

# Do published patient decision aids for end-of-life care address patients' decision making needs? A systematic review and critical appraisal

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## Abstract

**Background:** Many decisions are made by patients in their last months of life, creating complex decision-making needs for these individuals. Identifying whether currently existing Patient Decision Aids address the full range of these patient decision-making needs will better inform end-of-life decision support in clinical practice.

**Aims & Design:** This systematic review aimed to: a) identify the range of patients' decision-making needs; and b) assess the extent to which Patient Decision Aids address these needs.

**Data sources:** MEDLINE, PsychINFO and CINAHL electronic literature databases were searched (Jan 1990-Jan 2017), supplemented by hand-searching strategies. Eligible literature reported patient decision-making needs throughout end-of-life decision-making, or were evaluations of Patient Decision Aids. Identified Decision Aid content was mapped onto and assessed against all patient decision-making needs that were deemed 'addressable'.

**Results:** Twenty-two studies described patient needs, and seven end-of-life Patient Decision Aids were identified. Patient needs were categorised, resulting in 48 'addressable' needs. Mapping needs to Patient Decision Aid content showed that 17 patient needs were *insufficiently* addressed by current Patient Decision Aids. The most substantial gaps included inconsistent acknowledgement, elicitation and documentation of how patient needs varied individually for: the level of information provided, the extent patients wanted to participate in decision-making, and the extent they wanted their families and associated healthcare professionals to participate.

**Conclusions:** Patient decision-making needs are broad and varied. Currently developed Patient Decision Aids are insufficiently addressing patient decision-making needs. Improving future end-of-life Patient Decision Aid content through five key suggestions could improve patient-focused decision-making support at the end-of-life.

## Keywords

Systematic review, End-of-life care, Palliative care, Terminal Care, Decision Making, Decision Support Techniques

## Key statements

### What is known about the topic?

- Applying shared decision making approaches to decision-making involving patients in the last months of life is challenging.
- Patient decision aids can provide effective support for patients making these shared decisions.
- The full range of patient needs whilst making these shared decisions is currently unknown, as is extent to which patient decision aids can support contemporaneous (i.e. 'not in advance') decision-making at the end-of-life through addressing current patient needs.

### What this paper adds

- The decision-making needs experienced by patients approaching shared decision-making at the end-of-life are broader and more varied than previously evidenced.
- Currently available patient decision aids are inadequately meeting the full range of identified patient decision-making needs.
- Five key areas as 'suggestions for developers of patient decision aids' have henceforth been identified to inform future patient decision aid design, which outline key areas where current patient decision aids lack in their content or composition.

### Implications for practice, theory or policy

- Addressing these key suggestions in future patient decision aid design will better support clinicians, irrespective of care setting or professional role, to effectively provide and implement shared decision-making during 'contemporaneous' decision-making with patients in the last months of life.
- More patient decision aids specifically designed for contemporaneous, end-of-life decision-making now need to be developed and evaluated in light of these new suggestions to help address existing gaps within end-of-life shared decision-making support.
- Patient decision aid developers and healthcare professionals caring for people towards the end of their lives should find these results of interest to inform and aid their future practice, either to ensure more individualised shared decision-making for their patients, or to be used as a training tool for healthcare professional education.

## 1. Introduction

The end-of-life period (defined as 'the last 12 months of life') is a demanding and uncertain time for patients and families.<sup>(1)</sup> During this period, many high-stakes decisions may need to be navigated by these individuals, often during periods of significant emotional distress,<sup>(2-4)</sup> where the decision-making process can demand time, emotional investment and energy.<sup>(2-6)</sup> Decisional support at this time is critical, but we do not yet fully understand the range of patients' end of life decision-making needs, nor do we know whether the tools designed to support decision-making address the patients' needs.

Patient's end-of-life decisions can be made with two chronological approaches, either leading to an immediate outcome (i.e. 'contemporaneous' decisions), or to outcomes that dictate their future care and management (i.e. 'advance' decision). Advance decision-making forms part of Advance Care Planning and anticipatory care planning. Advance Care Planning is a voluntary process of discussion between an individual and their care providers, which aims to identify a person's wishes and preferences for future care, and may bring about decisions to determine such care in anticipation of a possible future deterioration in their capacity to make decisions (e.g. Advance Decisions to Refuse Treatment). In contrast, contemporaneous decision-making determines *immediate* outcomes and changes to care for patients with capacity, when considering their current situation. For example, as recognised by the United Kingdom General Medical Council guidelines,<sup>(7)</sup> patients may express preferences many months prior to their death during the Advance Care Planning process (e.g. for dying in their own home). However, as they reach the last months to days of life, their preferences may change when taking their current circumstances into account (i.e. changed preferences to now die in a hospice), meaning they need to be able to review, and re-make, their decision in a timely fashion to change their decision outcomes with *immediate* effect.

Though much of the literature focusses on Advance Care Planning, contemporaneous decision-making should be afforded equal importance to ensure that patients' changing preferences are appropriately considered in decisions. Due to the complex and varied nature of contemporaneous end-of-life decisions, such as those to stop life-sustaining treatment (e.g. ending dialysis treatment), these decisions may result in extensive decision-making needs for patients.<sup>(8-10)</sup> These needs may include needs to participate during the decision-making process, or for clear communication throughout.<sup>(5,6)</sup> Good and effective decision-making leads to better outcomes for patients; patients often define 'a good death' as one during which these decision-making needs are supported sufficiently.<sup>(11,12)</sup> Therefore, any identified patient decision-making needs should be supported as best as possible.

