within 1 year of dialysis initiation	1. Formula 2. Interactive website			1. C-statistic split sample=0.66 2. C-statistic external sample (men)=0.71 3. C-statistic external sample (women)=0.67	1. Calibration plot split sample 2. Calibration plot external sample	No	Not reported	No
No. 40: Lin random forest prediction model	Medical costs 1 year after dialysis initiation	Computer software package	Patients >65 years of age on dialysis	Comparison of performance in training and testing datasets	Mean absolute error=0.51	No	No	Not reported	No
No. 41: Lin random forest mortality prediction model	Death within 1 year after dialysis initiation	Computer software package			C-statistic=0.66	No	No	Not reported	No
No. 42: Lin artificial neural network model for costs	Medical costs 1 year after dialysis initiation	Computer software package			Mean absolute error=1.85	No	No	Not reported	No
No. 43: Lin artificial neural network model for mortality	Death within 1 year after dialysis initiation	Computer software package			C-statistic=0.68	No	No	Not reported	No
No. 44: Yoshida clinical nomogram	1. Death within 3 months of dialysis initiation 2. Death within 6 months of dialysis initiation 3. Death within 12 months of dialysis initiation	Nomogram	Patients >80 years of age on dialysis	Bootstrapping	1. C-statistic 3-month survival=0.83 2. C-statistic 6-month survival=0.82 3. C-statistic 12-month survival=0.81	1. Calibration plot and Hosmer-Lemeshow test 3-month survival (p=0.619) 2. Calibration plot and Hosmer-Lemeshow test 6-month survival (p=0.582) 3. Calibration plot and Hosmer-Lemeshow test 12-month survival (p=0.187)	No	Not reported	No
No. 45: Santos prognostic score	Death within 6 months of dialysis initiation	Point-based scoring system	Patients >65 years of age on dialysis (PD/HD)	Bootstrapping	C-statistic=0.79	Calibration plot and Hosmer-Lemeshow test (p=0.58)	No	Not reported	No
No. 46: Ranspek basic dialysis prognostic model	Death within 2 years of dialysis initiation	Formula	Patients >70 years of age with CKD stage 4–5	Bootstrapping	C-statistic=0.68	Calibration plot and calibration-in-the-large (32.5% vs 32.6%)	No	Not reported	No
No. 47: Ranspek extended dialysis prognostic model	Death within 2 years of dialysis initiation	Formula			C-statistic=0.75	Calibration plot and calibration-in-the-large (32.5% vs 32.6%)	No	Not reported	No
Start with CCM or not?									
No. 48: Ranspek basic CCM prognostic model	Death within 2 years of conservative care initiation	Formula	Patients >70 years of age with CKD stage 4–5	Bootstrapping	C-statistic=0.68	Calibration plot and calibration-in-the-large (56.3% vs 56.5%)	No	Not reported	No
No. 49: Ranspek extended CCM prognostic model	Death within 2 years of conservative care initiation	Formula			C-statistic=0.73	Calibration plot and calibration-in-the-large (56.3% vs 56.3%)	No	Not reported	No
Transplantation or dialysis?									

Continued



**Table 1** Continued

PT	Prediction*	Format	Population†	Validation	Discrimination‡	Calibrations§	External validation	Implemented	Evaluated
No. 50: iChoose Kidney	1. Death within 1 year of dialysis initiation 2. Death within 3 years of dialysis initiation 3. Death within 1 year of transplantation (DDKT/LDKT) 4. Death within 3 years of transplantation (DDKT/LDKT)	1. Formula 2. Interactive website	1. Patients on dialysis 2. Kidney transplantation recipients	Split sample	1. C-statistic dialysis 1-year mortality=0.69 2. C-statistic dialysis 3-year mortality=0.70 3. C-statistic transplantation 1-year mortality=0.69 4. C-statistic DDKT 1-year mortality=0.66 5. C-statistic LDKT 1-year mortality=0.74 6. C-statistic transplantation 3-year mortality=0.70 7. C-statistic DDKT 3-year mortality=0.66 8. C-statistic LDKT 3-year mortality=0.72	1. Calibration plot dialysis 3-year mortality 2. Calibration plot transplantation 3-year mortality	No	Yes	Yes
Accept or decline DDKT offer?									
No. 51: Kidney Donor Risk Index	Risk of deceased donor kidney graft failure	1. Formula 2. Interactive website	DDKT recipients	Cross-validation	C-statistic=0.62	No	Yes	Not reported	No
Accept or decline LDKT offer?									
No. 52: Living Kidney Donor Risk Index	Risk of living donor kidney graft failure	1. Formula 2. Interactive website	LDKT recipients	Bootstrapping	C-statistic=0.59	No	Yes	Not reported	No

\*Predictor formulated as reported in identified records.  
†Population formulated as reported in identified records.  
‡Discrimination describes how accurately a tool identifies a high probability of events in patients with the outcome of interest and is expressed as a slope or C-statistic. A C-statistic of 0.5 represents no predictive discrimination and a C-statistic of 1 represents perfect predictive discrimination. When the C-statistic is >0.7, a score has acceptable discriminatory power.  
§Calibration describes how accurately a tool identifies a high probability of events in patients with the outcome of interest and is expressed as a slope or C-statistic. A C-statistic of 0.5 represents no predictive discrimination and a C-statistic of 1 represents perfect predictive discrimination. When the C-statistic is >0.7, a score has acceptable discriminatory power.  
¶Abbreviations: AKD, acute kidney disease; CKD, chronic kidney disease; C-statistic, concordance statistic; DDKT, deceased donor kidney transplantation; eGFR, estimated glomerular filtration rate; HD, haemodialysis; IAC, Japan cohort; KRT, kidney replacement therapy; LDKT, living donor kidney transplantation; n.a., not applicable; NPV, negative predictive value; PD, peritoneal dialysis; PPV, positive predictive value; PTA, prognostic tools; REN, Renal Epidemiology and Information Network.

Most EPs were developed for the general population of patients with AKD, however some (n=5, 12.2%) were specifically developed for Hispanic and African-American patients (no. 20, 26–28, 40), and some (n=3, 7.3%) were specifically developed for suboptimal dialysis initiation patients (no. 13, 14, 31).

About one-third of the EPs (n=14, 34.1%) consist of a single medium format (no. 1, 6–11, 17, 20, 21, 28, 35–37). The remaining programmes consist of a combination of different medium formats. About half of the EPs (n=20, 48.8%) use coaches to guide patients through the programme (no. 3, 12–14, 18, 19, 22, 23, 25, 27, 28, 30–35, 39–41). A minority (n=7, 17.0%) were developed with the input of patients (no. 1, 10, 20, 26, 38–40) and even less (n=3, 7.3%) describe a reading level (no. 25, 39, 40). Only a few EPs (n=2, 4.9%) are publicly available (no. 20, 32).

More than half of the EPs (n=26, 63.4%) were reported to have been implemented in clinical practice (no. 2–6, 8, 11–19, 21, 26–34, 36). All but one (no. 33) have been evaluated for their effects on outcomes in the intended users.

Table 4 provides an overview of the studies<sup>71–86 88–118</sup> that evaluated the identified EPs. Table S4 in online supplemental appendix 4 provides additional details on these studies. The majority of these EPs (n=19, 47.5%) were evaluated in experimental studies (no.1, 3, 5, 7, 16, 19, 20, 22–27, 29, 35, 38–41), more than half of which (n=14, 73.7%) were randomised controlled trials (RCTs).<sup>71 74 86 88 90–92 101–103 111–113 115</sup> Less (n=16, 40.0%) were evaluated in observational studies (no.2, 4, 6, 11–15, 17, 18, 21, 28, 30–32, 34), a minority of which (n=4, 25.0%) were prospective cohort studies.<sup>76 94 95 117</sup> Five (n=5, 12.5%) EPs (no.8–10, 36, 37) were evaluated in studies presented in meeting abstracts.<sup>105–107 109 110</sup>

EPs were generally evaluated for their effects on health-related outcomes and on knowledge, communication and patient activation. None of the EPs were evaluated for their effects on SDM. Thirteen (n=13, 31.7%) EPs (no.1, 8, 9, 10, 11, 21, 34, 35, 36, 37, 39, 40, 41) were evaluated in studies published after the standardised outcome sets for CKD, dialysis and transplantation were published by ICHOM and SONG. None of these EPs were evaluated with these outcomes. EPs that promote particular treatment modalities (no.1, 5, 11, 13, 14, 22–28) appear to increase the number of patients planning to start with the promoted modalities (see table 4). Patients exposed to EPs generally had more favourable health-related outcomes than patients that were not exposed to EPs (see table 4). They were also more knowledgeable about their treatment options, better equipped to communicate about their treatment options and more active in choosing and requesting a preferred treatment modality (see table 4).

### Patient decision aids

We identified 27 PtDAs (excluding two currently under investigation). Fourteen were identified in peer-reviewed

**Table 2** Overview of PTs validated in independent external validation studies

PT	Source	Population*	Prediction†	Discrimination‡	Calibration§
Start preparation for kidney failure?					
No. 2	Retrospective cohort study <sup>60</sup>	African-American patients with an eGFR between 20 and 65 mL/min/1.73 m <sup>2</sup>	1. 1-year risk of kidney failure 2. 5-year risk of kidney failure	1. C-statistic 1-year risk of kidney failure=0.98 2. C-statistic 5-year risk of kidney failure=0.83	No
No. 2	Retrospective cohort study <sup>61</sup>	Patients with CKD stage 2–5	3-year risk of kidney failure	C-statistic=0.91	Calibration plot
No. 2	Multicentre retrospective cohort study <sup>62</sup>	Patients with an eGFR <60 mL/min/1.73 m <sup>2</sup>	5-year risk of kidney failure	C-statistic=0.95	Calibration plot
No. 2	Retrospective cohort study <sup>62</sup>	Patients with CKD stage 3–5	5-year risk of kidney failure	C-statistic=0.88	Calibration plot and Hosmer-Lemeshow test (p=0.05)
No. 3			5-year risk of kidney failure	C-statistic=0.89	Calibration plot and Hosmer-Lemeshow test (p=0.03)
No. 2	Multicentre retrospective cohort study <sup>67</sup>	Patients with CKD stage 3–5	1. 2-year risk of kidney failure 2. 5-year risk of kidney failure	1. C-statistic 2-year risk of kidney failure=0.90 2. C-statistic 5-year risk of kidney failure=0.88	1. Calibration plot 2-year risk of kidney failure 2. Calibration plot 5-year risk of kidney failure
No. 3			1. 2-year risk of kidney failure 2. 5-year risk of kidney failure	1. C-statistic 2-year risk of kidney failure=0.90 2. C-statistic 5-year risk of kidney failure=0.88	1. Calibration plot 2-year risk of kidney failure 2. Calibration plot 5-year risk of kidney failure
No. 3	Retrospective cohort study <sup>31</sup>	Patients >65 years of age with an eGFR <30 mL/min/1.73 m <sup>2</sup>	1-year risk of kidney failure	1. C-statistic development cohort=0.78 2. C-statistic validation cohort=0.78	No
No. 2	Multicentre prospective cohort study <sup>63</sup>	Patients >75 years of age with an eGFR <20 mL/min/1.73 m <sup>2</sup>	1. 2-year risk of kidney failure 2. 5-year risk of kidney failure	1. C-statistic 2-year risk of kidney failure=0.59 2. C-statistic 5-year risk of kidney failure=0.57	1. Calibration plot and Hosmer-Lemeshow test 2-year risk of kidney failure (p=0.57) 2. Calibration plot and Hosmer-Lemeshow test 5-year risk of kidney failure (p=0.70)
No. 4			1-year risk of kidney failure	C-statistic=0.66	Calibration plot and Hosmer-Lemeshow test (p=0.47)
No. 5			5-year risk of kidney failure	C-statistic=0.65	Calibration plot and Hosmer-Lemeshow test (p=0.72)
No. 19			1. 2-year risk of kidney failure 2. 4-year risk of kidney failure	1. C-statistic 2-year risk of kidney failure=0.64 2. C-statistic 4-year risk of kidney failure=0.65	1. Calibration plot and Hosmer-Lemeshow test 2-year risk of kidney failure (p=0.85) 2. Calibration plot and Hosmer-Lemeshow test 4-year risk of kidney failure (p=0.41)
Start with dialysis or not?					
No. 25	Multicentre retrospective cohort study <sup>64</sup>	Patients >67 years of age on dialysis	Death within 6 months of dialysis initiation	C-statistic=0.63	No
No. 25	Multicentre retrospective cohort study <sup>65</sup>	Patients >67 years of age on dialysis	Death within 6 months of dialysis initiation	1. C-statistic development cohort=0.66 2. C-statistic validation cohort=0.67	1. Calibration plot development cohort 2. Calibration plot validation cohort
No. 25	Retrospective cohort study <sup>65</sup>	Patients >65 years of age on dialysis (PD/HD)	Death within 6 months of dialysis initiation	C-statistic=0.70	No
No. 26	Multicentre retrospective cohort study <sup>65</sup>	Patients on dialysis	1. Death within 3 months of dialysis initiation 2. Death within 6 months of dialysis initiation 3. Death within 12 months of dialysis initiation	1. C-statistic 3-month mortality=0.74 2. C-statistic 6-month mortality=0.74 3. C-statistic 12-month mortality=0.74	No
No. 20	Retrospective cohort study <sup>66</sup>	Patients >75 years of age on dialysis	Death within 6 months of dialysis initiation	C-statistic=0.67	Calibration plot and Hosmer-Lemeshow test (p=0.004)
No. 25			Death within 6 months of dialysis initiation	C-statistic=0.61	Calibration plot and Hosmer-Lemeshow test (p=0.45)
No. 26			Death within 3 months of dialysis initiation	C-statistic=0.62	Calibration plot and Hosmer-Lemeshow test (p=0.03)
No. 30			1. Death within 3 months after dialysis initiation 2. Death within 6 months after dialysis initiation	1. C-statistic 3-month mortality=0.57 2. C-statistic 6-month mortality=n.a.	1. Calibration plot and Hosmer-Lemeshow test 3-month mortality (p=0.43) 2. Calibration plot 6-month mortality
No. 33			Death within 6 months of dialysis initiation	C-statistic=0.57	Calibration plot and Hosmer-Lemeshow test (p=0.43)
Accept or decline DDKT offer?					
No. 51	Multicentre retrospective cohort study <sup>68</sup>	DDKT recipients	1. 6-month DDKT graft survival 2. 1-year DDKT graft survival 3. 3-year DDKT graft survival 4. 5-year DDKT graft survival 5. 7.5-year DDKT graft survival	1. C-statistic 6-month DDKT graft survival=0.62 2. C-statistic 1-year DDKT graft survival=0.63 3. C-statistic 3-year DDKT graft survival=0.63 4. C-statistic 5-year DDKT graft survival=0.63 5. C-statistic 7.5-year DDKT graft survival=0.63	1. Calibration plot 6-month DDKT graft survival 2. Calibration plot 1-year DDKT graft survival 3. Calibration plot 3-year DDKT graft survival 4. Calibration plot 5-year DDKT graft survival 5. Calibration plot 7.5-year DDKT graft survival
Accept or decline LDKT offer?					
No. 52	Retrospective cohort study <sup>69</sup>	LDKT recipients	Risk of living donor kidney graft failure	C-statistic=0.55	Calibration plot

\*Population formulated as reported in identified records.

†Prediction formulated as reported in identified records.

‡Discrimination describes how accurately a tool identifies a high probability of events in patients with the outcome of interest and is expressed as a slope or C-statistic. A C-statistic of 0.5 represents no predictive discrimination and a C-statistic of 1 represents perfect predictive discrimination. When the C-statistic is &gt;0.7, a score has acceptable discriminatory power.

§Calibration describes the agreement between the observed and predicted outcomes and is generally expressed with a calibration plot, a calibration slope, as calibration-in-the-large or a goodness-of-fit test. A calibration plot compares the predicted risks with observed risks within subgroups of patients and provides the most information on calibration accuracy.

CKD, chronic kidney disease; C-statistic, concordance statistic; DDKT, deceased donor kidney transplantation; eGFR, estimated glomerular filtration rate; HD, haemodialysis; LDKT, living donor kidney transplantation; n.a., not applicable; PD, peritoneal dialysis; PTs, prognostic tools.

