



# Communicating health risk in chronic kidney disease: a scoping review

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## Abstract

**Background** Communicating risk is a key component of shared decision-making and is vital for the management of advanced chronic kidney disease (CKD). Despite this, there is little evidence to suggest how best to communicate health risk information to people living with CKD. The aim of this review was to identify and understand the nature of evidence-based risk communication strategies for people living with CKD.

**Methods** We searched MEDLINE, CINAHL and Scopus databases for articles which described or evaluated the use of risk communication strategies within the renal population. Similar risk communication strategies were collated and summarised narratively.

**Results** A total of 3700 sources were retrieved from the search, of which 19 were included in the review. Eleven studies reported primary research, and eight reported either narrative or systematic reviews. Seven main risk communication strategies were identified: framing, absolute versus relative risk, natural frequencies versus percentages, personalised risk estimates, qualitative risk communication, best-case/worst-case framework and use of graphs and graphics. There was a paucity of risk communication strategies specific to the CKD population.

**Conclusion** Evidence-based strategies to improve health risk communication for patients living with CKD are lacking. There is a need to establish the informational and communication preferences for patients living with CKD to better understand how to best communicate health risk information to individuals in this population.

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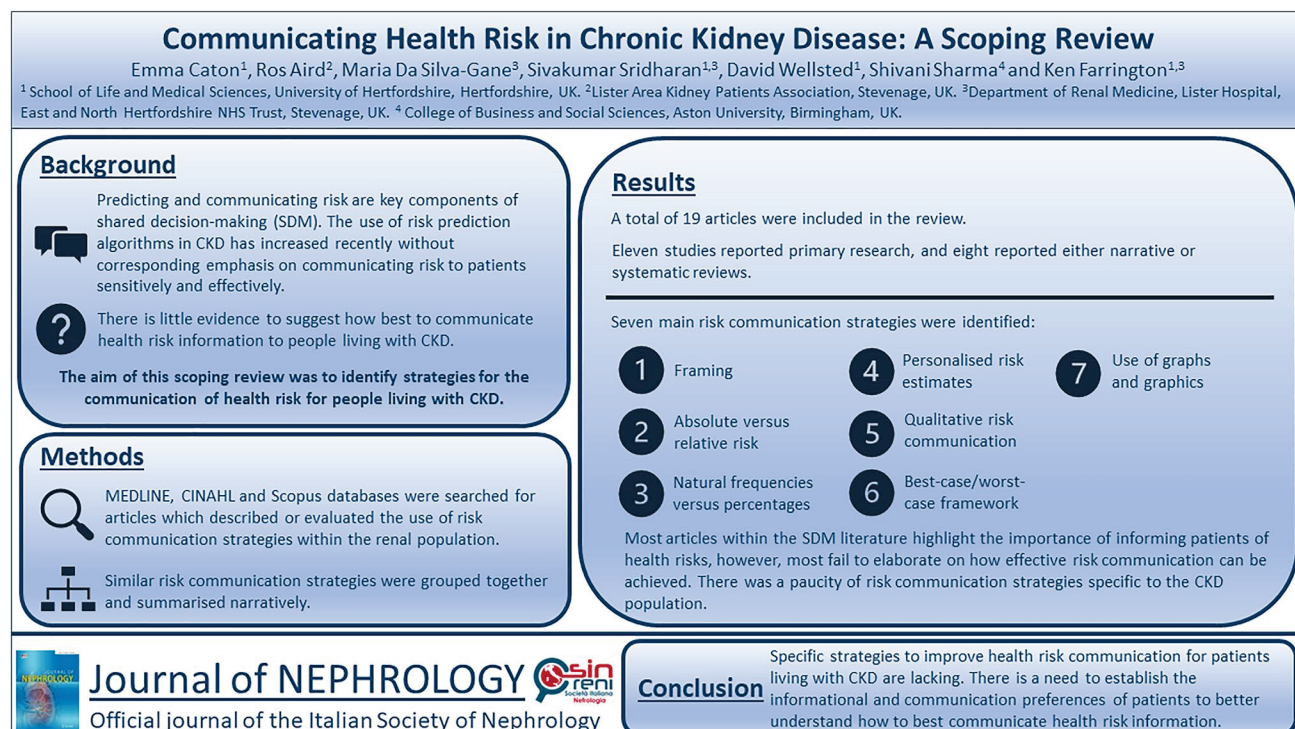
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## Graphical abstract