A shared decision-making process can support contemporaneous decision-making at the end-of-life. Shared decision-making is an evidence-based consultation approach that promotes equal patient and healthcare professional participation in decision-making.<sup>(13,14)</sup> Healthcare professionals use the best available evidence to inform patients about their options and support them to consider their personal preferences in relation to likely outcomes, to achieve the best decision for each patient.<sup>(6,15-17)</sup> Periods of severe, chronic illnesses are considered some of the most important medical contexts during which shared decision-making is appropriate.<sup>(7,18)</sup> Patient decision aids, are evidence-based tools developed to facilitate shared decision-making between patients and healthcare professionals, by presenting information about likely outcomes, and encouraging patients to consider their personal values against the likely outcomes whilst facilitating clinicians to support the shared decision-making process aligned with the patients' preferences.<sup>(19)</sup> Patient decision aids result in better outcomes for patients, including increased knowledge, lower decisional conflict and greater likelihood that patients make choices congruent with their personal values.<sup>(20)</sup>

Despite the evidenced benefits of shared decision-making, it is not yet routinely used, or sufficiently supported, within practice,<sup>(21–23)</sup> where few patient decision aids are currently developed for end-of-life decisions specifically.<sup>(24–28)</sup> The Palliative and End-of-life Care Priority Setting Partnership (2015) stated that the third of ten top unanswered research questions was to listen to and incorporate patients’ preferences into their clinical care.<sup>(29)</sup> Previous systematic reviews have either investigated priority setting, patient communication preferences, evaluated the practical use of end-of-life patient decision aids in clinical practice, or recommend the further exploration of patient decision aids use in routine end-of-life practice.<sup>(2,30–32)</sup> However, no systematic review has yet identified the full range of contemporaneous decision-making needs for patients.<sup>(2,4,18,30)</sup> Furthermore, no systematic review has yet evaluated the extent to which available end-of-life patient decision aids meet the specific and varied contemporaneous decision-making needs of end-of-life patients. This review seeks to evaluate the effectiveness of currently developed patient decision aids in supporting *contemporaneous* decisions at the end-of-life to inform the development of patient decision aids for use in end-of-life practice, both in specialist palliative care itself, as well as in other disciplines which frequently support patients at the end-of-life.<sup>(28,33)</sup>

## 1.1 Aim

This review aimed to systematically identify, synthesise, and compare the range of patient end-of-life decision-making needs, and to assess the extent to which existing patient decision aids address those needs. Our specific objectives were to:

- 1) Identify and synthesise the decision-making needs of patients in the last year of life/at the end-of-life (Search One);
- 2) Identify and describe the range of patient decision aids currently developed for clinical practice in end-of-life care (Search Two);
- 3) Appraise the content of identified patient decision aids to determine the extent to which they address the identified patient decision-making needs.

## 2. Methods

This systematic review was developed using the 2015 PRISMA framework.<sup>(34)</sup>

### 2.1 ‘End-of-life’ definition

Throughout this review, the term ‘end-of-life’ refers to the specific definition provided by the United Kingdom General Medical Council: “advanced, progressive [and] incurable conditions...*likely to die within the next 12 months*”<sup>(1)</sup> All eligible studies and patient decision aids included within this review must have explicitly identified their included patient study group to meet this definition. Furthermore, patients with Stage IIIb-IV lung cancer (median survival = 6-9 months), patients being managed as end-stage Motor Neurone Disease (median survival = 10 months), and conservatively managed end-stage kidney disease (median survival = 6 months) patients were also included.<sup>(35–42)</sup>

## 2.2 Search One – Decision-making needs identification (Objective 1)

Three electronic databases (MEDLINE, PSYCHINFO and CINAHL) were searched with search layers for: end-of-life care context, patients, healthcare setting, decision-type and decision-making needs (January 2017). A combination of key terms and Medical Subject Headings, guided by key systematic reviews in the field, were used, and tailored to each electronic database<sup>(4,6,25,30,31,43)</sup> (for search strategies, see Supplementary File Table S1). Identified articles were imported into Mendeley Desktop<sup>®(44)</sup> and duplicates were removed. Targeted hand-searching from reference lists of included studies and key systematic reviews<sup>(6,26)</sup> were also undertaken. Study titles and abstracts were screened for eligibility (GP) and categorised as ‘included’, ‘excluded’ or ‘unsure’. Articles categorised as ‘included’ or ‘unsure’ were requested as full-text. Twenty per cent of abstracts obtained were independently screened (KL). Full-text studies categorised as ‘unsure’ were discussed with KL for eligibility, and in-depth discussion occurred if there was eligibility disagreement (GP and KL).

## 2.3 Search Two – Patient decision aid identification (Objective 2)

Identifying the full range of existing patient decision aids designed for ‘contemporaneous’ decision-making for patients at the end-of-life was challenging. Therefore, we used multiple methods of searching, including 1) online patient decision aid databases (e.g. Ottawa A-Z Inventory of Patient Decision Aids; for a complete list, see Supplementary File Table S2), 2) electronic databases and hand-searching reference lists of identified papers, 3) online search engines (key search terms included ‘end-of-life + palliative care (patient) decision aid’, ‘decision support intervention’ and ‘end-of-life decision tool’), and 4) email contact with existing patient decision aid developers. patient decision aids using written communication, spoken communication and video and web-based tools, were all eligible.

Databases and websites were visually scanned for patient decision aids designed for patients with chronic, end-stage medical conditions, developed to support decisions in the last months of life. Any potentially relevant patient decision aids were viewed in detail, and then considered against the Search Two patient decision aid eligibility criteria (Table 1). MEDLINE, PSYCHINFO and CINAHL were also searched to identify evaluation of additional patient decision aids in clinical settings. Search strategies were guided by systematic reviews in the field,<sup>(4,6,20,25,30,31,43)</sup> where key terms and Medical Subject Headings terms were used under the same search layers as Search One, with the addition of patient decision-aids (for search strategy details, see Supplementary File Table S1). Supplementary searches included hand-searching reference lists of published systematic reviews,<sup>(20,26,32)</sup> of included studies, and of selected studies identified from Search One. Results were imported into Mendeley Desktop<sup>®(44)</sup> and abstracts were processed using the same methods utilised in Search One, with the collaboration of GP and KL. All eligible studies were accessed as full-text, to establish whether the patient decision aid was available for review. Hard copies of any patient decision aids described in each trial were sought online, or by contact with study authors.

## 2.4 Search One and Search Two – Eligibility criteria

Combined high-level summaries of the eligibility criteria for Search One (identifying the decision-making needs), and Search Two (identifying the patient decision aids) are shown in Text Table 1. For more detailed Search One and Search Two ‘a priori’ eligibility criteria, see Supplementary File Tables S3 and S4.