**Table 3** Overview of the identified EPs and their characteristics

EP	Format	Treatment options*	Promotes treatment modality	Coaching	Patient participation in development	Reading level	Implemented	Evaluated
Start PD or not?								
No. 1: customised video counselling	1 video (32 min)	PD	PD	No	Yes	n.a.	Not reported	Yes
What type of dialysis modality?								
No. 2: Toronto Hospital multidisciplinary predialysis programme	<ol style="list-style-type: none"> <li>Multiple outpatient consultations with clinicians (n.a.)</li> <li>2 sessions of group education (n.a.)</li> <li>4 sessions of individual education with clinicians (2.5 hours total)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> </ol>	No	No	No	n.a.	Yes	Yes
No. 3: Karolinska Hospital predialysis patient education	<ol style="list-style-type: none"> <li>Multiple outpatient consultations with clinicians (n.a.)</li> <li>4 sessions of group education (6 hours total)</li> </ol>	<ol style="list-style-type: none"> <li>PD; CAPD</li> <li>HD</li> </ol>	No	Yes	No	n.a.	Yes	Yes
No. 4: Birmingham Heartlands Hospital predialysis counselling	<ol style="list-style-type: none"> <li>Multiple consultations with clinicians (n.a.)</li> <li>1 session of individual education with CAPD nurse (1–2 hours)</li> <li>Printed materials (n.a.)</li> <li>1 video (n.a.)</li> <li>Visits to treatment centres</li> <li>Chance to meet peer patients</li> </ol>	<ol style="list-style-type: none"> <li>PD; CAPD</li> <li>HD; in-centre</li> <li>HD; home</li> </ol>	No	No	No	n.a.	Yes	Yes
No. 5: Two-phase educational intervention	<ol style="list-style-type: none"> <li>Printed materials (4 manuals)</li> <li>1 video (15 min)</li> <li>1 session of group education (1.5 hours)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD; self-care</li> <li>HD; home</li> </ol>	Self-care dialysis modalities	No	No	n.a.	Yes	Yes
No. 6: dialysis education	Multiple outpatient consultations with clinicians (n.a.)	Dialysis	No	No	No	n.a.	Yes	Yes
No. 7: multimedia interactive patient education	1 DVD (n.a.)	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> </ol>	No	No	No	n.a.	Not reported	Yes
No. 8: comprehensive PDEP	Multiple sessions of individual education by nephrologists and experienced nurse (n.a.)	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> </ol>	No	No	No	n.a.	Yes	Yes
No. 9: physician-led CKD education programme	1 session of group education (n.a.)	Dialysis	No	No	No	n.a.	Not reported	Yes
No. 10: patient-driven video educational tool	1 video (50 min)	<ol style="list-style-type: none"> <li>Dialysis</li> <li>Transplantation</li> </ol>	No	No	Yes	n.a.	Not reported	Yes
No. 11: King Fahad Armed Forces Hospital PDEP	Multiple outpatient consultations with clinicians (n.a.)	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> </ol>	PD	No	No	n.a.	Yes	Yes
Transplantation or dialysis?								
No. 12: Cliniques Universitaires St. Luc PDEP	<ol style="list-style-type: none"> <li>Multiple outpatient consultations with clinicians (n.a.)</li> <li>Printed materials (1 brochure)</li> <li>3 videos (60 min total)</li> <li>Visits to treatment centres</li> <li>Chance to meet peer patients</li> </ol>	<ol style="list-style-type: none"> <li>PD; APD</li> <li>PD; CAPD</li> <li>HD; in-centre</li> <li>HD; self-care</li> <li>HD; home</li> <li>DDKT</li> <li>LDKT</li> </ol>	No	Yes	No	n.a.	Yes	Yes
No. 13: RTN	<ol style="list-style-type: none"> <li>Multiple in-hospital consultations with RTN (n.a.)</li> <li>Printed materials (n.a.)</li> <li>Audio/visual materials (n.a.)</li> <li>Websites (n.a.)</li> <li>1 DVD (n.a.)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD; home</li> <li>DDKT</li> <li>LDKT</li> </ol>	Independent KRT modalities	Yes	No	n.a.	Yes	Yes
No. 14: in-hospital CKD education programme	<ol style="list-style-type: none"> <li>3–5 in-hospital consultations with advanced nurse practitioner (n.a.)</li> <li>Printed materials (pamphlets, manuals, flipcharts)</li> <li>DVDs (n.a.)</li> <li>Visits to treatment centres</li> <li>Chance to meet peer patients</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD; in-centre</li> <li>HD; home</li> <li>Trans-plantation</li> </ol>	Home dialysis modalities	Yes	No	n.a.	Yes	Yes
No. 15: multidisciplinary predialysis education	<ol style="list-style-type: none"> <li>1 session of individual education with educator (1.5–2 hours)</li> <li>1 session of group education (2 hours)</li> <li>1 video (20 min)</li> <li>Printed materials (2 booklets)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> <li>Transplantation</li> </ol>	No	No	No	n.a.	Yes	Yes

Continued

Table 3 Continued

EP	Format	Treatment options*	Promotes treatment modality	Coaching	Patient participation in development	Reading level	Implemented	Evaluated
No. 16: Faculty of Medicine Ataturk University PDEP	1. Multiple outpatient consultations with clinicians (n.a.) 2. Printed materials (visual cards, written cards)	1. PD 2. HD 3. Transplantation	No	No	No	n.a.	Yes	Yes
No. 17: Information on Dialysis (INDIAL)	2 sessions of group education (4 hours total)	1. PD 2. HD 3. Transplantation	No	No	No	n.a.	Yes	Yes
No. 18: renal school	1. Multiple outpatient consultations with clinicians (n.a.) 2. Printed materials (brochures, illustrated books) 3. Videos (n.a.) 4. DVDs (n.a.) 5. Visits to treatment centres 6. Chance to meet peer patients	1. PD 2. HD 3. Transplantation	No	Yes	No	n.a.	Yes	Yes
No. 19: kidney team at home	1. Multiple outpatient consultations with clinicians (n.a.) 2. Home visits by health educators (3.5 hours total) 3. Printed materials (n.a.) 4. 1 DVD (n.a.)	1. PD 2. HD 3. DDKT 4. LDKT	No	Yes	No	n.a.	Yes	Yes
No. 20: Informe Acerca de la Donación de Riñón en Vida (informate)	Website	1. PD 2. HD 3. DDKT 4. LDKT	No	No	Yes	n.a.	Not reported	Yes
No. 21: Nissan Tamagawa Hospital multidisciplinary care Pursue LDKT or not?	4 outpatient consultations with clinicians (n.a.)	1. PD 2. HD 3. Transplantation	No	No	No	n.a.	Yes	Yes
No. 22: home-based educational intervention	1. 1 outpatient consultation with transplant surgeon/nephrologist (n.a.) 2. 1 session of group education (60 min) 3. 1 home visit by health educator (60–90 min) 4. Printed materials (pamphlets, brochures, booklets) 5. 1 video (13 min)	LDKT	LDKT	Yes	No	n.a.	Not reported	Yes
No. 23: promoting live donor kidney transplantation	1. 1 session of individual education with health educator (n.a.) 2. Printed materials (brochures, leaflets) 3. 1 video (10 min)	LDKT	LDKT	Yes	No	n.a.	Not reported	Yes
No. 24: increasing the pursuit of living kidney donation	1. Printed materials (n.a.) 2. 1 session of group education (2 hours) 3. Chance to meet living kidney donor recipients 4. Chance to meet living kidney donors	1. Dialysis 2. DDKT 3. LDKT 4. CCM	LDKT	No	No	n.a.	Not reported	Yes
No. 25: Talking about Live Kidney Donation	1. Multiple outpatient consultations with clinicians (n.a.) 2. 1 video (20 min) 3. Printed material (booklet) 4. 2 home visits by social workers (1 hour total)	LDKT	LDKT	Yes	No	Moderate to low health literacy	Not reported	Yes
No. 26: Living About Choices in Transplantation and Sharing	1. 1 DVD (30 min) 2. Printed materials (1 booklet)	LDKT	LDKT	No	Yes	n.a.	Yes	Yes
No. 27: Hispanic Kidney Transplant Programme	1. Multiple outpatient consultations with clinicians (n.a.) 2. 2 sessions of group education (n.a.)	1. DDKT 2. LDKT	LDKT	Yes	No	n.a.	Yes	Yes
No. 28: patient navigator and education programme Dialysis or CCM?	Multiple sessions of individual education with patient navigators (n.a.)	1. DDKT 2. LDKT	LDKT	Yes	No	n.a.	Yes	Yes

Continued

Table 3 Continued

EP	Format	Treatment options*	Promotes treatment modality	Coaching	Patient participation in development	Reading level	Implemented	Evaluated
No. 29: St. Paul's Hospital multidisciplinary predialysis clinic	<ol style="list-style-type: none"> <li>Multiple outpatient consultations with clinicians (1.5–3 hours)</li> <li>1 session of individual education with nurse educator and social worker (2–3 hours)</li> <li>1 video (n.a.)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> <li>CCM</li> </ol>	No	No	n.a.	Yes	Yes	
No. 30: Birmingham Heartlands Hospital predialysis education	<ol style="list-style-type: none"> <li>Multiple outpatient consultations with clinicians (n.a.)</li> <li>1 home visit by educator (2–4 hours)</li> <li>Printed materials (leaflets, booklets)</li> <li>DVDs (n.a.)</li> <li>1 session of group education (4–6 hours)</li> <li>Visits to treatment centres</li> <li>Chance to meet peer patients</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD</li> <li>CCM</li> </ol>	No	Yes	n.a.	Yes	Yes	
<b>Transplantation, dialysis or CCM?</b>								
No. 31: Acute Start Dialysis Education and Support	<ol style="list-style-type: none"> <li>Multiple in-hospital consultations with acute start nephrology nurse practitioner (n.a.)</li> <li>Printed materials (n.a.)</li> <li>1 DVD (n.a.)</li> </ol>	<ol style="list-style-type: none"> <li>PD; APD</li> <li>PD; CAPD</li> <li>HD; in-centre</li> <li>HD; home</li> <li>Transplantation</li> <li>CCM</li> </ol>	No	Yes	n.a.	Yes	Yes	
No. 32: Treatment Options Programme (TOP)	<ol style="list-style-type: none"> <li>1 session of individual education with TOP educators (n.a.)</li> <li>3 sessions of outpatient consultations with TOP educators (n.a.)</li> <li>Printed materials (flipcharts, handouts)</li> <li>1 video (n.a.)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD; home-HD</li> <li>HD; in-centre</li> <li>Transplantation</li> <li>CCM</li> </ol>	No	Yes	n.a.	Yes	Yes	
No. 33: University of Michigan multidisciplinary and peer mentor education	<ol style="list-style-type: none"> <li>2 sessions of group education (4 hours total)</li> <li>Chance to meet peer patients</li> </ol>	<ol style="list-style-type: none"> <li>Dialysis</li> <li>Transplantation</li> <li>CCM</li> </ol>	n.a.	Yes	n.a.	Yes	No	
No. 34: comprehensive predialysis education	<ol style="list-style-type: none"> <li>Multiple outpatient consultations with clinicians (n.a.)</li> <li>1 session of group education (1 hour)</li> <li>4 sessions of individual education with clinicians (n.a.)</li> <li>Printed materials (n.a.)</li> </ol>	<ol style="list-style-type: none"> <li>PD</li> <li>HD; home</li> <li>HD; in-centre</li> <li>Transplantation</li> <li>CCM</li> </ol>	No	Yes	n.a.	Yes	Yes	
No. 35: digital modality decision programme	Interactive website	<ol style="list-style-type: none"> <li>PD</li> <li>HD; in-centre</li> <li>HD; home</li> <li>Transplantation</li> <li>CCM</li> </ol>	No	Yes	n.a.	Not reported	Yes	
No. 36: options class	1 session of individual education with a renal nurse (1–2 hours)	<ol style="list-style-type: none"> <li>PD</li> <li>HD; in-centre</li> <li>HD; home</li> <li>Transplantation</li> <li>CCM</li> </ol>	No	No	n.a.	Yes	Yes	
No. 37: individual chronic kidney disease education	1 session of individual education with various experts (n.a.)	<ol style="list-style-type: none"> <li>Dialysis</li> <li>Transplantation</li> <li>CCM</li> </ol>	Home therapy modalities	No	n.a.	Not reported	Yes	
<b>What type of transplantation?</b>								
No. 38: communicating about choices in transplantation	<ol style="list-style-type: none"> <li>1 session of group education (3 hours)</li> <li>4 videos (n.a.)</li> </ol>	<ol style="list-style-type: none"> <li>DBKT</li> <li>LDKT</li> </ol>	No	No	n.a.	Not reported	Yes	
No. 39: explore transplant (ET)	<ol style="list-style-type: none"> <li>4 sessions of individual education with transplant educator (2 hours total)</li> <li>4 videos (n.a.)</li> <li>Printed materials (brochures)</li> </ol>	<ol style="list-style-type: none"> <li>DBKT</li> <li>LDKT</li> </ol>	No	Yes	Low health literacy	Not reported	Yes	
No. 40: ET at home	<ol style="list-style-type: none"> <li>Printed materials (fact sheets, brochures, postcards)</li> <li>4 videos (20 min total)</li> <li>4 phone calls with educators (1.5 hours total)</li> <li>Optional educational text messages</li> </ol>	<ol style="list-style-type: none"> <li>DBKT</li> <li>LDKT</li> </ol>	No	Yes	Low health literacy	Not reported	Yes	

Continued



Table 3 Continued

EP	Format	Treatment options*	Promotes treatment modality	Coaching	Patient participation in development	Reading level	Implemented	Evaluated
No. 41: your path to transplant (YPT)	<ol style="list-style-type: none"> <li>4 sessions on computer-tailored programme (n.a.)</li> <li>1 session of individual education with YPT coach (n.a.)</li> <li>3 phone calls with YPT coach (n.a.)</li> <li>Videos (n.a.)</li> <li>Printed materials (brochures)</li> </ol>	<ol style="list-style-type: none"> <li>DDKT</li> <li>LDKT</li> </ol>	No	Yes	No	n.a.	Not reported	Yes

\*Treatment options formulated as reported in the identified records.  
 APD, ambulatory peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; CCM, conservative care management; CKD, chronic kidney disease; DDKT, deceased donor kidney transplantation; EPa, educational programmes; HD, haemodialysis; KRT, kidney replacement therapy; LDKT, living donor kidney transplantation; n.a., not available; PD, peritoneal dialysis; PDEP, predialysis education programme; RTN, renal triage nurse.

articles.<sup>57 119–131</sup> Thirteen were identified in the grey literature,<sup>132–141</sup> seven of which in meeting abstracts.<sup>132–135</sup>

Table 5 provides an overview of the identified PtDAs and their characteristics. Table S5 in online supplemental appendix 4 provides additional details on the identified PtDAs (eg, sources for publicly available PtDAs). One PtDA helps patients choose whether or not they should start with dialysis (no. 1) and one helps them decide when to start with dialysis if they decide to do so (no. 2). Nine help patients choose between dialysis options (no. 3–11) and five help them choose between transplantation and dialysis options (no. 12–16). One PtDA helps patients decide whether or not they want to accept an infectious risk donor kidney donation offer (no. 17). Four help patients choose between dialysis and CCM options (no. 18–21). Six help patients choose between transplantation, dialysis and CCM options (no. 22–27).

Most PtDAs were developed for the general population of patients with AKD, a minority (n=3, 11.1%) were specifically developed for elderly patients with AKD (no.18, 19, 21).

A large proportion of PtDAs (n=23, 85.2%) consist of a single medium format (no.1–8, 10–17, 19–23, 26, 27). Most of these PtDAs (n=11, 47.8%) are interactive websites (no.1–5, 11–14, 17). The remaining PtDAs consist of a combination of different medium formats. A majority of the PtDAs (n=17, 62.9%) contain values-clarification and preference-elicitation exercises (no.1–6, 8–11, 15, 18–20, 23–25).

Two-thirds of the PtDAs (n=18, 66.6%) were developed with the input of patients (no.3, 5–9, 11–14, 16, 19, 20, 22, 24–27), one of which was largely developed with the input of African-American patients (no.24). A minority (n=6, 22.2%) describe a reading level (no.5, 6, 16, 18, 24, 27). Only a few PtDAs (n=5, 18.5%) are not publicly available (no.7, 8, 18, 21, 24).

Ten PtDAs (n=10, 37.0%) were reported to have been implemented in clinical practice (no.6–9, 13, 15, 16, 25–27). The majority (n=17, 62.9%) have been evaluated for their effects on outcomes in the intended users (no.6–11, 13, 14, 16–18, 21, 22, 24–27).

Table 6 provides an overview of the IPDAS minimum standards component scores for 26 of the identified PtDAs. Table S6 in online supplemental appendix 4 provides these scores in greater detail. One PtDA (no. 21) could not be scored according to these criteria because the accompanying documentation did not provide enough information. Decision support interventions have to meet six qualifying criteria to qualify as PtDAs. Just about half (n=13, 48.1%) met all qualifying criteria (no.1, 4–7, 9, 11, 14, 18–20, 23–25). The sixth qualifying criterion ('the PtDA describes what it is like to experience the consequences of the options') was the least met criterion by the other PtDAs.