**Keywords** Risk communication · Chronic kidney disease · Shared decision-making · Prognosis

## Introduction

Shared decision-making describes a process in which patients work together with healthcare professionals to make decisions about their care. In shared decision-making, treatment options are chosen based on a combination of scientific evidence and the patient's individual preferences, goals and values [1]. Shared decision-making is a core principle of medical practice and has been associated with positive outcomes such as greater patient satisfaction, increased motivation to adherence to treatment, improved quality of life, and reduced decisional conflict [2, 3].

A key component of shared decision-making is the communication of risk. Communicating risk to patients with life-limiting long-term conditions is a major issue. There have been significant advances in predicting risk in patients with long-term conditions, and there are increasing numbers of risk-predicting algorithms. Despite this, there is little research on how to apply these tools in clinical practice. For example, European Best Practice Guidelines for management of advanced chronic kidney disease (CKD) in older adults [4] recommends using three different risk prediction models together to help healthcare professionals and people living with CKD to estimate the risk of disease progression,

of dying before end-stage kidney disease and the need for dialysis, and their likely prognosis should they start dialysis. This information is vital for making the appropriate decisions about clinical management in terms of planning for renal replacement therapy, conservative management, or end-of-life planning. However, there is little work guiding the use of such tools which relate to highly sensitive issues affecting very vulnerable patients and their carers.

Many patients would like to receive information about their prognosis, however healthcare professionals are often reluctant to disclose this information [5, 6]. Some healthcare professionals have expressed concerns about diminishing hope, providing uncertain information or lacking the skills necessary for prognosis communication [5, 7]. Potential harms of not disclosing risk information include the establishment of unrealistic expectations in the minds of patients and their families and carers. In a study conducted by Ghanem et al., 77% of patients were found to be in prognostic discordance with their nephrologist, suggesting that most patients overestimate their chance of survival [8]. This highlights the importance of shared decision-making and effective risk communication in renal care, as patients who overestimate their prognosis may opt for more intensive or invasive treatment options perhaps with little prospect

of benefit [8]. Despite this, evidence suggests that shared decision-making is not routinely adopted in renal care. For example, in a study conducted by Frazier et al., less than half of older adults with advanced CKD agreed that their decision about treatment was made in collaboration with their doctor [9].

The aim of this scoping review was to identify and understand the nature of evidence-based risk communication strategies for people living with CKD. A scoping review methodology was considered suitable to understand how risk communication has been conceptualised and implemented within renal decision-making, and identify the breadth of the literature.

## Methods

A study protocol was established to help guide the review process. This review was not pre-registered with PROSPERO as scoping reviews are ineligible for registration on this database.

### Search strategy

A literature search was conducted on 28th March, 2023. Studies were identified using MEDLINE, CINAHL and Scopus databases. Additional sources were identified from the secondary research articles included in the review (e.g. where a specific risk communication strategy had been referenced, the original source was obtained). Search terms were generated around concepts related to kidney disease (e.g. “kidney disease”, “dialysis”, “conservative management”) and risk communication (e.g. “risk communication”, “prognosis communication”, “shared decision making”). No date limit was applied to the search. The full search strategy can be found in Table S1 (See Supplementary information).

### Study selection and data extraction

To be eligible for inclusion, studies needed to describe or evaluate the use of health risk communication strategies within the renal population. With the exception of case studies, case series, and case reports, all study designs were eligible for inclusion in the review. Due to the limited language resources available to the research team, studies were only included in the review if they had been published in the English language. Where the full-text version of a manuscript could not be obtained, the article was excluded from the review. Articles were also excluded if they exclusively described risk communication strategies aimed at caregivers, surrogate decision-makers or paediatric patients, or if they addressed the risks associated with COVID-19.