**Text Table 1** – Eligibility Criteria

<b>Inclusion Criteria</b>
<p><b>Decision-making Needs:</b> studies should have reported at least one decision-making ‘need’ experienced by patients. Studies were included if they overtly reported the needs of <i>overt</i> decision-making.</p>
<p><b>Decision Type:</b> studies needed to focus on ‘patient-focused’ decisions, that were used to result in a ‘contemporaneous’ (i.e. not in advance) outcome. For example, deciding upon a treatment to commence with immediate effect, as opposed to ‘advance care’ decisions to forego future treatment, should the patient deteriorate. Decisions were only included if they were made by, or directly involved, patients into the decision-making process.</p>
<p><b>Patient Type:</b> included patients must have been explicitly described as “within the last 12 months of their life” (see Methods Section 2.1), and must have decision-making capacity. patient decision aids were only included if they were created for ‘end-of-life’ patients, by the above definition.</p>
<p><b>Patient Decision Aids:</b> met the updated Cochrane Review definition of patient decision aids.<sup>(20)</sup></p>
<b>Exclusion Criteria</b>
<p><b>Decision-making Needs:</b> studies that did not explicitly report decision-making needs of patients. Papers that only <i>discussed</i> the preferences of individuals, were excluded. This review was not an exercise to determine the needs of sharing preferences between decision stakeholders.</p>
<p><b>Decision Type:</b> ‘advance care’ decisions (to determine future care, treatment or management).</p>
<p><b>Patient Type:</b> recently deceased patients whose death was not naturally anticipated nor expected.</p>
<p><b>Decisional Capacity:</b> decisions made on behalf of patients who <i>lacked</i> decision-making capacity, i.e. a Health Attorney for the patient.<sup>(45)</sup></p>
<p><b>Patient Decision Aids:</b> developed before 1990.</p>

Eligible literature was published in a peer-reviewed journal, written in English, and reported original empirical data. Studies reporting the decision-making needs of unique populations (e.g. specific ethnic groups) were excluded if international generalisability appeared limited.

Studies discussing patients <18 years-old without separation of adult findings, were also excluded. Studies were not restricted based on evidence quality or study design.<sup>(46)</sup>

## 2.5 Search One - Data extraction, synthesis, analysis and quality appraisal (Objective 1)

For Search One included studies, descriptive data were extracted for study design, decision type and participant characteristics.<sup>(47)</sup> Thematic analysis<sup>(48)</sup> (using NVivo<sup>®</sup> software) of included study results and discussion sections was conducted to identify patient decision-making needs. Sub-group analysis of patient needs by ethnicity and disease type was conducted to account for variation in heterogeneous study populations. Preliminary thematic analysis generated an initial coding framework (GP) that was later refined during an iterative process, in discussion with KL. Findings were aggregated into broad analytical, intermediate descriptive and detailed sub-themes of decision-making needs. The identified patient decision-making needs were categorised as either 'addressable' (meaning they could realistically be addressed by patient decision aids in clinical practice) or 'inherently non-addressable', meaning needs that were 'inherent' to either the patient's physical illness, or to unavoidable healthcare system barriers. Therefore, patient decision aids would be unlikely to address and support these needs in isolation from other adopted measures (e.g. a patient need for more decision options to be available, which is limited by current science, research and treatment funding options for that disease).

Quality appraisal of included studies was undertaken, using the CASP Qualitative Checklist, the STROBE Statement for observational studies, CEBMa case study tool and the Mixed Methods Assessment Tool (2011), according to study design.<sup>(49-53)</sup> Supplementary File Table S5 summarises the key strengths and limitations of each study.

## 2.6 Search Two - Data extraction, synthesis and analysis (Objective 2 & 3)

Descriptive data were extracted from the contents of each included individual patient decision aid, and from patient decision aid descriptions included within evaluations (if available). If a patient decision aid was unavailable after contact with the developers, content assessment was based on patient decision aid descriptions in published trials. Patient decision aids were appraised by GP using two methods: (1) Patient decision aid quality was assessed using the 2005 International Patient Decision Aid Standards criteria;<sup>(54)</sup> (2) each patient decision aid was appraised for its ability to address the *patient* decision-making needs identified in Search One. Patient decision-making needs categorised as 'inherently non-addressable' were not included in this mapping exercise. The content of each individual patient decision aid was studied in detail by GP, and then rated against each of the patient needs that were deemed to be practically 'addressable' by a patient decision aid. The above methods used to rate the patient decision aids were discussed and piloted with the team to ensure a robust approach.

Each patient decision aid was awarded a score from 0-4 to reflect the extent to which their content addressed each 'addressable' need (from 1 = not addressed at all, to 4 = addressed). This individual patient decision aid analysis enabled assessment of each patient

decision aid to identify specific areas within each patient decision aid that may currently not fully support patient needs. The rating scores allocated for each 'addressable' need from each included patient decision aid were then added together, resulting in a total, 'collective score' out of 28. Adding the scores of each of the seven patient decision aids represented the extent to which each patient need was addressed *collectively* by all the identified patient decision aids within this review. The rationale for combining the scores from each of the seven patient decision aids provided another outcome for data analysis, to attempt to identify any broad areas where patient decision aids within end-of-life care collectively may be lacking to support patient needs. The 'collective scores' were allocated to one of the three following categories, to represent the extent to which the patient decision aids collectively addressed each 'addressable' patient need: 'sufficient' (score: 22-28), 'variable' (score: 15-21), or 'insufficient' (score: 7-14).