Table 7 provides an overview of the studies<sup>70 121–127 129 130 132 135 142–145</sup> that evaluated 17 PtDAs (no.6–11, 13, 14, 16–18, 21, 22, 24–27). Table S7 in online supplemental appendix 4 provides additional details on

**Table 4** Overview of studies evaluating the identified EPs

EP	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
Start PD or not?						
No. 1	RCT <sup>74</sup>	Patients with CKD stage 5	Total=120 ▶ Customised video counselling=60 ▶ Control=60	Pre-intervention and post-intervention/control: PD acceptance rate, PD catheter insertion on schedule	1. Pre-intervention/control: patient and clinical characteristics 2. Pre-intervention and post-intervention/control: patient knowledge, patient confidence 3. Post-intervention/control: rate of unplanned HD start, reasons for postponing PD	There were no significant differences in PD acceptance rate, PD catheter insertion on schedule, patient knowledge or confidence in PD between the intervention and control groups
What type of dialysis modality?						
No. 2	Retrospective cohort study <sup>75</sup>	Pre-dialysis patients	Total=141	Post-intervention: patient and clinical characteristics, initiation rates of dialysis access prior to the first dialysis session, rates of inpatient dialysis start	1. n.a. 2. n.a. 3. n.a.	66% of patients selected peritoneal dialysis 86.3% of patients had access at the initiation of dialysis There were no benefits in terms of elective dialysis initiation due to constraints in dialysis resources
No. 3	Non-randomised controlled study <sup>75</sup>	Patients with an eGFR <20mL/min/1.73 m <sup>2</sup>	Total=56 ▶ Pre-dialysis patient education=28 ▶ Control=28	1. Pre-intervention/control: patient and clinical characteristics 2. 3-9 months after dialysis start: frequency of disease-specific symptoms, perceived health, functional and emotional status	1. n.a. 2. n.a. 3. n.a.	1. Patients in the intervention group had significantly better functional and emotional scores than patients in the control group 2. There were no significant differences in the frequency symptoms and overall perceived health between the intervention and control groups 3. The differences between the two groups disappeared after 6 months of dialysis treatment
No. 4	Prospective cohort study <sup>76</sup>	Patients on KRT	Total=33 ▶ Pre-dialysis counselling=254	1. Pre-intervention: patient and clinical characteristics 2. Post-intervention: date of first dialysis, type of first dialysis, diagnosis, date of counselling and modality choice	1. n.a. 2. n.a. 3. n.a.	1. 254 of 353 patients received the intervention and were offered a free choice in dialysis modality 55% of patients chose HD and 45% of patients chose CAPD 2. Independent predictors for choosing CAPD were marriage (p=0.004), counselling before start of dialysis (p=0.019) and the distance to the dialysis units for patients (p<0.001) 3. Independent predictors for choosing HD were increasing age (p=0.030) and the male gender (p=0.041)
No. 5	RCT <sup>77</sup>	Patients with an eGFR <30mL/min/1.73 m <sup>2</sup>	Total=70 ▶ Two-phase education=35 ▶ Control=35	1. Pre-intervention/control: patient and clinical characteristics, intention to start dialysis with a self-care dialysis modality 2. 2 weeks post-intervention: intention to start dialysis with a self-care dialysis modality 3. 4 weeks post-intervention/control: intention to start dialysis with a self-care dialysis modality	1. Pre-intervention/control: knowledge, attitudes towards self-care dialysis modalities 2. 2 weeks post-intervention: knowledge, attitudes towards self-care dialysis modalities 3. 4 weeks post-intervention/control: knowledge, attitudes towards self-care dialysis modalities	1. 28 patients in the intervention group completed all the baseline and post-intervention surveys 82.1% of patients in the intervention group intended to start with self-care dialysis as compared with 50% of patients in the control group (p=0.004)
No. 6	RCT <sup>111</sup>	Patients with an eGFR <30mL/min/1.73 m <sup>2</sup>	Total=70 ▶ Two-phase education=35 ▶ Control=35	1. Pre-intervention/control: patient and clinical characteristics, perceived advantages of self-care dialysis 2. 2 weeks post-intervention: perceived advantages of self-care dialysis 3. 4 weeks post-intervention/control: perceived advantages of self-care dialysis	1. n.a. 2. n.a. 3. n.a.	28 patients in the intervention group completed all the baseline and post-intervention surveys 3 perceived advantages of self-care dialysis were identified: freedom, lifestyle and control Patients in the intervention group were more likely to perceive freedom and control as advantages of self-care dialysis as compared with patients in the control group Patients that identified freedom and lifestyle as advantages of self-care dialysis were more likely to choose self-care dialysis
No. 7	Multicenter retrospective cohort study <sup>77</sup>	Patients on maintenance dialysis	Total=1504	Post-intervention: patient and clinical characteristics, duration and type of nephrological care, number of medical visits in the year before dialysis start, education on dialysis modality options and CKD, time between education, permanent access creation and dialysis start, type of access for dialysis modality	1. n.a. 2. n.a. 3. n.a.	46% of patients started with non-planned dialysis Nearly half of all patients were never educated on dialysis options 18% of patients chose PD, 82% chose HD Planned dialysis start was associated with: young age, longer kidney and pre-dialysis follow-up, education on dialysis modality options and CKD, more medical visits, choice of PD, permanent access creation before dialysis start and better biochemical parameters before start of dialysis
No. 8	Quasi-experimental study <sup>78</sup>	Patients with an eGFR <15mL/min/1.73 m <sup>2</sup>	Total=60 ▶ Multimedia interactive patient education=30 ▶ Control=30	1. Pre-intervention/control: patient and clinical characteristics 2. Post-intervention, immediately 4 and 8 weeks post-intervention/control: knowledge, uncertainty, decisional regret	1. n.a. 2. n.a. 3. n.a.	There were significant differences in the improvement of knowledge (p<0.001), uncertainty (p<0.001) and decisional regret (p<0.001) between the intervention and control groups
No. 8	Meeting abstract of retrospective cohort study <sup>105</sup>	Patients on KRT	Total=209	Post-intervention: patient and clinical characteristics, selection of dialysis modality, parameters of treatment outcome	1. n.a. 2. n.a. 3. n.a.	91 patients were directed towards HD due to medical or psychosocial contraindications for PD 61.4% of the remaining 144 patients chose PD as their preferred dialysis modality 39.1% of patients that chose PD discontinued PD

Continued

**Table 4** Continued

EP	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
No. 9	Meeting abstract of retrospective cohort study. <sup>6c</sup>	Patients on dialysis	Total=1294	Post-intervention: Patient and clinical characteristics, participation in the educational programme, differences in treatment outcomes based on educational programme attendance	n.a.	<ol style="list-style-type: none"> <li>621 patients (48%) attended at least one class</li> <li>Participation in education was associated with decreased intravascular catheter use, increase home dialysis modalities and decreased hospitalisation for dialysis initiation (p&lt;0.001).</li> <li>Attendance when stratified by no participation vs 1–2 sessions vs ≥3 sessions revealed a progressive trend towards decreased intravascular catheter use, in-centre dialysis modalities and hospitalisations for dialysis initiation. (p&lt;0.001)</li> </ol>
No. 10	Meeting abstract of qualitative study. <sup>67</sup>	<ol style="list-style-type: none"> <li>Patients on KRT</li> <li>Providers</li> </ol>	Total=6	Patient reported themes of experiences to be included in a video-educational tool, provider feedback on the tool, patient feedback on the tool	n.a.	<ol style="list-style-type: none"> <li>Patient-reported themes included: their predetermined fear of dialysis was misplaced; they appreciated the value of adherence to life-sustaining therapies; adjustment to diet and lifestyle modifications was a big component in accepting ESKD care; and they did not realise the available flexibility of dialysis care which may allow them to travel, continue employment and maintain quality of life</li> <li>100% of providers found the video to be a critically important educational tool</li> <li>A shorted duration, and the inclusion of more discussion on transplantation was recommended by providers</li> <li>Patients felt that although they preferred a peer-driven educational component, it cannot replace the clinician's education</li> </ol>
No. 11	Retrospective cohort study. <sup>73</sup>	Patients on dialysis	Total=213 ▲ King Fahad Armed Forces Hospital PDEP=75	Post-intervention: patient and clinical characteristics, choice of dialysis modality	n.a.	<ol style="list-style-type: none"> <li>After the intervention 57.3% of patients chose HD and 42.7% chose PD</li> <li>Patients that did not receive the intervention chose HD significantly less often than patients that did receive the intervention (p&lt;0.001)</li> <li>After the intervention 45.8% of patients had central-line associated bloodstream infections, 3.3% had other infections and 0.5% had peritonitis</li> <li>81.8% of PD patients did not have infections compared with 42.3% of HD patients</li> </ol>
Transplantation or dialysis?						
No. 12	Retrospective cohort study. <sup>79</sup>	Patients on KRT	Total=242 ▲ Cliniques Universitaires St. Luc PDEP=185	Post-intervention: patient and clinical characteristics, influence of ESKD aetiology and age on the distribution of KRT modalities, the timing of dialysis initiation, the effects of late referral on the KRT modalities	n.a.	<ol style="list-style-type: none"> <li>4% of patients received a pre-emptive transplantation, 40% of patients opted for HD; in-centre, 31% of patients chose PD, 16% of patients chose self-care HD in a satellite unit and 9% chose HD; home after the intervention</li> <li>The proportion of patients with a chronic glomerulonephritis or chronic interstitial nephritis that chose self-care KRT was significantly higher than the proportion of patients with nephrosclerosis, diabetic nephropathy or an unknown cause of ESKD</li> <li>There were 58 late referral patients, of which 25 directly received HD; in-centre</li> <li>61% of the remaining 33 late referral patients chose a self-care treatment modality, a proportion that was similar to the rest of the cohort</li> </ol>
No. 13	Retrospective cohort study. <sup>81</sup>	Suboptimal HD start patients	Total=178 ▲ RTN=38	180 days post-intervention: the likelihood of patients switching to independent KRT therapy	180 days post-intervention/control: likelihood of independent KRT therapy after RTN education	<ol style="list-style-type: none"> <li>There were 78 suboptimal HD start patients, of which 38 received the intervention</li> <li>27.8% of patients that received the intervention switched to an independent KRT modality</li> <li>Suboptimal HD patients that received the intervention were more likely to transition to an independent KRT modality compared with patients that did not receive the intervention</li> <li>There was no significant difference in the rate of independent KRT choice between patients that did and did not receive the intervention</li> </ol>
No. 14	Retrospective cohort study. <sup>80</sup>	Acute start dialysis patients	Total=228	Post-intervention: patient and clinical characteristics, chosen dialysis modality at hospital discharge, comparison of patient characteristics between those choosing in-centre HD and HD home	n.a.	<ol style="list-style-type: none"> <li>71 patients chose HD; home and 132 chose HD; in-centre at hospital discharge</li> <li>Patients that chose HD; home had significantly more failed kidney transplants (p=0.045) and were less likely to have ischaemic nephropathy (p=0.03)</li> </ol>
No. 15	Retrospective cohort study. <sup>82</sup>	Patients with an eGFR <40 mL/m <sup>2</sup> /1.73 m <sup>2</sup>	Total=1218 ▲ MPE=159	Post-intervention: all-cause mortality, progression to ESKD, KRT initiation, cardiovascular outcomes, infectious events, hospitalisation rates	n.a.	<ol style="list-style-type: none"> <li>There were no significant differences in KRT initiation rates between patients that did or did not receive the intervention</li> <li>There were no survival differences between patients that did or did not receive the intervention</li> <li>The intervention significantly reduced the amount of unplanned urgent dialysis (p&lt;0.001)</li> <li>There was a lower incidence of cardiovascular events between patients that did and did not receive the intervention</li> </ol>
No. 16	Non-randomised controlled study. <sup>83</sup>	Kidney transplantation recipients	Total=88 ▲ Faculty of Medicine Ataturk University PDEP=61	Post-intervention: patient and clinical characteristics, pre-emptive LDKT rates	n.a.	<ol style="list-style-type: none"> <li>26 patients that received the intervention underwent pre-emptive LDKT compared with 5 patients that did not receive the intervention</li> <li>There were significantly more pre-emptive LDKTs among the patients that received the intervention as compared with patients that did not receive the intervention (p&lt;0.001)</li> </ol>
No. 17	Retrospective cohort study. <sup>84</sup>	Patients with an eGFR <15 mL/m <sup>2</sup> /1.73 m <sup>2</sup>	Total=227 ▲ INDIAL=70	Post-intervention: annual PD and HD incidence rates	n.a.	<ol style="list-style-type: none"> <li>54.3% of patients that received the intervention started with PD as compared with 28% of patients that did receive the intervention (p&lt;0.001)</li> </ol>

Continued

**Table 4** Continued

EP	Source	Population*	Sample size	Primary outcome(s)	Secondary outcome(s)	Main findings†
No. 18	Retrospective cohort study <sup>85</sup>	Patients with an eGFR <30 mL/min/1.73 m <sup>2</sup>	Total=234 ▲ Renal school=135	Post-intervention; emergency dialysis rates, acute catheter insertion rates, hospital length of stay, complication rates	n.a.	<ol style="list-style-type: none"> <li>47 patients that received the intervention refused to choose a treatment modality after the intervention</li> <li>52.8% of patients that received the intervention required emergency dialysis</li> <li>All patients that did not receive the intervention required emergency dialysis</li> <li>Emergency dialysis patients were admitted for a mean period of 8.5 days</li> <li>The rate of complications was 40.4% in the group that did not receive the intervention</li> <li>The rate of complications was 31.4% in the group that received the intervention</li> <li>95% of patients that received the intervention was satisfied with the information given</li> </ol>
No. 19	RCT <sup>86</sup>	<ol style="list-style-type: none"> <li>Patients with ESKD</li> <li>Members of their social network</li> </ol>	Total=409 (163 patients) ▲ Kidney team at home=84 ▲ Control=79	Pre-intervention and 3 days post-intervention/control: knowledge, risk perception, self-efficacy, attitude towards communication, communication on KRT, willingness to accept a LDKT	Up to 6 months post-intervention/control: amount of living donor inquiries, amount of living donor evaluations, amount of actual LDKTs	<ol style="list-style-type: none"> <li>79 patients and 246 invites received the intervention</li> <li>76 patients in the intervention group completed both the baseline and post-intervention surveys</li> <li>Knowledge (p&lt;0.001) and communication (p=0.012) improved significantly more in the intervention group than in the control group (p&lt;0.001)</li> <li>There were significant increases in knowledge (p&lt;0.001), attitude towards discussing KRT (p=0.023), willingness to donate a kidney (p=0.039) and a decrease in risk perception for LDKT (p=0.003) among invites that received the intervention</li> <li>There were significantly more donor inquiries (p&lt;0.001), evaluations (p&lt;0.001) and actual LDKTs (p=0.003) in the intervention group compared with the control group</li> </ol>
No. 20	RCT with cross-over <sup>13</sup>	<ol style="list-style-type: none"> <li>Patients with eGFR &lt;25 mL/min/1.73 m<sup>2</sup></li> <li>Members of their social network</li> </ol>	Total=390 (60 patients) ▲ Kidney team at home=40 ▲ Control=40	Pre-intervention, 4 and 8 weeks post-intervention/control: knowledge, frequency of communication on each KRT option in the past 4 weeks, the extent to which the participant intended to communicate about each KRT option with loved ones or the patient	<ol style="list-style-type: none"> <li>Pre-intervention, 4, and 8 weeks post-intervention/control: knowledge, frequency of communication on each KRT option in the past 4 weeks, the extent to which the participant intended to communicate about each KRT option with loved ones or the patient</li> <li>Pre-intervention/control: patient/attendees characteristics, whether attendees had previously been evaluated for living donation, whether attendees knew if there was a known medical reason why they would not be able to donate</li> <li>Pre-intervention, 4 and 8 weeks post-intervention/control: subjective norm to discuss each KRT option, perceived behaviour control to discuss KRT options, attitude towards discussing KRT options with family and friends, attitude towards PD, attitude towards HD, attitude towards DDKT, attitude towards LDKT, attitude towards living donation, anticipated affect for not having discussed KRT</li> <li>Up to 2 years post-intervention/control: the date and type of primary KRT, subsequent changes in KRT</li> </ol>	<ol style="list-style-type: none"> <li>80 patients and 310 attendees received the intervention</li> <li>75 patients completed both the baseline and post-intervention surveys</li> <li>Knowledge and communication improved significantly in patients and attendees after the intervention</li> <li>There was also a significant improvement in positive attitude towards LDKT and HD</li> <li>49 patients underwent KRT, of which 34 under LDKT. Of these 22 were pre-emptive LDKTs</li> </ol>
No. 21	Multicentre pre-post study <sup>14</sup>	Hispanic kidney transplantation candidates	Total=63	<ol style="list-style-type: none"> <li>Pre-intervention: patient characteristics</li> <li>Pre-intervention, immediately, and 3 weeks post-intervention: knowledge</li> <li>3 weeks post-intervention: attitudes on and use of the website</li> </ol>	n.a.	<ol style="list-style-type: none"> <li>There was a significant increase in knowledge immediately after receiving the intervention (p&lt;0.001), and at 3 weeks post-intervention (p&lt;0.001)</li> <li>Knowledge increased the most in the treatment options (p&lt;0.0001) and cultural beliefs and myths (p&lt;0.0001) sections of the intervention</li> <li>95% of patients agreed or strongly agreed that they would recommend the website to other Hispanic patients</li> </ol>
No. 22	Multicentre RCT <sup>15</sup>	<ol style="list-style-type: none"> <li>Hispanic kidney transplantation candidates</li> <li>Family and friends</li> </ol>	Total=282 (112 patients) ▲ Informate=56 ▲ Control=56	<ol style="list-style-type: none"> <li>Pre-intervention/control: patient characteristics</li> <li>Pre-intervention, immediately and 3 weeks post-intervention/control: knowledge</li> <li>3 weeks post-intervention: attitudes on and use of the website</li> </ol>	n.a.	<ol style="list-style-type: none"> <li>56 patients and 106 family members/friends received the intervention.</li> <li>There was a significant increase in knowledge immediately after receiving the intervention (p&lt;0.001), and at 3 weeks post-intervention (p=0.0001)</li> <li>92.6% of participants that used the website planned to return to the website in the future</li> </ol>
No. 23	Retrospective cohort study <sup>64</sup>	Patients with CKD	Total=112 ▲ Nissan Tamagawa Hospital MDC=53	Post-intervention: patient and clinical characteristics, annual decreases in eGFR values, time to dialysis initiation, urgent dialysis initiation rate, PD selection rates and PD retention rates	n.a.	<ol style="list-style-type: none"> <li>Patients that received the intervention had significantly lower annual decreases in eGFR (p=0.020), significantly longer times to dialysis initiation (p&lt;0.001), and significantly lower urgent dialysis initiation rates (p=0.005) compared with patients that did not receive the intervention</li> <li>Patients that received the intervention had significantly higher PD selection rates (p=0.038) and significantly higher PD retention rates (p=0.012) compared with patients that did not receive the intervention</li> </ol>