Search results were extracted into the reference management tool Rayyan [10]. Duplicate articles were identified by the tool and then manually removed by the researcher. Articles were initially screened via their title and abstract, with ineligible articles being excluded from the review. The remaining articles underwent screening via their full text. A subsection of full-text articles (18%) were independently assessed by two authors (RA and MDSG) and any conflicts were discussed and resolved within the research team.

Key data were extracted from each source. The data extracted included study characteristics (e.g. study title, study authors, year of publication, study design, study population), a description of the risk communication strategies, and key findings such as the impact of these strategies on patient’s knowledge, perception of risk and/or treatment decisions.

### Synthesis of results

Similar risk communication strategies were grouped together and summarised narratively. Both primary and secondary research studies have been included. Due to the heterogeneity of study methods, a risk of bias (quality) assessment was not performed.

## Results

### Study selection

A total of 3700 sources were identified. A PRISMA flow diagram outlining the full study selection process can be found in Fig. 1. Full-text screening was performed on 645 articles. Overall, a total of 19 studies were identified for inclusion in the review.

### Study characteristics

Eleven studies reported primary research (see Table 1). This included three qualitative studies [11–13], three mixed method studies [14–16], two intervention studies [17, 18], one survey study [19], one validation study [20] and one discrete choice experiment [21]. The intervention studies evaluated the use of the iChoose Kidney patient decision aid [17] and the best-case/worst-case communication tool [18]. Overall, six studies described the development, evaluation or use of patient decision aids, risk prediction models or other tools to support the shared decision-making process [13, 15–18, 20]. Six studies included patients [14, 16, 17, 19–21], four included patients and healthcare professionals [12, 13, 15, 18] and one study included only healthcare professionals [11].