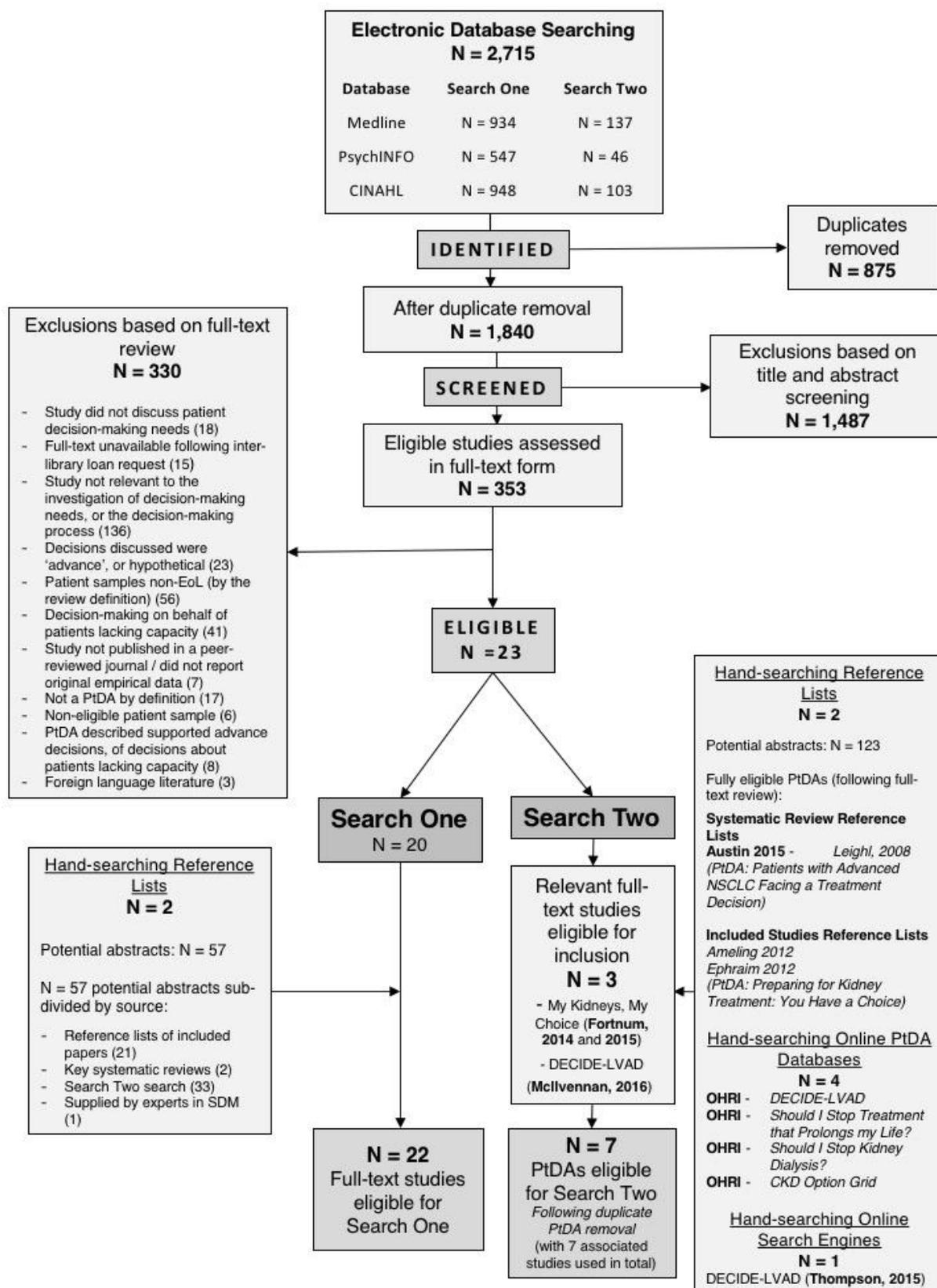
## 3. Results

### 3.1 Review of studies

Electronic databases from Search One and Search Two yielded 2,715 abstracts, of which 1,840 were screened for eligibility following duplicate removal. Twenty-two eligible studies remained for Search One (decision-making needs), and seven patient decision aids were identified by Search Two (Figure 1).

### 3.2 Search One Study Characteristics

Study characteristics are summarised in Supplementary File Table S5. Most studies originated from the USA,<sup>(12,55–58)</sup> Canada,<sup>(8,59–62)</sup> the UK<sup>(10,63–65)</sup> and The Netherlands.<sup>(66–69)</sup> Thirteen studies adopted an exclusively qualitative design.<sup>(8,10,67,68,70,12,40,55,56,59,61,65,66)</sup>



**Figure 1** - Flowchart for Searches (*for space efficiency, the following abbreviations have been included into the flowchart: Patient Decision Aid(s) to PtDA(s), shared decision-making to SDM and end-of-life to EoL*)

### 3.3 Patient decision-making needs

Patient decision-making needs were divided into three categories: 1) needs before decision-making, 2) needs during the decision-making process, 3) inherently non-addressable patient decision-making needs. Categories 1-3 are summarised here, with complete listing of *all* patient needs available in Supplementary File Table S6.

#### 3.3.1 Before decision-making

Patients wanted information to be provided *before* decision-making,<sup>(8,62,64,68,70–72)</sup> because earlier information equipped them with the understanding required to assume more autonomous decision-making roles.<sup>(8,68,71)</sup> However, preferences for the detail and timing of information provided varied between individuals, and were most commonly determined by the emotional burden individuals experienced when receiving truthful information. Hispanic and Latino patients in particular found the emotional burdens of detailed information about death unnecessary, needing as much information to be as withheld as possible. Additionally, patients living with motor neurone disease found information about their future trajectory provided before decision-making discouraging.<sup>(8,40,61)</sup>

#### 3.3.2 During decision-making

Patients needed healthcare professionals to elicit and uphold their preferences *during* decision-making, where patient decision-participation preferences varied between patients.<sup>(8,10,58,60,61,68,71–73)</sup> Despite most patients preferring active or shared involvement in discussions to maintain their decision-making autonomy,<sup>(10,58,61,62,64,68,70,72)</sup> stating particular preferences *for* shared decision-making,<sup>(12,33,68,70,73)</sup> a small proportion of patients wanted healthcare professionals to lead the decision-making process, preferring to adopt more *passive* roles throughout.<sup>(8,68,72,73)</sup> Reduced patient desire for autonomous control over decisions was often observed when patients discussed contemporaneous requests for euthanasia,<sup>(68)</sup> and with Asian and Latino patients making decisions who often preferred to defer decision-making responsibility to either their families or their associated healthcare professionals.<sup>(73)</sup> Furthermore, some patients expressed needs for information to be provided gradually, only as it became more relevant to their situation and relevant to a decision needing to be made in that moment.<sup>(40)</sup>

Both families *and* patients wanted the involvement of *more* and *different* healthcare professionals during decision-making,<sup>(56,62,68,72,74)</sup> to increase the breadth of information and support available to them.<sup>(74,75)</sup> Finally, patients largely wanted to involve their families more during decision-making<sup>(58,61,63,68,76)</sup> for either practical or emotional reasons,<sup>(65,71,77)</sup> and expected healthcare professionals to recognise their family-members as “involved [and equal] decisional parties” in shared decision-making.<sup>(33,61,65,68,71,73)</sup> However, the *extent* to which patients wanted involvement of their family members during decision-making varied between individual patients; patients allocated variable levels of influence to family members,<sup>(33)</sup> needing to balance family involvement with their own decisional autonomy.<sup>(68)</sup>