Continued

**Table 4** Continued

EP	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
No. 22	RCT <sup>88</sup>	Kidney transplant candidates	Total=132 ▶ Home-based educational intervention=63 ▶ Control=69	Post-intervention/control: the proportion of patients with living donor inquires, living donor evaluations and LDKT rates	Pre-intervention/control: LDKT knowledge, willingness and concerns regarding LDKT; the number of educated potential donors	1. Patients in the intervention group had significantly more living donor inquires (p=0.019), evaluations (p=0.005) and LDKTs (p=0.0013) compared with the control group. 2. White race, better LDKT knowledge, more willingness to discuss LDKT and less LDKT concerns were predictors of receiving a LDKT. 3. The intervention group had a significant increase in LDKT knowledge (p<0.0001) and in their willingness to discuss LDKT with others (p<0.0001) compared with the control group. 4. Patients in the intervention group had a significant decrease in LDKT concerns (p<0.0001) compared with the control group.
No. 23	Non-randomised controlled study <sup>89</sup>	HD patients eligible for kidney transplantation	Total=214 ▶ Promoting live donor kidney transplantation (proactive)=107 ▶ Promoting live donor kidney transplantation (reactive)=107	Pre-intervention and 1 week post-intervention/control: readiness to consider LDKT, readiness to talk about LDKT with friend or family, readiness to ask friends and family to donate a kidney	1. Pre-intervention/control: LDKT knowledge, willingness and concerns regarding LDKT in both black and white patients. 2. Post-intervention/control: the number of people that participated in the educational sessions, LDKT knowledge, willingness and concerns regarding LDKT	1. 64% of patients in the control group and 61% of patients in the intervention group did not consider LDKT at baseline. 2. Significantly more patients considered LDKT 1 week after the intervention as compared with baseline in both the intervention group (p=0.01) and the control group (p=0.002). 3. The odds of considering LDKT was higher among African-American patients, younger patients and patients who spent less time on dialysis 1 week after the intervention as compared with baseline. 4. There were no significant changes in the proportion of patients talking about LDKT with friends and family in both the intervention and control groups. 5. There were no significant changes in the proportion of patients asking friends and family to donate a kidney in both the intervention and control groups.
No. 24	RCT <sup>90</sup>	Kidney transplant candidates	Total=100 ▶ Increasing the pursuit of living kidney donation=50 ▶ Control=50	3 months post-intervention/control: whether a potential living kidney donor contacted the living donor programme on behalf of a patient	Pre-intervention/control: patient and clinical characteristics, knowledge about LDKT, ESKD treatment preference 2 weeks post-intervention/control: knowledge about LDKT, ESKD treatment preference	1. 39 patients in the intervention group completed both the baseline and the post-intervention surveys. 2. There was no significant difference in the number of living donors that contact the programme on behalf of the patients between the intervention and control groups. 3. Patients in the intervention group changes their treatment preference to LDKT significantly more (p=0.02) than patients in the control group.
No. 25	Multicentre RCT <sup>91</sup>	Patients with CKD stage 3–5	Total=130 ▶ TALK=43 ▶ TALK (no home visits)=43 ▶ Control=44	1–3 and 6 months post-intervention/control: self-reported achievement of at least one of the following five steps: discussing LDKT with a family member, discussing LDKT with their physician, initiating the clinical evaluation for LDKT recipients, completing the clinical evaluation for LDKT recipients and identifying a potential live kidney donor	Pre-intervention/control: patient and clinical characteristics, health literacy, patients' family structure and perceived functioning, prior receipt and perceived adequacy of information about LDKT, length and intensity of patients' relationships with their nephrologists, occurrence and perceived adequacy of prior discussions about dialysis or transplantation with their nephrologists, patients' satisfaction with the discussions, whether they discussed how differences between dialysis and transplantation could affect their life and whether their nephrologists had encouraged them to begin steps in seeking a transplant 1, 3 and 6 months post-intervention/control: the effects of the interventions on patients' interest in LDKT and their concerns about the risks associated with LDKT; whether they watched the TALK video and read the booklet, the usefulness of the video and booklet	1. 36 patients that received TALK and 35 patients that received control without social worker completed both the baseline and follow-up surveys. 2. 55% of all participants had not completed any LDKT discussion or pursuit behaviours at baseline. 3. 33% of all participants reported that they had prior information on LDKT at baseline. 4. 63% had previously discussed dialysis or transplantation with their nephrologists. 5. TALK led to greater patient activation in achieving pre-emptive LDKT discussions, transplant evaluations and donor identification after 6 months compared with TALK without social worker and standard care (p=0.03).

Continued



**Table 4** Continued

EP	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
No.26	RCT <sup>26</sup>	African-American kidney transplant candidates	Total=268 ▲ Living ACTS=136 ▲ Control=132	Pre-intervention, immediately and 6 months post-intervention/control: knowledge of LDKT, willingness to talk to family members about LDKT, perceived benefits of LDKT	n.a.	<ol style="list-style-type: none"> <li>1. Knowledge of LDKT had improved significantly more in the intervention group than in the control group at 6 months post-intervention (p=0.05)</li> <li>2. Patients in the intervention group expressed greater willingness to talk to family members about LDKT from baseline to 6 months post-intervention as compared with patients in the control group (p=0.008)</li> <li>3. Patients in the intervention group endorsed the benefits of LDKT more than patients in the control group at baseline (p&lt;0.001) but this effect disappeared at 6 months post-intervention</li> </ol>
No.27	Pre-post study <sup>23</sup>	<ol style="list-style-type: none"> <li>1. Hispanic kidney transplantation candidates</li> <li>2. Family and friends</li> </ol>	Total=113	<ol style="list-style-type: none"> <li>1. Pre-intervention: patient and clinical demographics, past interactions with donors</li> <li>2. Pre-intervention and post-intervention: knowledge of kidney donation and transplant, family members'/friends' attitudes about LDKT, patients' attitudes about LDKT</li> <li>3. Post-intervention: satisfaction with the educational sessions, value placed on culturally competent care</li> </ol>	n.a.	<ol style="list-style-type: none"> <li>1. 43 patients and 70 of their family members completed the surveys before and after the intervention</li> <li>2. There was a significant increase in knowledge about LDKT after the intervention (p&lt;0.001)</li> <li>3. There was a significant increase in patients' attitudes towards LDKT after the intervention (p&lt;0.02)</li> <li>4. There was a significant increase in family members' attitudes towards being a donor after the intervention (p&lt;0.001)</li> <li>5. There were high levels of satisfaction with the programme and value placed on culturally congruent care</li> </ol>
No.28	Prospective cohort study <sup>24</sup>	<ol style="list-style-type: none"> <li>1. Hispanic kidney transplantation candidates</li> <li>2. Non-Hispanic white kidney transplantation candidates</li> </ol>	Total=1286 ▲ HKTP=695	Pre-intervention and post-intervention: patient and clinical characteristics, waiting lists as a proxy for patient referrals, the ratio of Hispanic to non-Hispanic white LDKTs and DDKTs	n.a.	<ol style="list-style-type: none"> <li>1. The was a significant increase of 70% in the ratio of Hispanic to non-Hispanic white LDKTs after the intervention (p=0.001)</li> <li>2. The number of waiting list additions grew by 91% among Hispanics and by 4% among non-Hispanic whites</li> </ol>
No.29	Non-randomised controlled study <sup>72</sup>	Predialysis patients	Total=76 ▲ St. Paul's Hospital multidisciplinary predialysis clinic=37 ▲ Control=39	Pre-intervention and post-intervention/control: number of urgent versus elective dialysis starts, percentage of patients training as outpatients, the number of admissions and hospital days during the first of dialysis	Pre-intervention and post-intervention/control: patient and clinical characteristics	<ol style="list-style-type: none"> <li>1. 950 patients that received the intervention underwent a transplantation</li> <li>2. Patients that received the intervention had a significant higher likelihood of having a potential living donor inquiry (p=0.03) and screening (p=0.01)</li> <li>3. There were no differences in the amount of evaluated potential living donors between patients that received the intervention and patients that did not receive the intervention</li> </ol>
No.30	Prospective cohort study <sup>25</sup>	Patients with an eGFR <25 mL/min/1.73 m <sup>2</sup>	Total=118	Post-intervention: patient and clinical characteristics, patient reported factors affecting modality choice, attendance rates at patient education day	n.a.	<ol style="list-style-type: none"> <li>1. The was a significant difference in the number of urgent versus elective dialysis starts between the intervention and control groups (p&lt;0.05)</li> <li>2. There was a significant difference in patients that trained as outpatients between the intervention and control groups (p&lt;0.05)</li> <li>3. There was a significant difference in the number of hospital days during the first month of dialysis between the intervention and control groups (p&lt;0.05)</li> <li>4. There was no significant difference with respect to the modality choice of patients between the intervention and control groups</li> </ol>
No.31	Mixed methods: opinion and retrospective cohort study <sup>27</sup>	Acute start dialysis patients	Total=100	Post-intervention: treatment modality decisions	n.a.	<ol style="list-style-type: none"> <li>1. 70% of patients felt that they had received enough information to make a treatment modality decision</li> <li>2. 70% of patients chose HD, 20% chose PD and 10% chose CCM</li> <li>3. Age (p&lt;0.001) and comorbidity (p&lt;0.001) were significantly associated with treatment choice</li> <li>4. Patients ranked coping, fitting the treatment with their lifestyle, distance to the treatment centre and the received educational information as important in making treatment modality decisions</li> <li>5. Significantly more patients that chose PD attended a formal education day as compared with patients that chose HD and CCM (p=0.011)</li> <li>6. Factors predicting treatment choice in descending order for PD, HD and CCM were: marital status (p&lt;0.001), living with someone at home (p=0.003) and employment (p=0.0015)</li> </ol>
Transplantation, dialysis or CCM?						
44 patients decided to pursue a home dialysis modality after the intervention						

Continued

**Table 4** Continued

EP	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
No. 32	Quality improvement report <sup>18</sup>	Patients with CKD stage 3–4	Total=30217 ▶ TOP=3165	Post-intervention: patient and clinical characteristics, patient dialysis modality selection, vascular access type, mortality rates in the first 90 days of dialysis	n.a.	<ol style="list-style-type: none"> <li>1. Patients that received the intervention were younger, more likely to be white and had a larger body surface area than patients that did not attend the intervention (p&lt;0.001)</li> <li>2. There was a significant association between the intervention and selecting PD (p&lt;0.001)</li> <li>3. There was a significant association between the intervention and starting HD with a graft or fistula (p&lt;0.001)</li> <li>4. Patients that received the intervention had significantly better 90-day mortality rates compared with patients that did not attend TOP (p&lt;0.001)</li> </ol>
No. 34	Quality improvement report <sup>18</sup>	Patients with CKD stage 3 and 4	Total=73 500	Post-intervention: patient dialysis modality selection, vascular access type	n.a.	<ol style="list-style-type: none"> <li>1. Patients that receive the intervention use home therapy options more often than patients that do not attend the intervention</li> <li>2. Patients that receive the intervention start dialysis with a permanent vascular access more often than patients that do not attend the intervention</li> </ol>
No. 34	Retrospective cohort study <sup>36</sup>	Patients with CKD stage 4–5	Total=108	Post-intervention: patient and clinical characteristics, patient choice of dialysis modality, potential determinants for the choice of KRT modality	n.a.	<ol style="list-style-type: none"> <li>1. 108 patients received the intervention in the initial 22 months after its inception</li> <li>2. 70% of patients that received the intervention chose home dialysis (65% PD, 15% HD home)</li> <li>3. 54.6% of patients that received the intervention returned for follow-up visits of which 25.3% changed their modality preferences at least once</li> <li>4. All patients that received the intervention had chosen a KRT modality after five follow-up visits</li> <li>5. The intervention led to a growth of 21.6% in home dialysis census and a near doubling of home dialysis prevalence to 38% of all dialysis patients</li> </ol>
No. 35	Prospective cohort study <sup>17</sup>	Patients with CKD stage 4–5	Total=177	Post-intervention: patient and clinical characteristics, patient choice of dialysis modality, potential determinants for the choice of KRT modality	n.a.	<ol style="list-style-type: none"> <li>1. 77% of patients that received the intervention did not return for follow-up visits, while 22% returned for two follow-up visits and 1% returned for three follow-up visits</li> <li>2. 75% of patients that received the intervention chose home dialysis (70% PD, 2.8% HD home)</li> <li>3. 37.2% of patients that received the intervention started KRT, of which 62.1% started home dialysis</li> <li>4. 66% of patients that received the intervention and initially chose home dialysis initiated with a home dialysis modality</li> <li>5. The intervention led to a growth of 1.83% in home dialysis census, and home dialysis prevalence increased to 27% as compared with 12% of patients that did not receive the intervention</li> </ol>
No. 35	Pre-post study <sup>36</sup>	Patients with an eGFR <30 mL/min/1.73 m <sup>2</sup>	Total=25	<ol style="list-style-type: none"> <li>1. Pre-intervention: patient and clinical characteristics</li> <li>2. Post-intervention: immediately and 4 weeks post-intervention: CKD knowledge, confidence in treatment choice, CKD self-efficacy, patients' preferred KRT modality choice</li> <li>3. Immediately and 4 weeks post-intervention: satisfaction with the programme, whether the programme helped patients prepare of ESKD care</li> </ol>	n.a.	<ol style="list-style-type: none"> <li>1. All patients made KRT choice after receiving the intervention compared with 8 patients before the intervention</li> <li>2. There was a significant increase in patients that selected kidney transplantation as their preferred treatment choice after the intervention (p=0.01)</li> <li>3. There was a significant increase in patients that selected PD as their preferred dialysis choice after the intervention (p=0.004)</li> <li>4. There was a significant increase in patient knowledge (p&lt;0.001) and self-efficacy (p&lt;0.001) after the intervention</li> </ol>
No. 36	Meeting abstract of retrospective cohort study <sup>10</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Total=460	Post-intervention: patient and clinical characteristics, dialysis modality selection after options class, dialysis modality initiation after options class	n.a.	<ol style="list-style-type: none"> <li>1. After the option class, 43.3% patients chose a form of home dialysis; 37.3% chose PD and 5.4% chose HD; home, 26.5% of patients chose HD; in-centre and 3% chose CCM, 31% remained undecided on their care plan after attending option class</li> <li>2. 86 (11.7%) patients who attended options education have initiated dialysis. Among them 53.2% on home dialysis (50% with PD; 2.3% with HD; home); 47.6% with HD; in-centre, 2.3% received a pre-emptive transplant, 23% expired before dialysis initiation and 59.3% remained dialysis independent</li> </ol>
No. 37	Meeting abstract of pre-post study <sup>10</sup>	Patients with CKD	Total=39 ▶ Individual CKD education=n.a. ▶ Control=n.a.	Pre-intervention and post-intervention/control: self-assessed level of comprehension of KRT modalities	Pre-intervention and post-intervention/control: utilisation of written resources provided, an assessment of the factors that influence participants' selection on their choice of modality	<ol style="list-style-type: none"> <li>1. 30 patients completed pre-education and post-education surveys. They also received a follow-up phone call after 2 weeks</li> <li>2. Patients that received individual education had enhanced KRT modality comprehension, particularly for PD and transplantation, when compared with patients that received group education</li> <li>3. This increase in knowledge was not sustained after 2 weeks</li> <li>4. Utilisation of educational resources was similar between patients that received individual education compared with patients that received group education</li> <li>5. Life-style considerations were most important when deciding KRT modality for all patients</li> </ol>
What type of transplantation?						

Continued

**Table 4** Continued

EP	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
No. 38	Non-randomised controlled study <sup>100</sup>	Kidney transplant candidates	Total=20 ▲▲ COACH=10 ▲▲ Control=10	Pre-intervention, immediately and 1 month post-intervention/control: self-reported discussion of LDKT and/or DDKT	1. Pre-intervention/control: patient characteristics 2. Pre-intervention, immediately and 1 month post-intervention/control: transplant knowledge, communication self-efficacy, perceived conversational difficulties, intentions to communicate about transplantation 3. Immediately post-intervention: overall impressions with COACH, (dis)likes, suggestions for improvement	There were significant differences in transplant knowledge before and after the intervention between the intervention and control groups (p=0.02). The intervention group had a significant increase in transplant knowledge after the intervention compared with the control group (p=0.05). The intervention group had a significant increase in communication self-efficacy after the intervention as compared with the control group (p=0.009).
No. 39	Multicentre RCT <sup>101</sup>	Patients on dialysis	Total=253 ▲▲ ET=120 ▲▲ Control=133	Pre-intervention and 1 month post-intervention/control: patients' readiness to allow someone to be a living donor, patients' readiness to get on the DDKT wait list	1. Pre-intervention and 1 month post-intervention/control: transplant knowledge, perceived benefits and disadvantages of DDKT and LDKT, self-efficacy to pursue transplant 2. 1 month post-intervention/control: informed decision-making and protransplant steps 3. 6 months, 1, 2 and 3 years post-intervention/control: number of living kidney donor volunteering for each patient, whether patients called to begin or restart transplant evaluation, whether patients completed transplant evaluation or received a DDKT or LDKT	Patients in the intervention group were more likely to increase their stage of readiness for LDKT (p=0.03), had greater increases in their transplant knowledge (p<0.001) and were more likely to restart/begin with transplant evaluation (p=0.006) compared with patients in the control group. Black patients were more likely to take steps towards kidney transplantation compared with white patients.
No. 40	Multicentre RCT <sup>102</sup>	Black and low-income patients on dialysis	Total=561 ▲▲ ET at home=189 ▲▲ ET at home (no phone calls)=185 ▲▲ Control=187	Pre-intervention and post-intervention/control: DDKT and LDKT knowledge	1. Pre-intervention/control: patient and clinical demographics, whether they had previously read transplant brochures, whether they had previously watched transplant videos, health literacy, quality of social support, medical mistrust. 2. Pre-intervention and post-intervention/control: DDKT and LDKT attitudes, steps relating to taking transplant action 3. Post-intervention/control: informed decision-making, started a kidney transplant evaluation, tried to get a DDKT/LDKT	Both intervention groups had significantly better improvements in their DDKT and LDKT knowledge compared with the control group (p=0.02, p=0.01). More patients in the intervention groups were able to make informed decisions about starting a kidney transplant evaluation (p=0.003), pursuing DDKT (p=0.003) and pursuing LDKT (p<0.001) than patients in the control group.
No. 41	RCT <sup>103</sup>	Kidney transplant candidates	Total=802 ▲▲ YPT=407 ▲▲ Control=395	Pre-intervention, 4 and 8 months post-intervention/control: patients' readiness to pursue DDKT and LDKT	1. Pre-intervention/control: patient and clinical characteristics, kidney transplant delirium, whether they had previously read transplant brochures, watched transplant videos or visited transplant websites 2. Pre-intervention, 4- and 8 months post-intervention/control: transplant knowledge, progress towards transplant 3. 18 months post-intervention/control: waitlisted for DDKT, received LDKT	Patients in the intervention group had significantly better improvements in LDKT readiness (p=0.003) and transplant knowledge (p<0.001) compared with patients in the control group. Patients in the intervention group had significantly higher levels of transplant pursuit than patients in the control group (p=0.002).