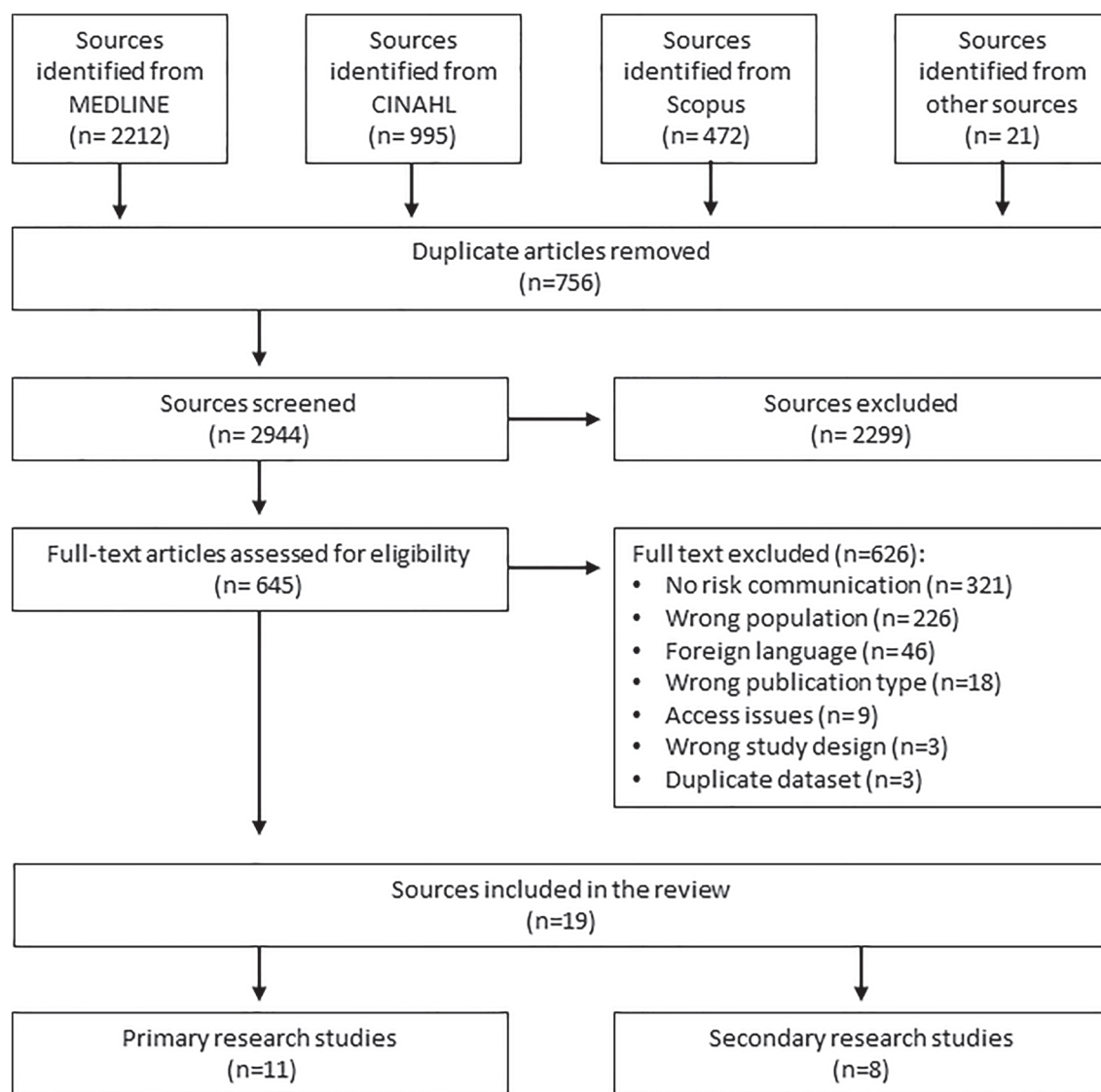


Fig. 1 Study selection PRISMA flow diagram

Eight studies were secondary research studies, including seven narrative reviews and opinion pieces [22–28] and one systematic review [29]. The systematic review aimed to evaluate patient decision aids for people with advanced kidney disease. Seventeen patient decision aids were identified in the review. None of the decision aids were eligible for inclusion in the current review due to the lack of published data or insufficient reporting of risk communication strategies.

### Risk communication strategies

Seven main risk communication strategies were identified from the literature and have been summarised in Table 2.

### Evaluation of risk communication strategies

#### Framing

Two studies described framing as a useful strategy to communicate health risk [25, 29]. Scherer et al. [25] recommend that risk information be presented in a way that is balanced (i.e. focussing on both the positive and negative outcomes). Winterbottom et al. [29] identified two patient decision aids which used positive and negative frames to communicate health risk information, although the impact of this technique on patient outcomes was not reported.

**Table 1** Characteristics of primary research studies

Study ID	Year of publication	Country	Study design	Type/number of participants	Risk communication strategies/components	Evaluated the impact of risk communication strategies?
Cardinal et al. [11]	2020	Canada	Qualitative interview study	HCPs ( $n = 15$ )	Personalised risk estimates Use of graphs and graphics Interpersonal communication skills Managing uncertainty Shared decision-making tools and patient education	No
Damron et al. [19]	2022	USA	Survey study	Patients ( $n = 1029$ )	Natural frequencies versus percentages	No
Downen et al. [14]	2017	New Zealand	Mixed methods survey study	Patients ( $n = 177$ )	Use of graphs and graphics	Yes
Engels et al. [15]	2022	Netherlands	Mixed methods study (Focus groups and survey)	Patients ( $n = 133$ ) and HCPs ( $n = 51$ )	Use of graphs and graphics Shared decision-making tools and patient education	No
Finlay et al. [12]	2020	Canada	Qualitative interview study	Patients ( $n = 20$ ) and HCPs ( $n = 10$ )	Personalised risk estimates Qualitative risk communication Shared decision-making tools and patient education	No
Ozdemir et al. [16]	2021	Singapore	Mixed methods study (Interviews and survey)	Patients ( $n = 20$ ) and caregivers ( $n = 12$ )	Use of graphs and graphics Shared decision-making tools and patient education	No
Patzer et al. [17]	2018	USA	Intervention study (Randomised controlled trial)	Patients ( $n = 470$ )	Absolute versus relative risk Use of graphs and graphics Shared decision-making tools and patient education	Yes
Peeters et al. [20]	2016	Belgium	Validation study	Patients ( $n = 3472$ ; registry data)	Use of graphs and graphics Shared decision-making tools and patient education	No
Tuot et al. [13]	2022	USA	Qualitative think-aloud study	Patients ( $n = 18$ ) and HCPs ( $n = 19$ )	Interpersonal communication skills Shared decision-making tools and patient education	No
Wilson et al. [21]	2023	Canada	Discrete Choice Experiment	Patients ( $n = 140$ )	Use of graphs and graphics	No
Zimmermann et al. [18]	2020	USA	(Pre/post-) Intervention study	Patients ( $n = 30$ ) and HCPs ( $n = 16$ )	Best-case/worst-case framework Shared decision-making tools and patient education	Yes