### **3.3.3 Inherently non-addressable patient decision-making needs**

Some patient decision-making needs were deemed inherently 'non-addressable' (for explanation, see Methods Section 2.5). The literature often highlighted that it was important for healthcare professionals to recognise physical disease factors that affect patients making decisions, where they often required assistance from family members or healthcare professionals to communicate their wishes.<sup>(10,57,61,63)</sup> Furthermore, healthcare system barriers also existed where patients either needed more accommodating physical locations or times to enable important decision-making within public healthcare environments,<sup>(56,59)</sup> or needed more time with healthcare members to develop the necessary patient-doctor rapport for shared decision-making, all of which would not be enhanced by a patient.<sup>(59,65)</sup>

## **4. Search Two Results**

### **4.1 Overview of patient decision aids**

Seven patient decision aids were identified. Five were developed in the USA,<sup>(78–82)</sup> one in Canada<sup>(39)</sup> and one in Australia.<sup>(83)</sup> They were last updated between 2008<sup>(39)</sup> and January 2017, with one due for update later in 2017.<sup>(78)</sup> Four were specific to patients with end-stage kidney disease;<sup>(79,81,84,85)</sup> only one was generalised to end-of-life care decisions.<sup>(80)</sup> The patient decision aids varied in their healthcare setting and timing of delivery. Five were readily accessible online (January 2017) for use within clinical practice,<sup>(78–80,83,84)</sup> one was provided following author contact,<sup>(39)</sup> and one was assessed through detailed patient decision aid descriptions contained within the associated publication.<sup>(81)</sup> There are currently few data available from formal studies of patient decision aids within end-of-life care. For summaries of included patient decision aids, see Supplementary File Table S7.

### **4.2 The quality and effectiveness of patient decision aids**

#### **4.2.1 International Patient Decision Aids Standards assessment**

The patient decision aids scored acceptably against the 2005 International Patient Decision Aids Standards criteria, indicating that they met essential patient decision aid quality thresholds. However, only four of the seven patient decision aids scored full marks for "ensuring that decision-making was informed and values-based",<sup>(79–81,86)</sup> and the quality of the content necessary for supporting end-of-life shared decision-making in particular varied between patient decision aids (for detailed International Patient Decision Aids Standards assessments, see Supplementary File Table S8).

#### **4.2.2 Published patient decision aid evaluations**

Three of the seven patient decision aids had associated published trials or pilot studies.<sup>(39,83,87)</sup> When available, the published trial data provided additional contextual information for each patient decision aid. However, in isolation, these published data provided limited evidence for how successful each patient decision aid was in addressing

the specific end-of-life decision-making needs identified in Search One. For a summary of evaluation study details, see Supplementary File Table S9.

### 4.2.3 Patient decision aid appraisal

Of the 65 patient decision-making needs identified, 48 were deemed as 'addressable', and the remaining 17 were classified as 'inherently non-addressable' (for a complete list, see Supplementary File Table S6).

**Text Table 2 – Mapping of the 'addressable' patient decision-making needs against the content of each patient decision aid**

<sup>1</sup> **4-point Likert rating scale:** 1 = not addressed, 2 = partially addressed, 3 = moderately addressed, 4 = addressed to a great extent

<sup>2</sup> **Summed score categories:** 'Sufficient' = score 22-28, 'Variable' = score 15-21, 'Insufficient' = score 7-14

Patient decision-making needs ( <i>descriptive and sub-themes</i> )		Patient Decision Aids							Collective Scores, and Resulting Score Category
		DECIDE-LVAD	My Kidneys, My Choice	Preparing for Kidney Treatment	Should I Stop Treatment That Prolongs My Life?	Should I Stop Kidney Dialysis?	Treatment Decision for Patients with NSCLC	Chronic Kidney Disease: Treatment Options	
<b>Needs before decision-making</b>									
<b>Information needs</b>	Recognition that information needs vary <i>between</i> patients	1 <sup>1</sup>	1	1	1	1	4	1	10 <b>Insufficient</b> <sup>2</sup>
	For personal information preferences to be elicited and individually tailored	1	1	1	1	1	2	1	8 <b>Insufficient</b>
	Healthcare professionals to provide more (non-specific) information <i>before</i> decision-making (through patient decision aids)	4	4	4	4	4	4	3	27 <b>Sufficient</b>
	Open and clear information	4	3	4	3	3	2	3	22

									<b>Sufficient</b>
Information on the diagnosis and prognosis of the illness	4	3	4	3	4	4	3	25	<b>Sufficient</b>
Information on the process of death	3	2	2	2	4	1	1	15	<b>Variable</b>
Specific information for particular decisions to be made available through patient decision aids (i.e. Information on the range of options available for each decision)	4	4	4	3	4	4	4	27	<b>Sufficient</b>
Honest information balanced with hope to manage patient motivation	3	4	3	3	2	4	3	22	<b>Sufficient</b>
More gradual, longitudinal information on the present	1	3	Unclear	1	1	1	1	8	<b>Insufficient</b>
For limited information about illness	1	1	1	1	1	1	2	8	<b>Insufficient</b>
Recognition of how patient and family information needs vary	3	2	Unclear	1	1	2	1	10	<b>Insufficient</b>
Information <i>sharing</i> between patients, families and healthcare professionals	2	3	2	2	2	3	2	16	<b>Variable</b>

<b>Decision-preparation needs</b>	Guidance how to acknowledge and discuss their limited prognosis	4	2	3	2	2	3	2	18 <b>Variable</b>
	Guidance how to organise and express thoughts and feelings	3	4	4	4	4	4	3	26 <b>Sufficient</b>
	Guidance how to address and express emotions about their health condition to doctors more competently (e.g. fears or doubts)	4	3	3	3	3	2	1	19 <b>Variable</b>
	Guidance on <i>how</i> and <i>when</i> to discuss decisions in the last months of life	3	4	3	3	4	3	3	23 <b>Sufficient</b>
	To have knowledge of <i>other</i> patients' previous experiences making decisions towards the end-of-life	4	2	4	4	4	4	1	23 <b>Sufficient</b>
<b>Decision-making needs during the decision-making process</b>									
<b>Patient needs from healthcare professionals / patient decision aids</b>	<i>Earlier</i> decision-making during stable periods of patient health	3	4	Unclear	1	1	2	1	12 <b>Insufficient</b>
	To tailor the timing of discussions to individual circumstance	1	3	3	2	4	3	1	17 <b>Variable</b>
	For concepts to be explained competently and honestly (by healthcare professionals or patient decision aids)	4	2	3	3	4	3	3	22 <b>Sufficient</b>