\*Population formulated as reported in the identified records.

†Outcomes formulated as reported in the identified records.

‡Main findings formulated as reported in the identified records.

§Main findings formulated as reported in the identified records.

100: retrospective analysis of patient-level data; 101: consecutive case management; 102: chronic kidney disease; COACH, communicating about choice in transplantation; DDKT, deceased donor kidney transplantation; eGFR, estimated glomerular filtration rate; ETs, educational programmes; ESKD, end-stage kidney disease; HD, haemodialysis; KRTT, Heparin-free kidney transplant programme; KRT, kidney replacement therapy; LDKT, living donor kidney transplantation; MDC, multidisciplinary care; n.a., not applicable; PD, Peritoneal dialysis; PDEP, Pre-dialysis education programme; RCT, Randomised controlled trial; SDM, shared decision-making; TALK, talking about live kidney donation; TOP, treatment options programme.

**Table 5** Overview of the identified PIDs and their characteristics

PIDA	Format	Treatment options*	Values-clarification/preference elicitation exercise(s)	Patent participation in development	Reading level	Implemented	Evaluated
Start with dialysis or not?							
No. 1: Kidney failure – should I start dialysis?	Interactive website	1. PD 2. HD	Yes	No	n.a.	Not reported	No
When to start dialysis?							
No. 2: Kidney failure— when should I start dialysis?	Interactive website	1. PD 2. HD	Yes	No	n.a.	Not reported	No
What type of dialysis modality?							
No. 3: My life, my dialysis choice	Interactive website	1. PD; APD 2. PD; CAPD 3. HD; in-centre 4. HD; daily 5. HD; nocturnal	Yes	Yes	n.a.	Not reported	No
No. 4: Kidney failure— what type of dialysis should I have?	Interactive website	1. PD 2. HD	Yes	No	n.a.	Not reported	No
No. 5: Yorkshire Dialysis Decision Aid (YODDA) - web	Interactive website	1. PD; APD 2. PD; CAPD 3. HD; in-centre 4. HD; home	Yes	Yes	Eighth to ninth grade level	Not reported	No
No. 6: YODDA - booklet	PDF document (48 pages)	1. PD; APD 2. PD; CAPD 3. HD; in-centre 4. HD; home	Yes	Yes	Eighth to ninth grade level	Yes	Yes
No. 7: Shared, end-stage renal patients decision-making (SHERPA-DM) option grid	PDF document (1 page)	1. PD 2. HD; home 3. HD; in-centre	No	Yes	n.a.	Yes	Yes
No. 8: SHERPA-DM decision aid	PDF document (4 pages)	1. PD 2. HD; home 3. HD; in-centre	Yes	Yes	n.a.	Yes	Yes
No. 9: Dialysis choice	1. PDF document (16 pages) 2. 4 videos (20 min total)	1. PD; no help 2. PD; with help 3. HD; in-centre 4. HD; home	Yes	Yes	n.a.	Yes	Yes
No. 10: The dialysis guide	Interactive application	1. PD; no help 2. PD; with help 3. HD; in-centre 4. HD; home	Yes	No	n.a.	Not reported	Yes
No. 11: Choosing dialysis – empowering patients on choices for renal replacement therapy (EPOCH-RRT) decision aid	Interactive website	1. PD; APD 2. PD; CAPD 3. HD; home 4. HD; in-centre	Yes	Yes	n.a.	Not reported	Yes
Transplantation or dialysis?							
No. 12: Kidney transplant P3 (patient provider partnerships)	Interactive website	1. Dialysis 2. DDKT 3. LDKT	No	Yes	n.a.	Not reported	No
No. 13: iChoose kidney	Interactive website	1. Dialysis 2. DDKT 3. LDKT	No	Yes	n.a.	Yes	Yes
No. 14: My transplant coach	Interactive website	1. PD 2. HD 3. DDKT 4. LDKT	No	Yes	n.a.	Not reported	Yes
No. 15: To choose the treatment that suits you for kidney disease	PDF document (16 pages)	1. PD; APD 2. PD; CAPD 3. HD; home 4. HD; in-centre 5. DDKT 6. LDKT	Yes	No	n.a.	Yes	No

Continued

Table 5 Continued

PDA	Format	Treatment options*	Values-clarification/preference elicitation exercise(s)	Patent participation in development	Reading level	Implemented	Evaluated
No. 16: Option grid: KRT	PDF document (1 page)	1. PD 2. HD 3. Transplantation	No	Yes	Common European framework of reference level B1	Yes	Yes
Accept or decline IPD kidney offer?	Interactive website	DDKT	No	No	n.a.	Not reported	Yes
No. 17: Inform me: about increased risk donor kidneys							
Dialysis or CCM?							
No. 18: OPTIONS tool	1. Booklet (66 pages) 2. Audio-recording (n.a.) 3. Personal worksheet (1 page)	1. PD 2. HD 3. CCM	Yes	No	Eighth grade level	Not reported	Yes
No. 19: The conservative kidney management decision aid	Interactive website	1. Dialysis 2. CCM	Yes	Yes	n.a.	Not reported	No
No. 20: Yorkshire dialysis and conservative care decision aid	PDF document (28 pages)	1. PD 2. HD 3. CCM	Yes	Yes	n.a.	Not reported	No
No. 21: Supportive kidney care video decision aid	1. video (11.5 min)	1. PD 2. HD 3. CCM	No	No	n.a.	Not reported	Yes
Transplantation, dialysis or CCM?							
No. 22: The option grid - chronic kidney disease treatment options	PDF document (1 page)	1. PD: APD 2. PD: CAPD 3. HD: in-centre 4. HD: home 5. DDKT 6. LDKT 7. CCM	No	Yes	n.a.	Not reported	Yes
No. 23: Patient decision aid—kidney failure treatment options	PDF document (28 pages)	1. PD: APD 2. PD: CAPD 3. HD: in-centre 4. HD: home 5. DDKT 6. LDKT 7. CCM	Yes	No	n.a.	Not reported	No
No. 24: Providing resources to enhance African-American patients' readiness to make decisions about kidney disease decision aid	1. video (60min) 2. Comprehensive handbook (159 pages) 3. Mini handbook (14 pages)	1. PD 2. HD 3. HD: in-centre 4. HD: home 5. DDKT 6. LDKT 7. CCM	Yes	Yes	Fourth to sixth grade level	Not reported	Yes
No. 25: My kidneys, my choice	1. Interactive website 2. PDF document (15 pages)	1. PD: APD 2. PD: CAPD 3. HD: in-centre 4. HD: home 5. DDKT 6. LDKT 7. CCM	Yes	Yes	n.a.	Yes	Yes
No. 26: The Dutch kidney guide	Website	1. PD: APD 2. PD: CAPD 3. HD: home 4. HD: in-centre 5. DDKT 6. LDKT 7. CCM	No	Yes	n.a.	Yes	Yes
No. 27: Option grid: KRT versus CCM	PDF document (1 page)	1. PD 2. HD 3. Transplantation 4. CCM	No	Yes	Common European framework of reference level B1	Yes	Yes

\*The best evidence from which to report is the identified source. APD, ambulatory peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; CCM, conservative care management; DDKT, deceased donor kidney transplantation; HD, hemodialysis; IRD, increased risk donor; LDKT, living donor kidney transplantation; n.a., not available; PD, peritoneal dialysis; PDA, patient decision aids; RRT, renal replacement therapy.





**Table 6** IPDAS minimum standards component scores of the identified PtDAs

PtDA	Total score	IPDAS-01	IPDAS-02	IPDAS-03	IPDAS-04	IPDAS-05	IPDAS-06	IPDAS-C1	IPDAS-C2	IPDAS-C3	IPDAS-C4	IPDAS-C5	IPDAS-C6
No .1	9	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes
No .2	9	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes
No .3	8	No	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
No .4	9	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes
No .5	10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
No .6	10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
No .7	9	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
No .8	3	No	Yes	Yes	No	No	No	No	No	Yes	No	No	No
No .9	8	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	No	Yes
No .10	7	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	No	No
No .11	10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
No .12	3	No	No	Yes	Yes	Yes	No	No	No	No	No	No	No
No .13	5	Yes	Yes	Yes	No	No	No	No	Yes	Yes	No	No	Yes
No .14	7	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No	Yes
No .15	5	Yes	Yes	Yes	No	No	No	No	No	Yes	No	No	Yes
No .16	7	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	No	Yes
No .17	8	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes
No .18	10	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
No .19	11	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
No .20	11	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
No .21	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
No .22	6	No	No	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	No
No .23	8	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	No
No .24	11	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
No .25	8	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes
No .26	8	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	No	No	Yes
No .27	7	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	No	Yes

IPDAS, International Patient Decision Aids Standards; n.a., not available; PtDAs, patient decision aids.

**Table 7** Overview of studies evaluating the identified PtDAs

PtDA	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
What type of dialysis modality?						
No. 6	Multicentre non-randomised controlled study <sup>21</sup>	Patients with CKD referred for predialysis services	Total=189 ▶ YODDA+standard care=84 ▶ Control=105	1. Immediately post-intervention/control: patient and clinical characteristics, illness perception, health-related quality of life, preparation for decision-making 2. Immediately and 6 weeks post-intervention/control: how easy were leaflets to read, useful in helping understand kidney disease, dialysis and the decision, sufficient to make a decision, views over control over choice sharing decisions with spouse/family/healthy professionals, knowing other patients' choices, views of others in decision-making, difficulty in refusing healthcare professionals' recommendation, dialysis choice preference, dialysis and CKD knowledge, perceived seriousness and risk-implications of HD and PD, stage of decision-making 3. 6 weeks post-intervention/control: use of YODDA, decisional conflict	n.a.	1. Patients in the intervention group had higher scores than patients in the control group for understanding kidney disease, reasoning about options, feeling in control and sharing their decision with family. 2. Patients in the intervention group valued receiving the intervention; 96% read it on their own and 72% shared it with family. 3. At 6 weeks follow-up, patients' dialysis preferences were spread around 50/50 for home and hospital treatment options in both groups
No. 7	Meeting abstract of pilot study <sup>132</sup>	1. Patients with an eGFR <30 mL/min/1.73 m <sup>2</sup> 2. Providers	Total=38 (17 patients)	Post-intervention: outcomes of acceptability, usability and feasibility of integrating the interventions into existing care models	n.a.	1. Over 95% of participants recommended the option grid and 100% recommended the decision aid. 2. Participants felt more prepared to identify a treatment option after using the option grid. 3. 100% of participants agreed that the explanation of the options were clear and relevant. 4. 100% of patients reported that the decision aid was relevant and helpful in preparing them to make a decision and plans for next steps. 5. 89.5% of providers found the tools helped patients to better participate in decision-making
No. 8						
No.9	Mixed methods: development and pilot study <sup>22</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Total=137 ▶ Questionnaires=16	Post-intervention: patient-reported SDM, decisional quality, the patients' choice of dialysis modality, registration of the dialysis mode for patients starting dialysis	n.a.	1. 80% of the patients chose dialysis at home after the intervention; an increase of 23% compared with prior rates. 2. The majority of the patients experienced the intervention as SDM
	Qualitative study: interviews <sup>142</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Total=249 ▶ Interviews=29	Post-intervention: patients' experiences on the impact of SDM and Dialysis Choice (DC) on their involvement in the decision-making process	n.a.	1. Patients experienced the decisions made as their own process. 2. Patients felt the meetings contributed to the decision process. 3. Patients felt SDM-DC contributed to the decision process. 4. Patients experienced the decision process as iterative
	Mixed methods: questionnaires and interviews <sup>143</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Total=249 ▶ Questionnaires=148 ▶ Interviews=29	Post-intervention: patient-reported SDM, decisional quality, results of semi-structured interviews	n.a.	1. The participants obtained a mean score for SDM of 86 out of 100. 2. There was no significant difference between those choosing home-based or hospital-based treatment. 3. Those choosing home-based treatment had higher knowledge scores than those choosing hospital-based treatment (p=0.006). 4. 83% of participants achieved a high-quality decision. 5. No significant differences were found in decision quality between patients choosing home-based or hospital-based treatment.
	Qualitative study: interviews <sup>144</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Total=249 ▶ Interviews=13	3 months after dialysis initiation: results of semi-structured interviews	n.a.	1. Patients who had chosen home-based treatment had become more involved in their healthcare. 2. The involvement of relatives and support from healthcare professionals contributed to this increase in self-management. 3. Patients who had chosen hospital-based treatment had become less involved in their healthcare.
No. 10	Mixed methods: development and evaluation <sup>123</sup>	Patients with an eGFR between 10 and 20 mL/min/1.73 m <sup>2</sup>	Total=22	1. Pre-intervention: decisional conflict 2. Post-intervention: decisional conflict, system usability	n.a.	1. There was no reduction in decisional conflict after using the intervention. 2. The intervention received a low usability score

Continued

**Table 7** Continued

PTDA	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)†	Main findings‡
No. 11	RCT <sup>24</sup>	Patients with an eGFR <25 mL/min/1.73 m <sup>2</sup>	Total=133 ▲▲ Choose dialysis=63 Control=70	<ol style="list-style-type: none"> <li>Pre-intervention/control: treatment preference, decisional conflict, decisional self-efficacy</li> <li>Immediately post-intervention/control: treatment preference, decisional conflict, decisional self-efficacy</li> </ol>	<ol style="list-style-type: none"> <li>Pre-intervention/control: patient characteristics, knowledge, health literacy, health numeracy</li> <li>Immediately post-intervention/control: preparation for decision-making, knowledge, user experience</li> </ol>	<ol style="list-style-type: none"> <li>Decisional conflict scores were significantly lower in the intervention group (p&lt;0.001)</li> <li>Knowledge scores were significantly higher in the intervention group (p&lt;0.001)</li> <li>Decisional self-efficacy scores were comparable between the intervention and control groups</li> <li>Uncertainty about the choice of dialysis treatment decreased from 46% to 16% in the intervention group</li> <li>&gt;90% of the intervention group reported that the decision aid helped them in decision-making</li> </ol>
Transplantation or dialysis?						
No. 13	Multicentre RCT <sup>20</sup>	Patients with ESKD and on dialysis for <1 year	Total=470 ▲▲ iChoose Kidney+standard care=238 Control=232	Pre-intervention and immediately post-intervention/control: transplant knowledge	<ol style="list-style-type: none"> <li>Pre-intervention/control: patient characteristics</li> <li>Within 1 year post-intervention/control: &gt;1 living donor inquiry, placement on the kidney transplant waiting list or the receipt of a living or deceased donor transplant</li> <li>Pre-intervention and immediately post-intervention/control: decisional conflict</li> <li>Pre-intervention and immediately post-intervention/control: patient treatment preferences</li> <li>Immediately post-intervention/control: provider use of estimates of patient survival or mortality to communicate risk estimates, discussion of the benefits of transplant versus dialysis and LDKT versus DDKT</li> </ol>	<ol style="list-style-type: none"> <li>226 patients in the intervention group completed both the baseline and post-intervention surveys</li> <li>There was a greater improvement in knowledge score for the intervention group compared with the control group (p&lt;0.0001)</li> <li>There was no difference in access to transplantation between the intervention and control groups</li> </ol>
No. 14	Mixed methods: development and pilot study <sup>25</sup>	Patients considering renal transplantation	Total=81	<ol style="list-style-type: none"> <li>Pre-intervention: patient characteristics, previous transplant education, access to and comfort with technology, access to mobile phone with internet or an iPad, comfort with downloading apps, knowledge of transplant options, ability to make an informed decision about ESKD treatment options</li> <li>Post-intervention: knowledge of transplant options, ability to make an informed decision about ESKD treatment options, acceptability and cultural competence of My Transplant Coach</li> </ol>	<ol style="list-style-type: none"> <li>n.a.</li> </ol>	<ol style="list-style-type: none"> <li>86% of patients reported that the intervention improved their knowledge</li> <li>67%–85% of patient-reported that the intervention was culturally appropriate for their race/ethnicity</li> <li>Knowledge scores were significantly higher in patients after the intervention (p&lt;0.001), including in patients with low health literacy scores</li> </ol>
No. 16	Meeting abstract of prospective cohort study <sup>26</sup>	<ol style="list-style-type: none"> <li>Patients</li> <li>Healthcare professionals</li> </ol>	Total=293 (176 patients)	Post-intervention: patient-reported SDM, SDM awareness and use of the Option grid; KRT, the Dutch Kidney Guide and the Option grid; KRT versus CCM by healthcare professionals	<ol style="list-style-type: none"> <li>n.a.</li> </ol>	<ol style="list-style-type: none"> <li>12 centres (2 academic, 10 non-academic) participated in the study</li> <li>When centres with the worst scores for SDM were compared with centres with the best scores for SDM, a difference was noticed in the use of the decision aids (50% vs 100%)</li> <li>Overall, no significant differences between centres in the scores for SDM were found</li> <li>56% of the professionals believed SDM was applied, but only 31%–33% of clinicians used the Option grid; KRT and the Option grid: KRT versus CCM. The Dutch Kidney Guide was used by 51%</li> </ol>
Accept or decline IRD kidney offer?						