HCPs = Health care professionals



**Table 2** Risk communication strategies

Risk communication strategy	Description of risk communication strategy	Articles including the risk communication strategy
Framing	Presenting information using either positive or negative terms (i.e. chance of survival versus chance of death)	[25, 29]
Absolute versus relative risk	Presenting the actual likelihood of an event occurring (absolute risk) versus the likelihood of an event occurring in one group compared to another group (relative risk)	[17, 24, 27]
Natural frequencies versus percentages	Presenting information using natural frequencies (e.g. 1 in 5) versus percentages (e.g. 10%)	[19, 29]
Personalised risk estimates	Calculating a person's individual risk using multiple predictors specific to the individual	[11, 12]
Qualitative risk communication	Presenting information using words (e.g. high risk, low risk) rather than numbers	[12, 26]
Best-case/worst-case framework	A visual aid which depicts two treatment options. Clinicians use narrative storytelling to describe the "best", "worst" and "most likely" scenarios for each option	[18, 23]
Use of graphs and graphics	Presenting information using graphs or pictures	[11, 14–17, 20, 21, 28, 29]

### Absolute versus relative risk

Absolute and relative risk estimates were mentioned in three studies [17, 24, 27]. Cassidy et al. [27] suggested that relative risk estimates may be easier to understand than absolute risk, although limited empirical evidence was presented. Patzer et al., [17] described the use of absolute and relative risk estimates to present health risk information within the iChoose Kidney decision aid. Findings suggest that the change in patients' knowledge of absolute and relative mortality risks pre- to post- intervention was significantly higher among patients receiving the iChoose Kidney intervention compared to those receiving standard education (control). There was no significant difference between the intervention and control group in relation to decisional conflict or treatment preference.

### Natural frequencies versus percentages

Damron et al. [19] speculated that patients may interpret risk information differently depending on whether risk is presented as percentages or natural frequencies. Winterbottom et al. [29] identified three patient decision aids which presented risk information in the form of percentages, and five which reported natural frequencies with either the same ( $n=4$ ) or different denominators ( $n=1$ ). The impact of these techniques on patient knowledge, risk perception or treatment decisions was not evaluated.

### Personalised risk estimates

Two studies mentioned personalised risk estimates [11, 12]. In both studies, healthcare professionals reported that being able to personalise risk scores using key patient

characteristics would help to support the shared decision-making process by making information more relevant to patients. None of the studies evaluated patient preference for how personalised risk data should be presented, nor did the studies examine the impact of this technique on patient knowledge, understanding, or treatment decision-making.

### Qualitative risk communication

Two studies reported the use of qualitative methods to convey risk [12, 26]. For example, a review of patient information leaflets for living donor kidney transplantation found that 35% of leaflets presented risk qualitatively [26]. Similarly, in a study conducted by Finlay et al. [12], clinicians presented the risk of needing dialysis following a coronary procedure as "high, medium or low risk." The use of qualitative methods was perceived by clinicians as useful in reducing the density of information presented to patients, although patient preference for this technique was not evaluated.

