

BMJ Open Decision aids for home and community care: a systematic review

Tania Lognon ^{1,2} Karine V Plourde ² Emmanuelle Aubin,³
Anik M C Giguere ^{2,4,5} Patrick M Archambault ^{2,5,6,7} Dawn Stacey ^{8,9}
France Légaré ^{2,5}

To cite: Lognon T, Plourde KV, Aubin E, *et al.* Decision aids for home and community care: a systematic review. *BMJ Open* 2022;**12**:e061215. doi:10.1136/bmjopen-2022-061215

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-061215>).

Received 25 January 2022
Accepted 17 July 2022

ABSTRACT

Objectives Decision aids (DAs) for clients in home and community care can support shared decision-making (SDM) with patients, healthcare teams and informal caregivers. We aimed to identify DAs developed for home and community care, verify their adherence to international DA criteria and explore the involvement of interprofessional teams in their development and use.

Design Systematic review reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Data sources Six electronic bibliographic databases (MEDLINE, Embase, CINAHL Plus, Web of Science, PsycINFO and the Cochrane Library) from inception to November 2019, social media and grey literature websites up to January 2021.

Eligibility criteria DAs designed for home and community care settings or including home care or community services as options.

Data extraction and synthesis Two reviewers independently reviewed citations. Analysis consisted of a narrative synthesis of outcomes and a thematic analysis. DAs were appraised using the International Patient Decision Aid Standards (IPDAS). We collected information on the involvement of interprofessional teams, including nurses, in their development and use.

Results After reviewing 10 337 database citations and 924 grey literature citations, we extracted characteristics of 33 included DAs. DAs addressed a variety of decision points. Nearly half (42%) were relevant to older adults. Several DAs did not meet IPDAS criteria. Involvement of nurses and interprofessional teams in the development and use of DAs was minimal (33.3% of DAs).

Conclusion DAs concerned a variety of decisions, especially those related to older people. This reflects the complexity of decisions and need for better support in this sector. There is little evidence about the involvement of interprofessional teams in the development and use of DAs in home and community care settings. An interprofessional approach to designing DAs for home care could facilitate SDM with people being cared for by teams.

PROSPERO registration number CRD42020169450.

BACKGROUND

Home and community care affords assistance for people with various health conditions to live as independently as possible in their home and community.¹ Home-based

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first systematic review focusing on decision aids (DAs) for use in home and community care.
- ⇒ All DAs presented are free and publicly available. These DAs are accessible to all, including low-income users.
- ⇒ The definition of home and community care varies by country and health system, and therefore our keyword search may have missed some relevant tools.

services mobilise diverse health professionals, including doctors, nurses, occupational therapists, physiotherapists, social workers, dietitians and non-regulated home care workers, to form an interprofessional care team.^{2,3} An interprofessional approach is when health professionals (two or more) from different disciplines collaborate to provide integrated and cohesive care for their clients.⁴

Clients in home and community care face difficult decisions such as whether to move, or about advance care directives. They frequently need support with making such decisions. In shared decision-making (SDM), health providers collaborate with patients to consider the best available evidence regarding the risks and benefits of available options and help them make explicit their values and preferences regarding the options.^{5,6} An interprofessional SDM approach is particularly appropriate for home care, where care may be provided by healthcare teams as well as caregivers.^{5,6} It is a collaborative process that involves the patient, their caregivers (family, friends) and interprofessional teams working together to support clients' decisions with respect for their choices, preferences, priorities and goals.⁷

Decision aids (DAs) are decision support tools that facilitate SDM with patients.^{8,9} They present information about the options, their benefits and risks, and the associated probabilities based on recent scientific evidence. They also help patients clarify their values



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Dr France Légaré;
france.legare@mfa.ulaval.ca

regarding the outcomes of options.¹⁰ DAs increase patients' knowledge, active participation in decision-making process and accuracy of risk perceptions.⁹ In the context of home care, DAs should be part of the support offered by care teams and relatives for clients making decisions. A DA developed and used by an interprofessional team could promote better coordination and continuity of care, better consistency of information, strengthen the therapeutic relationship and improve intrateam communication.¹¹ One study indicated healthcare providers in home care had a positive intention to engage in the interprofessional SDM process and that DAs should support its implementation.⁷

DAs usually aim to facilitate clinician–patient dialogue, that is, they assume a dyadic patient–health professional relationship. In home and community care, nurses are often the patient's first contact with the healthcare system. Patients have identified nurses as the health professional who explains information and medical concepts, listens to their preferences and mediates between themselves and the doctor.¹² Nurses provide physicians with information about patient preferences and play a large part in the SDM process. Nurses are thus one of the key players in use of the DA with the client.^{13 14}

In a systematic literature review, Stacey *et al.*⁹ assessed the effects of DAs in people facing treatment or screening decisions.⁹ However, their systematic review included only published randomised controlled trials (RCTs) comparing DAs to usual care. As most studies on home and community care are not RCTs, relevant studies may have been excluded. Another systematic review evaluated the efficacy of DAs for older adults facing treatment, screening or care decisions,¹⁵ but used similar study design criteria as Stacey *et al.*⁹ A more recent systematic review evaluated the effectiveness of DAs developed using the Ottawa Decision Support Framework,¹⁶ but none related to home and community care.