Continued

**Table 7** Continued

PRDA	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)†	Main findings‡
No. 17	RCT <sup>136</sup>	Kidney transplant candidates	Total=288 ▶ Inform n=133 ▶ Control=155	Immediately and at 1 week post-intervention/control: IRD knowledge kidneys, willingness to accept an IRD kidney offer, experiences with Inform Me	Pre-intervention/control: patient characteristics, health literacy, health numeracy	1. 105 patients in the intervention group completed both the baseline and post-intervention surveys 2. Patients in the intervention group had significantly higher knowledge scores immediately after the intervention compared with patients in the control group (p<0.001) 3. Patients in the intervention group had significantly higher knowledge scores 1 week after the intervention compared with patients in the control group (p<0.001) 4. There was no difference in the willingness to accept an IRD kidney offer between the groups
Dialysis or CCM?						
No. 18	RCT <sup>127</sup>	Patients >70 years of age with AKD	Total=41 ▶ OPTIONS: tool+consultations with a trained renal nurse=19 ▶ Control=22	1 month and 3 months post-intervention/control: decisional regret, decisional conflict	1. Pre-intervention/control: patient and clinical characteristics 2. 1 month post-intervention/control: knowledge, preparation for decision-making 3. 1 and 3 months post-intervention/control: clinical characteristics health-related quality of life	1. There were no significant differences in decision conflict, decision regret or health-related quality of life between the intervention and control group 2. The intervention group had a significantly better improvement in knowledge score than the control group (p<0.001) 3. The intervention was helpful in preparing patients to make a treatment decision
No. 21	Multicentre RCT <sup>128</sup>	Patients >65 years of age with an eGFR <25 mL/min/1.73 m <sup>2</sup>	Total=104 ▶ Supportive kidney care video education=54 ▶ Scripted verbal education=51	Pre-intervention and post-intervention/control: supportive kidney care knowledge	1. Pre-intervention/control: patient characteristics, health literacy 2. Pre-intervention and post-intervention: preference for KRT 3. Post-intervention: satisfaction with and acceptability of the intervention	1. 50 patients in the intervention group completed both the baseline and the post-intervention surveys 2. Knowledge of supportive kidney care increased significantly after education among all participants (p<0.001) 3. There were no differences in knowledge between the intervention and the control group 4. There were no differences in preference for supportive kidney care between the intervention and the control group 5. 96% of patients were comfortable with watching the video 6. 96% of patients felt that the content of the video was helpful 7. 96% of the patients reported they would recommend the video to others
Transplantation, dialysis or CCM?						
No. 22	Mixed methods: development and evaluation <sup>139</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Total=65	Pre-intervention and 2 months post-intervention: decisional quality	n.a.	1. 39 patients completed both the baseline and post-intervention surveys 2. Comparison of the decisional quality at baseline and follow-up showed improvements in patients' overall knowledge on their treatment options 3. Comparison of the decisional quality at baseline and follow-up showed improvements in patients' readiness to decide on a treatment option
No. 24	Multicentre RCT <sup>145</sup>	Self-reported African-Americans with ESKD <2 years	Total=92 ▶ PREPARED=30 ▶ PREPARED+living donor financial assistance programme=31 ▶ Control=31	1, 3 and 6 months post-intervention/control: discussing LDKT with family members, discussing LDKT with their doctor, initiation of the recipient medical evaluation for LDKT, completion of a potential live kidney donor, participants beliefs about kidney transplant and their concerns about LDKT	1. Pre-intervention/control: patient and clinical characteristics, experiences with HD care, preparation for KRT or LDKT, perceived involvement in kidney treatment decisions, concerns regarding LDKT 2. 1, 3 and 6 months post-intervention: fidelity and usefulness, whether participants shared the donor financial assistance programme with family members or friends	1. 62% of participants in the intervention groups reported that it helped them their decision-making about KRT 2. There were no significant improvements in LDKT action in both groups over 6 months 3. There were no participants that used the living donor financial assistance programme

Continued

Table 7 Continued

PtDA	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)†	Main findings‡
No. 25	Multicentre pre-post study <sup>78</sup>	Patients referred for ESKD education	Total=97	Pre-intervention and post-intervention: patient characteristics, knowledge, worries, values and decision-making experience with the decision-aid, experienced education-methods, utilisation level of the decision-aid, whether decision-making involved significant others, ranking of preferred treatment options	n.a.	<ol style="list-style-type: none"> <li>72 patients completed the both the baseline and post-intervention surveys</li> <li>Knowledge levels increased significantly after the intervention (p&lt;0.001)</li> <li>Worry and flexibility scores all increased significantly after the intervention (p&lt;0.05)</li> <li>This preliminary assessment revealed high patient acceptance and usability of the intervention</li> </ol>
No. 26	Meeting abstract of prospective cohort study <sup>25</sup>	1. Patients 2. Healthcare professionals	Total=293 (176 patients)	Post-intervention: patient-reported shared decision-making, SDM awareness and use of the Option grid: KRT, the Dutch Kidney Guide and the Option grid: KRT versus CCM by healthcare professionals	n.a.	<ol style="list-style-type: none"> <li>12 centres (2 academic, 10 non-academic) participated in the study</li> <li>When compared with the worst scores for SDM were compared with centres with the best scores for SDM, a difference was noticed in the use of the decision aids (50% vs 1.00%)</li> <li>Overall, no significant differences between centres in the scores for SDM were found</li> <li>56% of the professionals believed SDM was applied but only 31%–33% of clinicians used the Option grid: KRT and the Option grid: KRT versus CCM. The Dutch Kidney Guide was used by 51%</li> </ol>
No. 27						

\*Population formulated as reported in the identified records.  
†Outcomes formulated as reported in the identified records.  
‡Main findings formulated as reported in the identified records.

Abbreviations: CKD, Chronic Kidney Disease; DDKT, deceased donor kidney transplantation; eGFR, estimated glomerular filtration rate; ESKD, end-stage kidney disease; HD, haemodialysis; IRD, increased risk devices; KRT, Kidney Replacement Therapy; LDXT, Living Donor Kidney Transplantation; n.a., not applicable; PD, peritoneal dialysis; PREPARED, providing resources to enhance African-American patients' readiness to make decisions about kidney disease; PtDAs, patient decision aids; RCT, randomised controlled trial; RRT, renal replacement therapy; SDM, shared decision-making; YODDA, Yorkshire dialysis decision aid.

these studies. Most (n=8, 47.0%) were evaluated in experimental studies (no.6, 11, 13, 17, 18, 21, 24, 25), three-quarter of which (n=6, 75.0%) were RCTs.<sup>70 124 126 127 129 145</sup> Five (n=5, 29.4%) PtDAs (no.7, 8, 16, 26, 27) were evaluated in studies presented in meeting abstracts.<sup>132 135</sup> The remaining four (n=4, 23.5%) PtDAs (no.9, 10, 14, 22) were evaluated in observational studies<sup>142 144</sup> and mixed-methods studies,<sup>122 123 125 130 143</sup> two of which included pilot evaluations.<sup>122 125</sup>

PtDAs were generally evaluated for their effects on health-related outcomes, and on knowledge, decisional quality and patient activation. Only one PtDA (no.7) was evaluated for its effects on SDM.<sup>122 143</sup> One meeting abstract presented a study that evaluated whether SDM scores differed among hospitals if PtDAs (no.16, 26, 27) were used or not.<sup>135</sup> Ten (n=10, 37.0%) PtDAs (no.9, 10, 11, 13, 16, 18, 21, 24, 26, 27) were evaluated in studies published after the standardised outcome sets for CKD, dialysis and transplantation were published by ICHOM and SONG. None of these PtDAs were evaluated with these outcomes. Patients that used PtDAs were generally more knowledgeable about their treatment options, and had better scores of decisional quality and patient activation than patients that did not use PtDAs (see table 7). The two studies that evaluated the PtDA (no.7) on outcomes of SDM showed that patients experienced the intervention as SDM (see table 7). The meeting abstract that presented a study that evaluated whether SDM scores differed among hospitals if PtDAs were used or not showed that hospitals that used these PtDAs (no.16,26,27) generally had better scores for SDM compared with hospitals that did not use them (see table 7). However, these differences were not significant (see table 7).

### Multicomponent initiatives

We identified nine MIs (excluding four currently under investigation). Eight were identified in peer-reviewed articles,<sup>146–155</sup> one was identified in two meeting abstracts found in the grey literature.<sup>156 157</sup>

Table 8 provides an overview of the identified MIs and their characteristics. Table S8 in online supplemental appendix 4 provides additional details on the identified MIs (eg, sources for publicly available MIs). One MI was developed to promote PD (no.1) and helps patients choose whether to start with PD or not. One MI as developed to help patients choose between dialysis options (no.2). Two MIs help patients choose between transplantation and dialysis options (no.3,4), one of which promotes transplantation and strives to reduce racial disparities in access to kidney transplantation (no.3). Five help patients choose between transplantation, dialysis and CCM options (no.5–9), with three promoting a particular treatment modality (no.5,7,9). Almost all MIs were developed for the general population of patients with AKD, one (no.8) was specifically developed for suboptimal dialysis initiation patients.

All MIs include an educational component for patients. One MI also educates clinicians (no.3). Two-thirds



**Table 8** Overview of the identified MIs and their characteristics

MI	Format	Treatment options*	Values-clarification/ preference elicitation exercise(s)	Promotes treatment modality	Coaching	Patient participation in development	Reading level	Implemented	Evaluated
Start PD or not?									
No. 1: Kidney Disease Therapy Society cooperative programme	1. National CKD cooperative programme between general practitioners and specialists (shared clinical pathways) 2. National CKD education programme (outpatient consultations with clinicians, pamphlets, public lectures) 3. National PD promotion programme (educational sessions with clinicians, pamphlets, public lectures) 4. National HD; home promotion programme (outpatient consultations with clinicians, pamphlets, public lectures)	1. PD 2. HD; in-centre 3. HD; home 4. Transplantation	No	PD	No	No	n.a.	Yes	Yes
What type of dialysis modality?									
No. 2: structured modality information programme	1. Multiple outpatient consultations with clinicians (n.a.) 2. Decision-making tools (printed materials, DVDs) 3. Visits to treatment centres	1. PD 2. HD	Yes	No	Yes	No	n.a.	Yes	Yes
Transplantation or dialysis?									
No. 3: Reducing Disparities in Access to Kidney Transplantation	1. Facility policy and protocol level activities (transplant referral improvement plan, quality improvement assistance and review, transplant referral/evaluation data reports, patient/family advisory group, peer mentor programme, transplant education month, facility-wide movie night, journal goals, obstacles and successes) 2. Facility leadership and staff level activities (kick-off to improve transplant referrals, transplant conference, monthly webinars, electronic module on patient safety and transplantation) 3. Patient-level activities (bulletin board, paper handouts/pamphlets, iChoose Kidney decision aid, living ACTS DVD)	1. Dialysis 2. DDKT 3. LDKT	Yes	Transplantation	Yes	No	n.a.	Yes	Yes
Transplantation, dialysis or CCM?									
No. 4: shared decision-making programme	1. Three outpatient consultations with renal disease case manager (n.a.) 2. Decision support tool (paper based) 3. Three phone calls with renal disease case manager (n.a.)	1. PD 2. HD 3. Transplantation	Yes	No	Yes	No	n.a.	Not reported	Yes
Transplantation, dialysis or CCM?									
No. 5: Haemodialysis Orientation Unit	1. Physically separate HD orientation unit with own staff 2. Multiple outpatient consultations with clinicians (n.a.) 3. Printed materials (posters, drawings, flash cards) 4. Videos (n.a.) 5. 6 weeks curriculum with weekly tasks for patients	1. PD 2. HD; in-centre 3. HD; home 4. Transplantation 5. CCM	No	Self-care dialysis modalities	No	Yes	n.a.	Yes	Yes
No. 6: shared decision-making process for kidney replacement therapy choice	1. Multiple outpatient consultations with clinicians (2.5 hours total) 2. Printed materials (flipcharts, brochures, leaflets, forms, values cards) 3. Decision-making software (two electronic questionnaires) 4. One DVD (n.a.)	1. PD; APD 2. PD; CAPD 3. HD; in-centre 4. HD; home 5. DDKT 6. LDKT 7. CCM	Yes	No	Yes	No	n.a.	Yes	Yes
No. 7: GUIDE	1. One home visit by case manager (n.a.) 2. Electronic questionnaire for case manager and nephrologist (n.a.) 3. Electronic questionnaire for patient (n.a.) 4. Electronic dashboard (n.a.) 5. One multidisciplinary conference (n.a.) 6. One session of individual education from clinicians (n.a.) 7. Printed materials (brochures) 8. Videos (n.a.) 9. Chance to meet peer patients	1. PD 2. HD, in-centre 3. HD, home 4. Transplantation 5. CCM	Yes	Transplantation	Yes	No	n.a.	Yes	Yes
No. 8: Unplanned dialysis start (UPS)	1. Process improvement approach to analyse UPS patient flow in dialysis units 2. Three sessions of individual education with nurse (n.a.) 3. Printed materials (booklet, photograph based book) 4. One video (n.a.) 5. Visits to treatment centres 6. Decision aids (decision cards, self-completion balance scale, Ottawa online decision aid)	1. PD 2. HD, in-centre 3. HD, home 4. Transplantation 5. CCM	Yes	No	Yes	No	n.a.	Yes	Yes

Continued

Table 8 Continued

MI	Format	Treatment options*	Values-clarification/ preference elicitation exercise(s)	Promotes treatment modality	Coaching	Patient participation in development	Reading level	Implemented	Evaluated
No. 9: shared decision-making for renal replacement therapy	1. Electronic health information order system (n.a.) 2. Internet-based patient educational programme (n.a.) 3. Electronic decision-making questionnaire (n.a.) 4. Interactive games (n.a.) 5. Videos (n.a.)	1. PD 2. HD 3. Transplantation 4. CCM	Yes	1. PD 2. Transplantation	Yes	No	n.a.	yes	Yes

\*Treatment options furnished as reported in the identifier records.  
ACTS: living about choice in transplantation and dialysis; APD: ambulatory peritoneal dialysis; CAPD: continuous ambulatory peritoneal dialysis; CCM: conservative care management; CKD: chronic kidney disease; DDKT: deceased donor kidney transplantation; HD: haemodialysis; KRT: kidney replacement therapy; LDKT: living donor kidney transplantation; n.a.: not available; PD: peritoneal dialysis; RRT: renal replacement therapy.

(n=6, 66.7%) include decision support interventions or other tools that help patients make values-based and preferences-based decisions (no.2, 3, 6–9). One MI (no.3) includes a previously identified PtDA (no.13) and components of a previously identified EP (no.26). The majority (n=7, 77.8%) of MIs (no.2–4, 6–9) use coaches to support patients and guide them through the programme. Almost half of the MIs (n=4, 44.4%) were developed as quality improvement initiatives and include nationwide, or facility level, policy and protocol changes (no.1, 3, 5, 8). Some MIs (n=3, 33.3%) were specifically developed to implement SDM in clinical practice (no.4, 6, 9).

Only one MI (no.4) was developed with the input of patients. None contain reading level information. Only one MI (no.3) consists of components that are publicly available.

All but one MI (no.4) were reported to have been implemented in clinical practice. All MIs have been evaluated for their effects on outcomes in the intended users, most of which (n=8, 88.9%) were patients (no.1, 2, 4–9). One MI (no.3) was evaluated for its effects on a dialysis facility level.

Table 9 provides an overview of the studies<sup>146–157</sup> that evaluated the identified MIs. Table S9 in online supplemental appendix 4 provides additional details on these studies. Two-thirds of MIs (n=6, 66.6%) were evaluated in observational studies (no.1, 5–9), three of which (n=3, 33.3%) were prospective cohort studies.<sup>146 149–153 155</sup> A minority (n=2, 22.2%) were evaluated in experimental studies (no.3, 4), only one of which was an RCT.<sup>147</sup> One MI (no. 2) was evaluated in two sequential studies presented in two meeting abstracts.<sup>156 157</sup>

MIs were generally evaluated for their effects on health-related outcomes and on patient activation. None of the MIs were evaluated for their effects on SDM. Four (n=4, 44.4%) MIs (no.2, 3, 4, 9) were evaluated in studies published after the standardised outcome sets for CKD, dialysis and transplantation were published by ICHOM and SONG. None of these MIs were evaluated with these outcomes. Patients exposed to MIs generally had more favourable health-related outcomes (see table 9). They were also more active in choosing and requesting treatments (see table 9). MIs that promote particular treatment modalities (no.1, 3, 5, 7, 9) appear to increase the number of patients planning to start with these modalities (see table 9). The MI that was evaluated for its effects on a dialysis facility level (no.3) reported significant changes in the proportion of patients referred for transplantation<sup>147</sup> and high fidelity to the intervention.<sup>154</sup> It also appeared to reduce racial disparities in access to kidney transplantation.<sup>147</sup>

### Interventions currently under development or investigation

We identified 16 interventions currently under investigation. The majority of these interventions (n=12, 75.0%) were identified in the grey literature,<sup>158–169</sup> the remaining interventions (n=4, 25.0%) were identified in published protocol papers.<sup>170–173</sup>