For the healthcare professional to be aware of patient preferences before a decision is officially finalised	4	4	3	4	4	4	4	27 <b>Sufficient</b>
(For the patient decision aid) to elicit holistic information about the patient during decision-making	2	4	4	4	4	4	2	24 <b>Sufficient</b>
Sensitive information delivery	2	3	Unclear	3	2	4	4	18 <b>Variable</b>
Empathetic information delivery	4	3	Unclear	3	4	3	2	19 <b>Variable</b>
For acknowledgement of patient ethnicity	1	1	3	1	1	1	4	12 <b>Insufficient</b>
For patient decision aids to acknowledge a patient's specific religious, faith or spirituality requests	2	1	1	3	1	4	1	13 <b>Insufficient</b>
To have an opportunity to question healthcare professionals	3	4	2	4	4	4	4	25 <b>Sufficient</b>
To involve more, and varying, multidisciplinary team members in decision-making	1	3	4	1	1	1	3	14 <b>Insufficient</b>
For more support to be available to minimise the emotional anxieties of decisions made in the last months of life	3	2	2	4	4	4	4	23 <b>Sufficient</b>

<b>Needs for healthcare professionals to uphold varying patient decision-participation preferences</b>	For healthcare professionals to recognise that individual patient preferences for decision-participation will vary	1	4	Unclear	2	3	4	1	15 <b>Variable</b>
	For healthcare professionals/patient decision aids to elicit, acknowledge and document patient preferences for decision-participation	1	2	1	2	2	4	1	13 <b>Insufficient</b>
	For healthcare professionals/patient decision aids to assess patients' 'readiness to participate' in decision-making	1	3	Unclear	4	4	1	2	15 <b>Variable</b>
	For decisions to be 'shared' by patients and healthcare professionals	4	4	3	4	4	4	4	27 <b>Sufficient</b>
	To have (patient) autonomy and self-determination maintained during decision-making	3	3	3	4	4	4	3	24 <b>Sufficient</b>
	For guidance on how to balance patient autonomy with patient non-abandonment during decision-making	4	4	2	3	3	4	4	24 <b>Sufficient</b>
	For healthcare professionals/patient decision aids to recognise (and be capable of) leading decision-making when patients need them to	1	1	Unclear	3	3	4	1	13 <b>Insufficient</b>

	For healthcare professionals/patient decision aids to recognise the role of family members during decision-making	4	3	4	3	3	3	3	23 <b>Sufficient</b>
<b>Family involvement in decision-making</b>	For healthcare professionals/patient decision aids to recognise that patient needs to involve family members during decision-making will vary	2	4	1	2	1	1	1	12 <b>Insufficient</b>
	Need for healthcare professionals/patient decision aids to elicit and document varying patient preferences for family decisional-involvement	1	3	1	1	1	1	1	9 <b>Insufficient</b>
	To involve families in decision-making (involvement of families in the patient decision aid)	4	3	4	3	2	2	2	20 <b>Variable</b>
	For healthcare professionals/patient decision aids to provide information specifically to family members	4	2	2	1	1	1	1	12 <b>Insufficient</b>
	To balance family decisional-involvement with patient's decisional-autonomy	3	3	Unclear	3	2	2	1	14 <b>Insufficient</b>
	For healthcare professionals and family-members to respect and support patient choices	3	3	3	3	3	4	3	22 <b>Sufficient</b>
	To exercise control over what their family members are told	2	3	Unclear	2	2	3	1	13 <b>Insufficient</b>

How needs vary <i>throughout</i> the end-of-life period									
<b>Need for healthcare professionals to recognise how needs can vary</b>	For continuous information throughout the end-of-life trajectory	1	3	Unclear	3	3	3	2	15 <b>Variable</b>
	For acknowledgement that their decision- <i>participation</i> preferences may change over time	1	1	1	1	2	1	1	8 <b>Insufficient</b>
	For acknowledgement that their preferences for decision <i>options</i> may change over time	1	4	3	4	1	3	1	17 <b>Variable</b>
	For healthcare professionals to be sensitive to when patients would like to pursue comfort measures only	3	3	Unclear	4	4	4	1	19 <b>Variable</b>

### 4.3 Patient Decision Aid Assessment

Following the rating exercise, the 48 'addressable' patient decision-making needs were grouped into the following categories, as the extent to which they were addressed by the patient decision aids.

'Insufficiently' addressed needs represent the key gaps within the content of currently developed patient decision aids, therefore highlighting the key areas for improvement:

**Text Table 3** – Number of patient decision-making needs addressed by available patient decision aids

Category	Frequency
Sufficient	18
Variable	13
<b>Insufficient</b>	<b>17</b>

#### 4.3.1 'Sufficiently' addressed patient decision-making needs

All seven patient decision aids provided sufficient information *before* decision-making about the illness, condition prognosis, and the range of decision options available (usually in table format). Patient decision aids also showed evidence of preparing users for the decision-making process, by including information and guidance on how and when the patient should engage with decision discussions.

Furthermore, all patient decision aids explicitly provided values clarification exercises for patients to organise their thoughts after reading about their options, encouraging active consideration of each option by patients, alongside their personal values. This type of content helps patients prepare to share their option preferences with their healthcare professional during subsequent decision-making.

Finally, all patient decision aids either indirectly or explicitly promoted patient involvement during decision-making, by reaffirming that the decision in question was between the patient *and* the doctor. In so doing, each patient decision aid promoted patient decisional autonomy, whilst reiterating that support was still available from healthcare professionals should they need it throughout the process. All seven patient decision aid therefore offered opportunities for patients to fully engage with shared decision-making.

#### 4.3.2 'Variably' addressed patient decision-making needs

The patient decision aids variably addressed how patients' preferences may change over the illness trajectory, with three patient decision aids insufficiently addressing this need.<sup>(78,79,84)</sup> Two patient decision aids explicitly reaffirmed that preferences could be

revisited again by patients over the illness trajectory, highlighting that they could change their decision if needed, and if practically possible, at this late stage in their disease trajectory.<sup>(78,80)</sup>

Moreover, four of the patient decision aids partially addressed patients' readiness to participate in decision-making.<sup>(39,78,83,84)</sup> The two Healthwise patient decision aids explicitly addressed this need ('readiness to participate') by including an explicit statement at the end of the patient decision aid to elicit and document how ready patients felt to participate in decision-making after working through the patient decision aid.<sup>(79,80)</sup>

### **4.3.3 Insufficiently addressed patient decision-making needs**

Seventeen of the 48 patient needs were 'insufficiently addressed' by the patient decision aids. Individual patients wanted varying levels of involvement and participation during the decision-making process. Recognition of this variability between individuals was only addressed clearly by one patient decision aid,<sup>(81)</sup> suggesting that patient decision aids overall *assumed* homogeneity of decision-participation desires amongst patients. Overall, patient decision aids failed to recognise, elicit *and* address that different patients prefer varying levels of contribution to decision-making, appearing to assume that all patients wanted 'active' participation in the decision.