### Best-case/worst-case framework

Two articles highlighted the "Best-case/Worst-case" framework as a useful method for discussing risk and promoting shared decision-making [18, 23]. The "Best-case/Worst-case" tool is primarily a visual aid depicting two treatment options. Clinicians use narrative storytelling to describe the "best", "worst" and "most likely" scenarios for each option. This allows clinicians to incorporate their knowledge of the risk and benefits of each treatment option whilst also prioritising the concerns and values of the patient. In a pilot study conducted by Zimmermann et al., [18] the "Best-case/Worst-case" tool was used to improve shared-decision making about dialysis initiation in older adults with life-limiting

kidney disease. The study found that use of the “Best-case-Worst-case” tool can positively influence treatment decisions, with patients of nephrologists who used the tool being less likely to initiate dialysis and more likely to be referred to palliative care. As well as being used for decisions about dialysis initiation, Highet et al. [23] recommend that the “Best-case-Worst-case” tool also be used by transplant providers to aid decisions surrounding transplantation and high-risk donor organs.

### Use of graphs and graphics

The use of visual aids, such as illustrations or graphs, was mentioned in nine studies [11, 14–17, 20, 21, 28, 29]. Pictographs were frequently used in patient decision aids to communicate health risk [15–17, 20], as well as being incorporated within research materials such as discrete choice surveys [21, 28]. The use of pictographs as a risk communication strategy was not evaluated in these studies. Nevertheless, in a study conducted by Cardinal et al. [11], nephrologists acknowledged that the use of pictures could help transplant candidates to better understand statistical information related to graft- and patient- survival.

Graphs can often convey more information to patients compared to statistical data alone. One study investigated comprehension and patient preference for different graphs in people with chronic kidney disease [14]. Most participants were able to correctly interpret Kaplan Meier curves, pie charts, histograms and pictograms, and 87% of participants found graphs useful in aiding their understanding. Participants mentioned that clear, simple visual aids were particularly useful for CKD risk communication, as their interpretation of complex information may be affected by their condition (“when you have kidney failure the brain is slower”).

### Important components of health risk communication

#### Interpersonal communication skills

The practical components of risk communication were mentioned in several studies. These mostly focused on the interpersonal skills required by healthcare professionals when disclosing prognosis information to patients with CKD.

Prior to any discussion with patients about prognosis information, clinicians should establish how much the patient already knows about their condition and/or treatment options, and how much information they would like to receive [22]. Clinicians should recognise the emotional impact that prognosis discussions can have on the patient, acknowledge their emotions, and respond with empathy [22, 25].

Where possible, the use of ambiguous language and clinical/statistical jargon should be avoided [13, 22]. In a study conducted by Tout et al. [13], clinicians identified potential tension between lay and medical terminology for CKD. Clinicians expressed concerns that in some cases, patients may not recognise the term “Chronic Kidney Disease” because clinicians are more likely to use descriptive terms such as “your kidneys are not functioning properly” rather than naming the condition directly. The use of consistent terminology and risk communication strategies between clinicians is also important in improving patients’ understanding of risk. In a study conducted by Cardinal et al., [11], transplant nurses reported that the type of information provided to transplant candidates often varied between transplant nurses.

### Managing uncertainty

Three studies mentioned that clinicians should discuss the uncertainty and reliability of risk estimates with their patients [11, 22, 25]. It is important to acknowledge that outcomes such as survival and disease progression can be hard to predict, and that estimates derived from large populations can make it difficult to provide a precise estimate for individual patients [11]. Some articles recommend managing uncertainty by avoiding exact time frames, for example, by using ranges (e.g. “hours to days”, “days to weeks”, “weeks to months”) instead of specific dates or percentages [22].

### Shared decision-making tools and patient education

The use of decision aids and patient education programmes were identified by clinicians as key facilitators of shared decision-making [11, 12]. In Cardinal et al. [11], nephrologists reported that it was easier to present transplant candidates with information about deceased donor organs when candidates had previously received education about the different types of deceased donors. Whilst clinicians may deem educational opportunities as beneficial to the shared decision-making process, patients noted that CKD education could be improved by including concrete actionable recommendations to reduce the risk of disease progression [13].

In this review, six studies reported the development, evaluation or use of shared decision-making tools such as patient decision aids or risk prediction models [13, 15–18, 20]. A further 17 patient decision aids for CKD have been identified in the systematic review conducted by Winterbottom et al. [29]. Findings from these studies suggest that shared decision-making tools can improve patient knowledge and understanding of kidney disease and its treatments, influence treatment decisions, and reduce decisional conflict.