**Table 9** Overview of studies evaluating the identified MIs

MI	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
Start PD or not?						
No. 1	Quality improvement report <sup>146</sup>	Patients with CKD in the advanced stage	Total=63	Post-intervention: PD selection rate	n.a.	After the intervention there was an increase in PD selection from 8.8% to 1.5% over 2 years
What type of dialysis modality?						
No. 2	Meeting abstract of retrospective cohort study <sup>145</sup>	<ol style="list-style-type: none"> <li>Patients with stage 4 and 5 CKD</li> <li>Patients after unplanned dialysis start</li> </ol>	Total=1141	Post-intervention: patient clinical characteristics, use of decision-making tools by patients, KRT modality choice, KRT modality start	n.a.	<ol style="list-style-type: none"> <li>1141 patients were educated in 45 clinics</li> <li>Written information was largely used for 89%–95% of patients</li> <li>DVDs were used for 14%–30% of patients</li> <li>Treatment centre touring visits were used for 10%–76% of patients</li> <li>An increase in PD take-on occurred in the clinic-network after introduction of the structured modality information programme</li> <li>Most patients who chose PD (9%) were chronically ascribed to PD (31%), representing at least one-third of the suitable patients for both dialysis modalities</li> </ol>
Meeting abstract of retrospective cohort study <sup>147</sup>						
		Patients with stage 4 and 5 CKD	Total=2012	Post-intervention: patient clinical characteristics, use of decision-making tools by patients, KRT modality choice, KRT modality start	n.a.	<ol style="list-style-type: none"> <li>2012 patients were educated in 48 clinics</li> <li>Written information was largely used for 97% of patients</li> <li>DVDs were used for 27% of patients</li> <li>Treatment centre touring visits were used for 49% of patients</li> <li>Most patients who chose PD (65%) were chronically ascribed to PD (31%); representing at least one-third of the suitable patients for both dialysis modalities</li> </ol>
Transplantation or dialysis?						
No. 3	Multicentre RCT <sup>147</sup>	Dialysis facilities	Total=134 ▲▲ RADIANT=67 Control=67	Pre-intervention and 12 months post-intervention: facility-level transplant referral	<ol style="list-style-type: none"> <li>1. Patient and dialysis facility characteristics</li> <li>2. Pre-intervention and 12 months post-intervention: black versus white racial disparity in transplant referral, number of transplant evaluation starts, number of patients waitlisted for transplant</li> </ol>	<ol style="list-style-type: none"> <li>134 dialysis facilities, involving &gt;9000 patients participated in the study</li> <li>Dialysis facilities in the intervention group referred a higher proportion of patients for transplantation at 12 months post-intervention (p&lt;0.001)</li> <li>The difference between intervention and control dialysis facilities in the proportion of patients referred for transplant was higher among black than white patients (p&lt;0.05)</li> </ol>
Multicentre prospective cohort study <sup>148</sup>						
		Dialysis facility staff members	Total=94	<ol style="list-style-type: none"> <li>1. Post-intervention: staff, patient and dialysis facility characteristics</li> <li>2. Post-intervention: fidelity, sustainability, reach and context of the intervention, associations between process data and intervention outcomes</li> </ol>	n.a.	<ol style="list-style-type: none"> <li>Staff from 65 of the 67 dialysis facilities completed the questionnaire</li> <li>50.8% reported high fidelity to the RADIANT intervention</li> <li>63.1% reported that RADIANT was helpful or very helpful</li> <li>90.8% were willing to continue with at least one of the intervention components after the study</li> <li>Variation in facility-level fidelity to RADIANT did not significantly influence the difference in the proportion of patients referred for transplant pre-intervention and post-intervention</li> </ol>
No. 4	Quasi-experimental study <sup>148</sup>	Patients with an eGFR <30 mL/min/1.73 m <sup>2</sup>	Total=72 ▲ SDM programme=36 ▲ Control=36	<ol style="list-style-type: none"> <li>1. Pre-intervention/control: patient and clinical characteristics, decisional conflict, decisional self-efficacy</li> <li>2. Immediately and 1 month post-intervention/control: decisional conflict, decisional self-efficacy</li> </ol>	n.a.	<ol style="list-style-type: none"> <li>Patients in the intervention group had a significant increase in decision self-efficacy and a significant decrease in decisional conflict immediately after (p&lt;0.001, p&lt;0.001) and 1 month after the intervention (p&lt;0.001, p&lt;0.001)</li> <li>The intervention group had significantly higher decision self-efficacy scores than the control group immediately after (p&lt;0.001) and 1 month after the intervention (p&lt;0.001)</li> <li>The control group had lower decisional conflict scores than the intervention group immediately after (p&lt;0.001) and 1 month after the intervention (p&lt;0.001)</li> </ol>
Transplantation, dialysis or CCM?						
No. 5	Retrospective cohort study <sup>149</sup>	Patients on HD	Total=93	Post-intervention: number of patients treated in the HD orientation unit, patient and clinical characteristics, distribution of treatment modality 1 year after operation of the HD orientation unit	n.a.	<ol style="list-style-type: none"> <li>62% of patients transferred from in-centre HD to home HD, or were planning to do so</li> <li>24% of patients transferred to CCM</li> <li>41% of patients were able to self-puncture their fistulas after receiving the intervention</li> </ol>
No. 6	Multicentre prospective cohort study <sup>150</sup>	Patients with CKD	Total=1044 ▲ SDM process for KRT choice=967	Post-intervention: patient and clinical characteristics, KRT choice and treatment initiation, chosen KRT modality and definitive KRT modality	n.a.	<ol style="list-style-type: none"> <li>569 patients in that received the intervention made a KRT choice by the end of follow-up: 88.4% dialysis (43% HD and 45% PD), 3.2% pre-emptive LDKT and 8.4% CCM</li> <li>399 patients began KRT during the post-intervention period: 83.4% dialysis (63.6% HD, 40% PD), 1.3% pre-emptive LDKT and 5.3% CCM</li> <li>Patients that received the intervention changed their mind about their KRT modality less than patients who did not receive the intervention</li> <li>The concordance between the final KRT choice and definitive modality in patients that received the intervention was higher compared with patients that did not receive the intervention</li> <li>Patients that did not receive the intervention chose PD less often and changed their decision more often compared with patients that did receive the intervention</li> </ol>

Continued

**Table 9** Continued

MI	Source	Population*	Sample size	Primary outcome(s)†	Secondary outcome(s)‡	Main findings§
No. 7	Retrospective cohort study <sup>151</sup>	Patients with eGFR <15 mL/min/1.73 m <sup>2</sup>	Total=102	<ol style="list-style-type: none"> <li>1. Pre-intervention: treatment modality distribution</li> <li>2. Post-intervention: patient and clinical characteristics, timeline of each patients' GUIDE process and the outcome of the steps, treatment modality distribution</li> </ol>	n.a.	<p>The intervention was started at a mean eGFR of 12 mL/min/1.73 m<sup>2</sup></p> <ol style="list-style-type: none"> <li>1. 84% of patients were recommended to undergo dialysis of which 62.8% were recommended home dialysis</li> <li>3. 72% of patient that received the intervention chose dialysis, of which 42.5% chose a form of home dialysis (34.2% PD, 8.2% HD; home)</li> <li>4. 22.5% of patients that received the intervention started home dialysis as their first therapy compared with 17.6% of patients that did not receive the intervention</li> <li>5. 32.1% of patients that received dialysis therapy after the intervention received home dialysis compared with 19.5% of patients that did not receive the intervention</li> </ol>
No. 8	Multicentre prospective cohort study <sup>152</sup>	Unplanned dialysis start patients	Total=270 ▲ UPS=214	Up to 12 months post-intervention; patient and clinical characteristics, the number of patients receiving and completing the programme, the number of patients making a dialysis modality decision, the final dialysis modality chosen, the number of patients receiving their chosen modality	n.a.	<ol style="list-style-type: none"> <li>1. 177 were able to decide on a dialysis modality after the intervention, of which 159 received their treatment of choice</li> <li>2. Initial dialysis modality and country specific practices were predictive of receiving the intervention (p=0.001, p=0.001) and dialysis modality decision-making (p&lt;0.001, p=0.02)</li> <li>3. Age was predictive of receiving the intervention (p=0.01)</li> </ol>
No. 9	Multicentre prospective cohort study <sup>153</sup>	Unplanned dialysis start patients	Total=270 ▲ UPS=214	Pre-intervention, 6 and 12 months post-intervention; patient and clinical characteristics, dialysis modality, details of when changed if changed, details of access procedures if changed, details of dialysis-related infectious events, number and length of hospitalisations, predictors of receiving PD or HD, flow of patients through the programme	n.a.	<ol style="list-style-type: none"> <li>1. 203 completed the intervention, after which 177 chose a dialysis modality (59% PD, 42% HD)</li> <li>2. Patients that did not complete the intervention were significantly older (p=0.01) and had a higher CCI (p&lt;0.01)</li> <li>3. 86% of patients that chose PD and 95% of patients that chose HD received their treatment of choice</li> <li>4. Diabetes and receiving the intervention predicted receiving PD (p=0.03, p&lt;0.001)</li> <li>5. Patients that chose PD had a higher CCI (p=0.01), prevalence of congestive heart failure (p&lt;0.001), myocardial infarction (p=0.02) and were more likely in-patients (p=0.02) or referred from primary care (p=0.02)</li> <li>6. 11 year survival rates between PD or HD patients were comparable</li> </ol>
No. 9	Retrospective cohort study <sup>153</sup>	Patients with an eGFR <15 mL/min/1.73 m <sup>2</sup>	Total=310 ▲ SDM for RRT=220	1 year post-intervention; patient- and clinical characteristics, evaluated for LDKT; receiving a LDKT; receiving PD or HD	n.a.	<ol style="list-style-type: none"> <li>1. 66 patients received PD, 67 patients entered the evaluation of LDKT and 18 patients received a LDKT 1 year after the intervention</li> <li>2. Compared with patients that did not receive the intervention there was an increase of 31.4% in patients receiving an evaluation for LDKT, an increase of 38.5% in patients receiving a LDKT and an increase of 112.9% in patients receiving PD</li> <li>3. 53% of patients that started PD after the intervention started without temporary HD as compared with 21.6% of patients that did not receive the intervention</li> <li>4. 91.3% of patients were satisfied with the intervention</li> </ol>

\*Population formulated as reported in the identified records.  
 †Outcomes formulated as reported in the identified records.  
 ‡Main findings formulated as reported in the identified records.  
 §Main findings formulated as reported in the identified records.  
 CCI, chronic kidney disease; CCKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; HD, haemodialysis; KRT, kidney replacement therapy; LDKT, living donor kidney transplantation; MIs, multicomponent initiatives; n.a., not applicable; PD, peritoneal dialysis; RADJANT, Reducing Disparities in Access to Kidney Transplantation; RCT, randomised controlled trial; RRT, renal replacement therapy; SDM, shared decision-making; UPS, unplanned dialysis start.

Table 10 provides an overview of these interventions. Table S10 in online supplemental appendix 4 provides additional details on these interventions. More than half (n=10, 62.5%) are EPs (no.1, 2, 4, 5, 7–11, 16), one-quarter (n=4, 25.0%) are MIs (no.3, 6, 14, 15) and one-eighth (n=2, 12.5%) are PtDAs (no.12,13). Four interventions help patients choose between dialysis options (no.1–4), two of which promote a particular treatment modality (no.1, 4). Seven interventions promote LDKT and help patients choose whether or not to pursue LDKT (no.5–11). Two help patients choose between dialysis or CCM options (no.12, 13). Only one helps patients choose between transplantation, dialysis and CCM options (no.14). Two help patients choose between transplantation options (no.15, 16).

A quarter of these interventions (n=4, 25.0%) included components of previously identified interventions (no.8, 11, 14, 16), and two (n=2, 12.5%) are modifications (no.6, 7) of another intervention under investigation (no.5). Two interventions (n=2, 12.5%) have been previously evaluated and are undergoing additional evaluation (no.9, 10).

Half of the interventions (n=8, 50.0%) have been developed for specific patient populations, most of which (n=5, 62.5%) were developed for African-American, Hispanic or non-white race patients (no.5–8,11). Less (n=3, 37.5%) were developed for elderly patients (no.2, 12, 13). The remaining interventions can be used by the general population of patients with AKD.

Table 11 provides an overview of the studies<sup>158–173</sup> evaluating these interventions. Table S10 in online supplemental appendix 4 provides additional details on these studies. Almost all of the interventions (n=15, 93.8%) will be evaluated in experimental studies, the majority (n=14, 93.3%) of which (no.1–9, 11, 12, 14–16) in RCTs.<sup>158–164 166 168–171 173</sup> Selected outcomes include health-related outcomes, knowledge, communication, patient activation and decisional quality. None of the authors report evaluating these interventions for their effects on SDM. Nine (n=9, 56.3%) interventions (no.2, 3, 4, 8, 10, 11, 12, 14, 16) were identified in registries or protocol papers published after the standardised outcome sets for CKD, dialysis and transplantation were published by ICHOM and SONG. The authors for these interventions do not report evaluating their interventions with these outcomes. Six of the studies have completed their recruitment procedures,<sup>159 161 163 164 171 173</sup> five are recruiting,<sup>158 160 162 165 172</sup> three are active but not recruiting,<sup>166 168 169</sup> one has an unknown recruitment status<sup>170</sup> and one does not provide a recruitment status.<sup>167</sup>

## DISCUSSION

We identified a considerable number of interventions that can be used to support SDM for treatment modality decisions in AKD. We observed that there are interventions that support a decision between a limited number of treatment modalities, and that there are interventions

that support a decision between all treatment modalities for kidney failure. Almost all PTs that we identified make predictions that support decisions encompassing a single action or a single treatment modality (eg, start or delay preparations for kidney failure, accept or reject LDKT offer, start or forego dialysis). One PT compares prognostic information of two treatment options (transplantation and dialysis), which can be used to help patients make a treatment modality decision based on their personal risks.<sup>57</sup> Similarly, most of the EPs, PtDAs and MIs we identified either provide information on a single treatment modality (eg, dialysis) or on two different treatment modalities (eg, dialysis and transplantation). A minority of the identified interventions provide information on all treatment modalities for kidney failure, including CCM. We recommend that clinicians use interventions appropriate to the decisions their patients have to make. With regard to treatment modality decisions in AKD, patients go through a ‘hierarchy of nested decisions rather than a choice between discrete options’.<sup>19</sup> For example, patients will first have to decide whether they would prefer KRT or CCM, after which those that opt for KRT have to choose between their treatment options (eg, transplantation or dialysis modalities). With the right tools, clinicians can help patients: (1) navigate this decision-making process and (2) make choices based on their values and preferences. Values-clarification and preference-elicitation are important in the deliberation phase of SDM, and may ultimately lead to making a shared decision based on what ‘matters most to patients’.<sup>9 10</sup> Most of the PtDAs we identified contain exercises that help patients in this process, and in that regard offer more than just education alone. Ideally, clinicians should use a combination of EPs, PtDAs and PTs to support and engage their patients in the decision-making process and make treatment modality decisions according to the principles of SDM. MIs cater to this idea, but most of the MIs we identified combine education with decision aids or other tools that help patients make values-based and preference-based decisions. We identified one novel MI (no.14) that combines all three of these tools. This MI is currently being evaluated in an RCT, which may provide some of the first evidence on the effectiveness (on patient-reported, biomedical and health system outcomes) of an intervention that combines education with prognostic information and decision support for patients with AKD.<sup>173</sup>

We observed considerable variation in the level of detail provided regarding the content of the interventions we identified. Most researchers and developers gave information on the structure and the medium that were used for the interventions, but they generally left the topics that were discussed unmentioned. They also varied in how they called treatment modalities (eg, independent vs self-care dialysis), and in the level of detail in which they described treatment modalities (eg, PD vs CAPD and APD). We found most of this variation in EPs, which may be explained by a lack of standardisation to specify and report on their contents.<sup>20</sup> On the contrary, for PtDAs

**Table 10** Overview of interventions currently under development or investigation

Intervention	Type of intervention	Format	Treatment options*	Values-clarification/preference elicitation exercise(s)	Coaching	Promotes treatment modality
What type of dialysis modality?						
No. 1: Web-based Interactive Health Communication Application for successful Home Dialysis (WISHED)	EP	Interactive application (n.a.)	1. PD 2. HD: in-centre 3. HD: home	No	No	Home dialysis
No. 2: Chronic Kidney Disease Enhanced Dialysis Education	EP	Multiple sessions of individual education and coaching with coaches (n.a.)	Dialysis	No	Yes	No
No. 3: decision support intervention	MI	1. Multiple outpatient consultations with clinicians (n.a.) 2. Multiple sessions of individual education with educator (n.a.) 3. Decision aids (n.a.)	1. PD 2. HD	Yes	Yes	No
No. 4: comprehensive preESRD patient education	EP	Three sessions of individual education with educators (n.a.)	1. PD, home 2. HD, in-centre 3.	No	No	Home dialysis modalities
Pursue LDKT or not?						
No. 5: house calls educational intervention	EP	1. Multiple outpatient consultations with clinicians (n.a.) 2. Printed materials (pamphlets, brochures, booklets) 3. One DVD (n.a.) 4. Optional session of group education health educator (60-90min) 5. Optional home visit by health educator (60-90min) 6. Optional session of outpatient individual education with health educator (60-90min)	1. DDKT 2. LDKT	No	Yes	LDKT
No. 6: house calls+web-based decision support	MI	1. Multiple outpatient consultations with clinicians (n.a.) 2. Printed materials (pamphlets, brochures, booklets) 3. One DVD (n.a.) 4. One home visit by health educator (60-90min) 5. Web-based decision support (interactive website)	1. DDKT 2. LDKT	Yes	Yes	LDKT
No. 7: house calls+peer mentorship	EP	1. Multiple outpatient consultations with clinicians (n.a.) 2. Printed materials (pamphlets, brochures, booklets) 3. One DVD (n.a.) 4. One home visit by health educators (60-90min) 5. Peer mentorship (n.a.)	1. DDKT 2. LDKT	No	Yes	LDKT
No. 8: destination transplant	EP	1. One session of group education (60-90min) 2. Printed materials (explore transplant fact sheets, postcards) 3. One phone call with transplant educator (n.a.) 4. Optional additional printed material (booklet)	1. DDKT 2. LDKT	No	Yes	LDKT
No. 9: Talking about Live Kidney Donation (TALK)	EP	1. Multiple outpatient consultations with clinicians (n.a.) 2. One video (20min) 3. Printed material (booklet) 4. Two home visits by social workers (1 hour total)	LDKT	No	Yes	LDKT
No. 10: communicating about choices in transplantation	EP	1. One session of group education (3hours) 2. Videos (n.a.)	1. DDKT 2. LDKT	No	No	LDKT
No. 11: Living About Choices in Transplantation and Sharing (ACTS)—website	EP	1. Website 2. Five videos (25min total)	LDKT	No	No	LDKT
Dialysis or CCM?						
No. 12: Decision Aid for Renal Therapy (DART)	PIDA	Interactive website	1. Dialysis 2. CCM	Yes	No	No
No. 13: decision aid for elderly patients with kidney failure	PIDA	1. One video (18min) 2. Printed material (booklet)	1. PD 2. HD: in-centre 3. CCM	Yes	No	No
Transplantation, dialysis or CCM?						
No. 14: Patient-centred kidney transition care	MI	1. Electronic health information tools (disease registry, care navigation and tracking tool, treatment preferences broadcast) 2. Multiple outpatient consultations with kidney transitions specialist (n.a.) 3. PREPARED PIDA 4. Eight-variable KFRE	1. PD 2. HD: in-centre 3. HD: home 4. DDKT 5. LDKT 6. CCM	Yes	Yes	No
What type of transplantation?						