Patients also needed varying amounts of information to prepare for decision-making, either because they were at different stages of the decision-making process, or as a result of variations between their individual preferences. Just one patient decision aid sufficiently recognised that these information needs varied between patients.<sup>(81)</sup> Thus, the need for individual information preferences to be explicitly elicited *and* documented within patient decision aids, to enable healthcare professionals to act upon these preferences *before* decision-making takes place, remained largely unaddressed.

Furthermore, despite patients frequently preferring more family involvement during decision-making, the extent to which patient decision aids actively promoted or involved family members was variable and minimal. Whilst most patient decision aids recognised patients may want to discuss their options with family members, only one patient decision aid *explicitly* suggested that family members could, or should, be involved in the decision-making process.<sup>(78)</sup> This patient decision aid highlighted the family's role in decision-making, and provides focused information tailored to the needs of the family. Moreover, patient decision aids insufficiently recognised that patients had varying needs for the *extent* that families were involved during decision-making between individuals, particularly not recognising patients who wanted *less* family involvement.

No patient decision aid actively promoted the roles of nurses and allied health professionals within the shared decision-making process. Despite three of the seven patient decision aids recognising that 'healthcare teams' may be involved in decision-making with the patient, in addition to the traditional doctor-patient dyad,<sup>(81,83,84)</sup> all three patient decision aids then reverted to referring to the decision between just the 'doctor' and the 'patient'. In the remaining patient decision aids, the only healthcare professional mentioned was a 'doctor'.

Finally, just one patient decision aid<sup>(84)</sup> elicited the ethnicity or cultural background of the patient, meaning healthcare professionals would then be unlikely to subsequently adapt to variations for culturally-specific patient information and decision participation needs.

## 5. Discussion

### 5.1 Main Findings

Our review identified the decision-making needs experienced by patients at the end of their lives, and how some of these identified needs were often inadequately addressed by currently available patient decision aids.

Whilst the decision-making needs of patients were largely addressable and interrelated, many were currently under-recognised within clinical practice. Variation of individual needs was often related to participant ethnicity, disease type, decision type, and most commonly, individual preferences.<sup>(38,40,88,89)</sup>

We identified seven patient decision aids created to support contemporaneous end-of-life decision-making. Overall, the extent to which the ‘addressable’ patient needs were *sufficiently* addressed was variable across the range of needs, and was *inconsistent* between each patient decision aid.

The most substantial gaps included inconsistent acknowledgement, elicitation and documentation of how *individual* patient needs varied for:

1. The level of information provided,
2. The extent patients wanted to participate in decision-making, and
3. The extent they wanted their families and associated nurses to participate.

### 5.2 What this study adds

#### 5.2.1 *The role of shared decision-making in ‘a good death’*

Despite the wider literature recognising that ‘shared’ approaches to end-of-life decision-making contribute to a ‘good patient death’,<sup>(30,90)</sup> our results show that healthcare professionals should not assume that all patients *want* a ‘shared’ approach.<sup>(91)</sup> Patient decision-participation needs vary between individuals. Whilst most patients wanted ‘shared’ or ‘active’ decision-participation roles alongside their healthcare professionals, many other patients wanted to *defer* their decision-making responsibility to either their healthcare professionals or family members. It is more likely patients will adopt decision-making roles that are incongruent with their actual preferences if healthcare professionals are unaware of their individual decision-participation needs. For example, Heyland *et al* (2003) reported that doctors wrongly estimated patients’ preferred role in decision-making in 68% of decisions.<sup>(33)</sup> Therefore, current practice does not necessarily adequately assess, nor uphold, varying patient participation needs *before* engaging in end-of-life decision-making;<sup>(33)</sup> an area that remains largely unaddressed by patient decision aids.

Furthermore, our review demonstrates the need to elicit *and* document participation preferences, and individual decision-participation needs clearly *before* the decision and shared decision-making is approached,<sup>(92)</sup> to ensure healthcare professionals more successfully facilitate shared decision-making according to the patient's needs. Explicitly acknowledging these patient needs and desires should facilitate healthcare professionals to support patient participation *throughout* the subsequent decision-making process.

### **5.2.2 The role of the family**

Current practice often only promotes or supports family input into contemporaneous patient-focused shared decision-making as 'surrogate decision-makers', when the patient's capacity to make their own decisions begins to deteriorate.<sup>(7,93)</sup> Often this is because healthcare professionals consider family involvement in shared decision-making for patients who *retain* decision-making capacity complicates the fragile patient-doctor dyads, a concern that is echoed by current practice guidelines and the wider literature.<sup>(40,64,77,94,95)</sup> Despite this previous evidence, our comprehensive review now reaffirms that, in reality, the family role in contemporaneous shared decision-making as a 'surrogate decision-maker' is assumed much *before* the patient begins to lose capacity. Furthermore, our review found that patients who retain capacity frequently want *more* family support and decisional involvement in their shared decision-making, despite the traditionally recognised concerns amongst healthcare professionals. Therefore, our evidence highlights that patients often need their family's involvement during decision-making to be better supported whilst they *retain* decision-making capacity, rather than restricting family support and involvement once they have lost capacity.<sup>(66,96)</sup> Patient decision aids should therefore individually elicit, document and acknowledge these needs *before* contemporaneous shared decision-making begins, to ensure healthcare professionals can better support shared decision-making for patients, to be more aligned with their specific family-involvement needs whilst they retain decision-making capacity.<sup>(66,97)</sup>

### **5.2.3 The role of nurses and allied health professionals**

The role of non-medical healthcare professionals, and in particular nurses, within shared decision-making is currently under-utilised in clinical practice.<sup>(98)</sup> Our findings about patient decision-making needs corroborate the wider literature that supports that families *and* nurses would like more nurse-involvement in end-of-life shared decision-making.<sup>(57,98–100)</sup> Furthermore, healthcare professionals, and in particular doctors, also express needs to more widely share decisional responsibility amongst additional members of the multidisciplinary team to alleviate their personal anxieties experienced with end-of-life decision-making.<sup>(101)</sup> Promoting decision-participation of nurses, in practice and in patient decision aids, now warrants renewed focus to meet these patient needs. We hypothesise that introducing, promoting and enhancing the role of nurses via the content of patient decision aids could help alleviate and share the healthcare professional burdens associated with end-of-life decision-making.