## Discussion

The aim of this scoping review was to identify strategies for the communication of health risk for people living with CKD. The majority of articles within the shared decision-making literature highlight the importance of informing patients of the risk and benefits of each treatment option, however, most fail to elaborate on how effective risk communication can be achieved.

Findings from this review suggest that there are very few evidence-based risk communication strategies specific to the CKD population. Less than 30% of the primary research articles identified in this review evaluated the impact of risk communication strategies on patient outcomes. Indeed, this creates challenges in assessing the acceptability and effectiveness of risk communication strategies within the CKD population. In the primary research articles that did evaluate the impact of risk communication strategies, the main outcomes which were assessed were patient knowledge, information preferences, decisional conflict, and treatment decisions. Improvement in outcomes such as patient knowledge, decisional conflict and decision regret would demonstrate the effectiveness of risk communication strategies. The use of patient reported outcome measures can be useful tools for evaluating the impact of risk communication strategies and should be utilised more frequently within shared decision-making research.

One potentially useful risk communication strategy identified in this review is the use of personalised risk estimates. In renal medicine, several risk prediction models have been developed to obtain personalised risk estimates relating to disease progression and mortality [30]. Whilst these estimates are important for determining the clinical management of a patient, it is also important to consider other prognostic factors which may be of value to patients. For example, in a meta-synthesis of qualitative studies, patients stated that they based their treatment decisions on which modality would be least intrusive in their lives [31]. This suggests that effective risk communication may involve more than merely presenting the risk of clinical outcomes. In addition, data relating to the use of such prognostic tools in individual consultations with patients is sparse.

Several studies noted that patient preferences for risk information should be considered throughout the shared decision-making process, especially when determining the amount and type of information a patient would like to receive. Clinicians may require additional time to build a rapport with their patients and understand their informational preferences before disclosing prognostic information. This is particularly pertinent in contexts where

factors such as language and/or literacy may complicate communication further. Future research involving people with CKD is needed to identify the factors important to patients during discussions about risk, to understand patient preferences regarding the type of information they would like to receive, and to explore effective strategies for risk communication, acknowledging that patients may have unique needs depending on life and social factors.

There are several limitations of this review. First is the strict focus on communication strategies for disclosing risk information, which may have resulted in articles which describe more general communication strategies for kidney-related shared decision-making to be excluded from the review. Similarly, this criterion may have resulted in the exclusion of several CKD-specific decision aids or risk algorithms which did not explicitly describe how risk information was presented. Nevertheless, it is important to differentiate patient decision aids and risk prediction models as tools to support the communication of health risk, rather than being risk communication strategies in and of themselves. Second, this review did not include foreign language articles or unpublished (grey) literature due to limited time and practical resources. There are also limitations which are more broadly associated with scoping review methodology. For example, scoping reviews aim to provide an overview of existing literature in order to identify potential areas for future research [32]. As a result, scoping reviews do not assess the quality of included studies nor do they make judgements as to the 'weight' of evidence associated with particular interventions [33]. In spite of this, a scoping review methodology was deemed appropriate to meet the aims of this review, especially given the lack of current knowledge of risk communication strategies within the CKD population.

Overall, findings from this review suggest that specific strategies to improve health risk communication for patients living with CKD are lacking. Further research is needed to explore the informational and communication preferences for patients living with CKD in order to better understand how risk can be communicated effectively within the renal setting.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s40620-024-02098-0>.

**Author contributions** This study was conceptualised by Ros Aird, Maria Da Silva-Gane, Sivakumar Sridharan, David Wellsted and Ken Farrington. All authors contributed to the study design. Data collection was performed by Emma Caton, Ros Aird and Maria Da Silva-Gane. Data extraction and analysis was performed by Emma Caton. All authors contributed to the interpretation of the data. The first draft of the manuscript was written by Emma Caton. All authors contributed to and approved the final manuscript.

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**Data availability** All relevant data are included in this published article.

## Declarations

**Conflict of interest** The authors have no competing interests to declare.

**Ethical approval and informed consent** This review reports secondary data, thus no ethical approval or informed consent is required.

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