Continued



Table 10 Continued

Intervention	Type of intervention	Format	Treatment options*	Values-clarification/preference elicitation exercise(s)	Coaching	Promotes treatment modality
No. 15: Enhance Access to Kidney Transplantation and Living Kidney Donation	MI	<ol style="list-style-type: none"> <li>1. Data collection and reports</li> <li>2. Education toolkits for CKD programme staff, patients and families</li> <li>3. Transplant ambassadors (n.a.)</li> <li>4. Provincial administrative support and resources</li> </ol>	Kidney transplantation	No	No	Kidney transplantation
No. 16: Explore transplant at home	EP	<ol style="list-style-type: none"> <li>1. Printed materials (fact sheets, brochures, postcards)</li> <li>2. Four videos (20 min total)</li> <li>3. Optional educational text messages</li> </ol>	<ol style="list-style-type: none"> <li>1. DDKT</li> <li>2. LDKT</li> </ol>	Yes	No	No

\*Treatment options formulated as reported in the identified records: CKD, Conservative Care Management; DDKT, Decided Donor Kidney Transplantation; EP, Educational Programme; ESRD, End-Stage Renal Disease; HD, haemodialysis; WFE, Kidney Failure Risk Equation; LDKT, Living Donor Kidney Transplantation; MI, Multicomponent Initiative; PD, Peritoneal Dialysis; PtDA, Patient Decision Aid.

the IPDAS criteria were developed to standardise and improve their contents, development, implementation and evaluation.<sup>174</sup> These criteria are widely accepted, and researchers and developers use them to develop and score their PtDAs.<sup>121 126 131</sup> We also scored the PtDAs we identified with these criteria and found that just about half officially qualified as PtDAs. There is a need for a similar set of criteria that can be used for the development, implementation and evaluation of EPs. The variation in the literature makes it difficult to understand causal relationships between the interventions and the reported outcomes. It also hampers the development of new and effective interventions because it limits the possibility of synthesising evidence and replicating effective interventions.<sup>20</sup>

About one-third of the interventions we identified were reported to have been implemented in clinical practice. We found that PTs were the interventions with the least information on implementation status, followed by PtDAs, EPs and MIs. Most of the PTs could not be used by both patients and clinicians because their developers only presented them as formulas. This has been noted before and limits their usability in clinical practice.<sup>21</sup> In fact, the only PT that was reported to have been implemented was designed as a PtDA that can be used by both patients and clinicians. On the contrary, PtDAs are almost always either printed materials or interactive websites that patients can use at the convenience of their own time. This enhances their usability and makes them an important supplemental resource for patients to learn about their treatment options.<sup>175</sup> EPs tend to vary in their components,<sup>20</sup> but generally consist of multiple outpatient consultations or educational sessions that are supplemented with printed and/or audio-visual materials, websites and coaches that guide patients through the programme. Hospitals often develop their own proprietary EPs, which may explain why more than half of the EPs we identified were reported to have been implemented in clinical practice. Most of the MIs we identified were also reported to have been implemented in clinical practice, presumably because they were often part of quality improvement initiatives that used multifaceted implementation strategies to support the implementation process. Implementation is important because only this ultimately leads to patients actually using these interventions. It can also provide real-world evidence on their effects and on the effectiveness of different implementation strategies. The implementation of future interventions should be facilitated by developing them with usability in mind, and by offering them through implementation strategies that combine different approaches.<sup>176</sup> In addition, involving stakeholders and end-users (eg, patients and clinicians) will also facilitate the implementation process.<sup>177</sup> Overall, end-user participation was low in the development of the interventions we identified. It seems plausible that this might have affected their implementation rates, but we cannot support this with the available data.



**Table 11** Overview of current studies evaluating the novel interventions

Intervention	Source	Population*	Study arms	Primary outcome(s)**	Secondary outcome(s)**	Recruitment status	Date of completion
What type of dialysis modality?							
No. 1	Multicentre RCT <sup>70</sup>	Patients with an eGFR <20 mL/min/1.73 m <sup>2</sup>	Intervention: 1. WISHED Control: 1. Standard care	Within 3 months of dialysis initiation: the proportion of patients who receive any home-based dialysis modality	Pre-intervention, 6 and 12 months post-intervention/control: patient characteristics, the proportion of patients intending to perform home-based dialysis, dialysis knowledge, decisional conflict, level of social support	Not reported	Estimated study completion date: June 2017
No. 2	RCT <sup>68</sup>	Patients >75 years of age with an eGFR <25 mL/min/1.73 m <sup>2</sup>	Intervention: 1. CKD-EDU Control: 1. Standard care	Up to 24 months post-intervention/control: feasibility of the intervention, acceptability of the intervention	n.a.	Recruiting	Estimated completion date: May 2021
No. 3	RCT <sup>69</sup>	Patients with CKD stage 5	Intervention: 1. Decision support intervention Control: 1. Standard care	Post-intervention/control: control preference, knowledge, decisional self-efficacy, decisional conflict	Post-intervention/control: satisfaction with the decision, decisional regret	Completed	Actual study completion date: December 2019
No. 4	RCT <sup>60</sup>	Veterans with CKD stage 4–5	Intervention: 1. Comprehensive pre-ESRD patient education Control: 1. Standard care	Pre-intervention and 48 months post-intervention/control: home dialysis use	1. Pre-intervention and 4 weeks post-intervention/control: home dialysis selection, kidney disease knowledge, confidence in dialysis decision-making 2. 3 and 48 months post-intervention/control: kidney disease quality of life, satisfaction on dialysis	Recruiting	Estimated completion date: September 2023
Pursue LDKT or not?							
No. 5	RCT <sup>71</sup>	Black kidney transplant candidates	Intervention: 1. House calls educational intervention (with home visits option) 2. House calls educational intervention (with group education option) Control: 1. House calls educational intervention (with individual outpatient education option)	Up to 2 years post-intervention/control: the occurrence of LDKT	1. Up to 2 years post-intervention/control: living donor inquiries, living donor evaluations, absolute number of living donor evaluations 2. Pre-intervention, 1 and 6 weeks post-intervention/control: LDKT readiness, LDKT willingness, living donation knowledge, concerns about LDKT	Completed	Actual completion date: June 2020
No. 6	RCT <sup>61</sup>	Non-white race, Hispanic ethnicity or low-income kidney transplant candidates	Intervention: 1. House calls+web-based decision support 2. House calls educational intervention (no web-based decision support) Control: 1. Standard care	Up to 2 years post-intervention/control: the occurrence of LDKT	1. Up to 2 years post-intervention/control: living donor inquiries, living donor evaluations, absolute number of living donor evaluations 2. 12 weeks post-intervention/control: LDKT knowledge, LDKT readiness, LDKT concerns, healthcare mistrust, self-efficacy in discussing LDKT, amount of time spent discussing LDKT	Completed	Actual completion date: May 2020
No. 7	Multicentre RCT <sup>62</sup>	Black kidney transplant candidates	Intervention: 1. House calls+peer mentorship 2. House calls educational intervention (no peer mentorship) Control: 1. Standard care	1 year post-intervention/control: the occurrence of LDKT	1. 1 year post-intervention/control: living donor inquiries, living donor evaluations, absolute number of living donor evaluations 2. Pre-intervention, 1, 6 and 12 weeks post-intervention/control: LDKT knowledge, LDKT readiness, healthcare mistrust, LDKT concerns, self-efficacy in discussing LDKT, amount of time spent discussing LDKT, self-efficacy in discussing LDKT	Recruiting	Estimated completion date: January 2021
No. 8	RCT <sup>63</sup>	Black kidney transplant candidates	Intervention: 1. Destination transplant Control: 1. Standard care	Pre-intervention, 1 week and 9 months post-intervention/control: readiness to pursue LDKT	1. Pre-intervention/control: patient and clinical characteristics, transplant barriers, previous transplant education, health literacy, family and social support, availability of potential living donors 2. Pre-intervention, 1 week and 9 months post-intervention/control: knowledge of LDKT steps taken to pursue LDKT, readiness for LDKT, decisional balance regarding LDKT, self-efficacy regarding LDKT 3. Pre-intervention and 9 months post-intervention/control: health-related quality of life, medical mistrust 4. 1 week and 9 months post-intervention/control: cultural competence on the project staff, decisional conflict 5. 18 months post-intervention/control: receipt of LDKT, number of donor volunteers recruited and evaluated, status on DDKT waiting list	Completed	Actual completion date: August 2018

Continued

Table 11 Continued

Intervention	Source	Population*	Study arms	Primary outcome(s)**	Secondary outcome(s)**	Recruitment status	Date of completion
No. 9	RCT <sup>64</sup>	Patients with ESKD	Intervention: 1. TALK Control: 1. Standard care	Up to 43.6 months post-intervention/control: receipt of kidney transplant	1. Pre-intervention and 1 year post-intervention/control: kidney transplant decision making 2. 1 year post-intervention/control: time to complete transplant evaluation, booklet and video helpfulness, kidney disease quality of life 3. Up to 43.6 months post-intervention/control: type of transplant	Completed	Actual completion date: August 2020
No. 10	Non-randomised controlled study <sup>65</sup>	Patients on HD	Intervention: 1. COACH Control: 1. Standard care	Pre-intervention, 3 months and 1 year post-intervention/control: transplant knowledge, the number of transplant steps completed	3 months and 1 year post-implementation/control: completion of transplant work-up, self-reported requests for living donation	Recruiting	Estimated completion date: July 2022
No. 11	Multicentre RCT <sup>72</sup>	African-American kidney transplant candidates	Intervention: 1. Living ACTS Control: 1. Standard care	12 months post-intervention/control: the proportion of patients with at least one living donor inquiry	1. Pre-intervention/control: patient and clinical characteristics, self-rated health 2. control: knowledge and understanding of LDKT motivation to ask a family member to be a living donor, confidence in initiating a conversation about LDKT, intention to discuss LDKT with family members and comfort in initiating conversations about LDKT	Recruiting	Estimated completion date: May 2022
Dialysis or CCM?							
No. 12	Multicentre RCT <sup>66</sup>	1. Patients >70 years of age with CKD stage 4–5 2. Care-partners	Intervention: 1. DART Control: 1. Standard care	Pre-intervention, 3, 6 and 18 months post-intervention/control: decisional conflict	Pre-intervention, 3, 6 and 18 months post-intervention/control: advance directives completion, healthcare evaluation, instability of patients' preferences; patient/care-giver concordance on the goals of care	Active (not recruiting)	Estimated completion date: March 2022
No. 13	Mixed-methods study <sup>67</sup>	Elderly patients with ESKD	Intervention: 1. Patient decision aid for elderly patients with kidney failure Control: 1. Standard care	Pre-intervention and post-intervention/control: treatment choice	n.a.	Not reported	Not reported
Transplantation, dialysis or CCM?							
No. 14	Multicentre RCT <sup>73</sup>	Patients with AKD	Intervention: 1. Patient-centred kidney transition care Control: 1. Standard care	Pre-intervention, 12, 24 and 36 months post-intervention/control: patient empowerment, confidence with self-care, proportion of patients deciding to initiate self-care treatment, hospitalisations, proportion of patients with advance care plans for kidney failure treatment preferences broadcast in electronic health record	Pre-intervention, 12, 24 and 36 months post-intervention/control: proportion of patients with self-care biomedical care plans; proportion of patients achieving values aligned care within 6 months of kidney failure treatment initiation; values and preferences documented in electronic health record; emergency dialysis initiation; time to kidney failure; vascular access at HD initiation; patient characteristics; financial distress/being, kidney function, presence and control of kidney disease progression risk factors; comorbid health conditions, depression, anxiety, need for mental health support, quality of life, self-management, diet, exercise, medication adherence, duration and frequency of care, patient centredness of care, health literacy, control preference, decisional conflict, decisional self-efficacy, patient activation, barriers to complex treatment plans, kidney transitions specialist adherence to protocol, sustainability of the intervention	Completed	Actual completion date: October 2020
What type of transplantation?							
No. 15	Multicentre RCT <sup>68</sup>	Dialysis facilities	Intervention: 1. EtAKT LDK Control: 1. Standard care	Up to 2 years post-intervention/control: composite outcome of living kidney donor candidate referral and transplant recipient referral rate	Up to 2 years post-intervention/control: kidney transplantation rate, rate of pre-emptive kidney transplantation, rate of kidney transplant wait listing, average healthcare costs	Active (not recruiting)	Estimated completion date: March 2021
No. 16	Multicentre RCT <sup>69</sup>	Patients with CKD stage 3–5	Intervention: 1. ET at home Control: 1. Standard care	Pre-intervention and 6 months post-intervention/control: DDKT and LDKT knowledge	1. Pre-intervention/control: patient and clinical characteristic, socioeconomic barriers to pursuit of transplant, medical mistrust, health-related quality of life, health-literacy and the amount of previous transplant education received 2. Pre-intervention and 6 months post-intervention/control: ability to make an informed decision about transplant, self-efficacy to pursue DDKT and LDKT, steps taken towards transplant 3. 6 months post-intervention/control: patients' experiences with the educational materials	Active (not recruiting)	Estimated completion date: August 2020

\*Study population (provided as reported in the identified records).  
†Outcomes (summarised as reported in the identified records).  
‡AND, advanced kidney disease; CKD, chronic kidney disease; CKD-EU, chronic kidney disease enhanced dialysis education; COACH, communicating about choices in transplantation; DDKT, deceased donor kidney transplantation; eFR, estimated glomerular filtration rate; ESKD, end stage kidney disease; ET, explore transplant; HD, haemodialysis; KRT, kidney replacement therapy; LDKT, living donor kidney transplantation; n.a., not applicable; PJ, peer-review dialysis; RCT, randomised controlled trial; SDM, shared decision-making; WISHEB, web-based interactive health communication application for successful living donation.



There are significant knowledge gaps when it comes to the effects these interventions have on patients, on the decision-making process, on SDM, and on the effects that SDM has on both patients and the decision-making process. First of all, only about half of the interventions were evaluated for their effects. The majority of these interventions were MIs, EPs and PtDAs. The only PT that was evaluated was the PT that was designed as a PtDA.<sup>57 70</sup> This PT was also evaluated as part of an MI, but its use was not mandatory so its contribution to the reported effects remains undetermined.<sup>147</sup> More evidence is needed on how PTs can be used to support patients and clinicians in the decision-making process, and there are multiple validated PTs that can be used in future research projects.

Patients who were exposed to EPs, PtDAs and MIs generally had better outcomes than patients that were not exposed to these interventions. It is difficult to say which intervention was the most effective because the majority were evaluated in observational studies and the exact 'ingredients' that elicit the reported outcomes are often unknown.<sup>20</sup> Moreover, there was considerable variation in the selection of outcomes used to evaluate these interventions. Also, none of the interventions that were evaluated in studies published after the standardised outcome sets for CKD, dialysis and transplantation from ICHOM and SONG were published were evaluated with these outcomes. This highlights a need for: (1) more experimental research and (2) a standardisation in the selection of outcome measures for health-related outcomes (eg, the ICHOM or SONG standard sets), as well as for knowledge, decisional quality and SDM.

Finally, there is a clear lack of evidence when it comes to the effects that these interventions have on SDM. Notably, none of the MIs that were explicitly developed to enhance SDM in clinical practice were evaluated for their effects on SDM.<sup>148 150 153</sup> Only a minority of PtDAs were evaluated for their effects on SDM, and SDM outcomes were generally better in patients that used them.<sup>122 135 143</sup> Interventions should be evaluated on outcomes of SDM, especially if the intention is to support and implement SDM through these interventions. It is unfortunate that none of the researchers and developers of the interventions currently under evaluation report evaluating these interventions for their effects on SDM.

This scoping review is unique in the fact that we did not limit ourselves to a certain type of intervention, or to interventions that were developed to support or promote a particular treatment modality decision. We also did not identify reviews that categorised interventions based on the treatment modality decision(s) they support like we did. Even though we limited our search query to records published in English, the proportion of excluded records published in another language was small. We did exclude a larger number of records due to the fact that they were not available to us, either because of: (1) subscription limitations, (2) internet protocol address geo-blocking or (3) stakeholders that did not reply to our emails requesting access to their contents. Nevertheless,

we feel that the selection of interventions presented in this review is a realistic reflection of the current state of developments in this field. We hope it stimulates clinicians to use these interventions in clinical practice, and that it incentivises researchers and developers to address the knowledge gaps we identified.

## CONCLUSIONS

This scoping review provides clinicians, researchers and other stakeholders with one comprehensive, but digestible source of information on interventions that can be used to support SDM for treatment modality decisions in AKD. The usability of these interventions for SDM largely depends on whether patients can use them to compare all their treatment options, and whether they contain questions or exercises that help patients make decisions based on their values and preferences. It also depends on whether patients can access them at the convenience of their own time, and on how easily they can be used during healthcare encounters. Clinicians interested in SDM can select interventions from this review based on these properties, and ideally combine interventions that complement each other.

The implementation of the identified interventions in clinical practice was moderate and most likely depended on usability and the presence or absence of an implementation strategy.

No conclusive advice can be given on which intervention is the most efficacious in supporting SDM for treatment modality decisions in AKD. Outcomes seem to be better in patients exposed to these interventions, but this is largely based on observational research. In addition, the effects of these interventions on SDM are under-reported. There is a definite need for more experimental research and a standardisation in the development, implementation and evaluation of these interventions.

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