## **5.3 Strengths and Weaknesses**

This review adopts unique methods of evaluation to appraise each patient decision aid for its ability to meet patient decision-making needs. The generalisability of these findings across various healthcare and global settings, the use of multiple methods to identify both evaluated *and* non-evaluated patient decision aids, and the investigation of *contemporaneous* decision-making with end-of-life patients who *retain* decisional capacity, strengthen the shortcomings of previous systematic reviews.<sup>(31,32)</sup> However, this review has some limitations. Search One did not exclude studies based upon study design or quality, due to limited research available within end-of-life practice.<sup>(29,46,102)</sup> Furthermore, restricting study eligibility to patients *explicitly* within the last 12-months of life, and using a search strategy designed for precision more than recall in this heterogeneous field may have excluded relevant studies and patient decision aid materials. Direct contact with key patient decision aid authors was an attempt to mitigate this risk in the review. We have included a range of designs of patient decision aids, meaning that our conclusions about these tools are broad enough to adapt to any future patient decision aids.

## 5.4 Implications for future research and practice

Analysis of the collective scores of patient decision aids showed that there are substantial areas that patient decision aids are currently insufficiently addressing for patients at the end of their lives. Newly created patient decision aids should now recognise that patient needs vary between individuals, either because of individual preference, cultural priorities or the type or stage of each patient's disease trajectory. Patient decision aid design should also account for difference of patient needs between different disease-types, and also for the different stages of their illness. To meet these needs and variations, we propose five key 'suggestions for developers of future patient decision aids' based upon our findings (see Text Table 4).

**Text Table 4** – Suggestions for developers of patient decision aids for end-of-life care

- 
1. Patient decision aids should *recognise* how end-of-life decision-making needs may vary with the patient's **individual preferences, cultural values, type** and **stage** of their life-limiting illness.
- 
2. Patient decision aids should enhance efforts to *address, elicit* and *document* these **individual information** and **decision-participation needs** before contemporaneous decision-making begins, including supporting clinicians to initiate these discussions before any decisions requiring an urgent answer are required.
- 
3. Patient decision aids should enhance efforts to *elicit* and *document* individual patient needs for **family involvement** *before* decision-making begins, to assist healthcare professionals to better acknowledge these needs during subsequent shared decision-making and ensure family involvement is aligned to the extent that the patient needs.
- 
4. Patient decision aids should *promote* and support the role of **multi-disciplinary healthcare professional involvement** in decision-making.
-

- 
5. Patient decision aids should be **conscious of both the underlying life-limiting illness** as well as the **different stages of the same illness**, and how this may affect the patient's needs when making contemporaneous decisions.
- 

Renewed emphasis on developing and evaluating *more* patient decision aids specifically designed for contemporaneous, end-of-life decision-making, in light of these new suggestions, could now be helpful to address these gaps. High-quality evaluations of such patient decision aids are now essential to assess how useful they are for involved patients, families and healthcare professionals, and the extent of their uptake and implementation within practice.

We recognise that the way in which these tools are utilised may differ between health and social care professions, areas of work, or area of specialty within clinical practice. However, all healthcare professionals from different backgrounds will be able to use these enhanced tools. For example, professionals not routinely involved with palliative care may use these tools to support their practice to ensure more individualised shared decision-making. On the other hand, palliative care specialists could use these tools to directly aid their consultations and better implement individualised contemporaneous shared decision-making for their patients. Alternatively, they could also use patient decision aids as a 'contemporaneous' shared decision-making training framework, to educate and ensure their colleagues provide better support for patients and those close to them when undertaking shared decision-making in the last months of life. Therefore, these results should be of interest to many health and social care workers who encounter (contemporaneous) decision-making within end-of-life care within any specialty, irrespective of care setting or professional role.

Moreover, we believe that any existing limitations within the International Patient Decision Aids Standards to assess digital patient decision aids can now be strengthened. By applying the newly developed needs-assessment template in Text Table 2, patient decision aids will be more thoroughly and specifically assessed for quality and usefulness for individual patients specifically within the end-of-life context – an important step to modernise digital end-of-life patient decision aid assessment in this field.

Furthermore, high-quality research is also now warranted to investigate the full range of decision-making needs experienced by family members and healthcare professionals involved with contemporaneous end-of-life decision-making *alongside* patients. Finally, to ensure the successful implementation and use of patient decision aids in clinical practice, healthcare professional attitudes and necessary expertise to approach shared decision-making should be assessed, which may require intervention and evaluation.<sup>(6)</sup>

## 6. Conclusion

This systematic review shows that the needs of patients approaching end-of-life decision-making are more varied and extensive than previously understood. Furthermore, currently available patient decision aids aiming to support patients and healthcare professionals making contemporaneous, shared decisions at the end-of-life do not adequately address the full range of these existing patient needs. Improving support for patients through more robust patient decision aids could be beneficial to better implement individualised shared decision-

making within end-of-life care. This systematic review offers assistance in the assessment of patient needs during end-of-life decision-making, and identifies key areas where support for contemporaneous end-of-life decision-making can be improved.

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## Declarations

### Authorship

All authors contributed to this manuscript and have consented to the submission of this paper. All authors defined the search aims, objectives and methodology. G.P. conducted this search with collaboration from all authors to strengthen the search strategy. Study selection and data extraction was carried out by G.P., where she was assisted by K.L. to validate these methods. A.E. (primary care) and M.P. (palliative medicine) provided clinical context.

### Supplementary file access

Supplementary file data, which includes the full data set of this systematic review, can be accessed via a link provided alongside this article on SAGE Journals.

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### Conflicts of interest

The authors declare there are no conflicts of interest present.

### Ethics and consent

Research Ethics Committee approval was not necessary as this is secondary research as a systematic review.

### Data sharing

For access to further data from this study, please contact [liffordkj@cardiff.ac.uk](mailto:liffordkj@cardiff.ac.uk)

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### Declaration of no conflicting interests

The authors declare that there is no conflict of interest.

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