We therefore aimed to (1) identify publicly available DAs that could help patients, caregivers and interprofessional teams to share decision-making in the context of home and community healthcare, (2) report on DA characteristics (eg, decision point, targeted users, mention of nurses and healthcare teams), (3) assess the DA's adherence to the International Patient Decision Aid Standards (IPDAS), and (4) explore whether the DA had been developed (ie, designed or evaluated) by, or for use by, more than one professional, that is, the nature of any interprofessional involvement.

METHODS

Design

Systematic review.

Patient and public involvement

Our review team included a caregiver with experience of home care with her elderly parents. She was an equal partner on the research team, participating in the study design and choice of outcome measures during focus group sessions, giving feedback on results and coauthoring this review. Through these iterative processes, the caregiver partner has made valuable contributions by sharing her experience as a caregiver or user of DAs. Moreover, some authors had relatives or close friends who received home and community care or faced a health decision related to this sector.

Eligibility criteria

We considered all RCTs and all types of uncontrolled trials (except knowledge syntheses studies such as rapid reviews or environmental scans) on developing, citing, using or assessing DAs. The PICO strategy guided our DA eligibility criteria:

Participants

Any person, organisation or system involved in delivering or receiving home or community care, that is, care at home rather than in a hospital or long-term care facility; who used a community service to maintain independence at home; and who had assessed whether he/she could stay or return to her home with the support of caregivers, care teams and the community.

Interventions

DAs developed for home and community care settings or that included home care or community services as options. We included DAs designed to be used with or by patients and caregivers to help prepare them for SDM. We considered a DA as an intervention that met the six minimum qualification criteria of the IPDAS: (1) describes the health condition or problem for which an index decision is required; (2) states explicitly the decision that needs to be considered; (3) describes the options available for the index decision; (4) describes the positive features (benefits, advantages) of each option; (5) describes the negative features (harms, side effects or disadvantages) of each option; (6) describes what it is like to experience the consequences of the options (physical, psychological, social).¹⁷ As our research was oriented towards SDM, we excluded DAs focusing on decisions about lifestyle changes, DAs used only by health professionals, guidelines for clinicians, algorithms, training programmes and programmes that promoted a specific choice. As we were interested only in tools used by health professionals and patients together, we excluded professional DAs, clinical guidelines, lifestyle change tools and algorithms. DAs promoting a specific choice were excluded because they contravene SDM principles.

Comparators

A control group was not needed for our study.

Outcomes

We included all primary or secondary outcomes and any type of study design.

Data sources and search strategy

Literature search

An information specialist from our team developed an Ovid-MEDLINE and Web of Science strategy with input from project team members, who then revised it iteratively. Research keywords included 'Decision Aid' and 'Home and Community Care'. Once approved, the information specialist translated the search strategy into MEDLINE (via Ovid), Embase (via Elsevier), CINAHL Plus (via EBSCOhost), Web of Science, PsycINFO (via Ovid) and the Cochrane Library from inception to 8 November 2019 (online supplemental material 1). There were no restrictions on language, study design or date of publication.

Other sources

We conducted further searches in: (1) the most recent Cochrane review on 'Decision aids for people facing health treatment or screening decisions'⁹; (2) the Decision Aids Library Inventory of the Ottawa Patient Decision Aids Research Group at the Ottawa Hospital Research Institute until November 2020; (3) websites of organisations involved in DA creation such as EBSCO Health Option Grid Decision Aids, National Institute for Health and Care Excellence, Peace Health, Healthwise, Laval University's Decision Boxes (January 2021); (4) experts in our SDM research network (eg, International Shared Decision Making Facebook group), and LEGACy (scaling up shared decision making for patient-centred care) newsletters from November 2020. In addition, if a DA was not available, we emailed its author (up to twice) to ask for access to a copy of the content. If a financial contribution was necessary, we did not pursue it. Evidence shows that low income is associated with low patient involvement in decision-making.¹⁸

This strategy ensured that we captured as many tools as possible before they were published in peer-reviewed articles and identified the most recent tools directly from the tool designers.

Study selection

Studies found were imported into EndNote V.X9 and Covidence software was used to review them. First, two reviewers (TL, KVP) independently assessed each study title and abstract for mention of DA and home and community care. Articles with abstracts that did not appear to meet the exclusion criteria or were ambiguous were retained and reviewed as full text. We excluded knowledge syntheses (eg, systematic reviews, rapid reviews, environmental scans), conference summaries, editorials, letters to the editor, commentaries, opinion pieces and duplicates. Articles that were not available electronically were ordered via interlibrary loan, or the

corresponding author was contacted if an email was available. Publications not available in full text were excluded. The remaining studies were assessed for eligibility through full-text examination. For studies assessed as unclear, or if reviewers disagreed, reviewers discussed the studies and, if necessary, consulted a third reviewer for a resolution.

DA selection

All DAs identified in all sources were screened independently and in duplicate assessment by the reviewer team (TL, KVP). Any language (eg, French, English, Japanese) and format (eg, paper, video, web based, application) were eligible. If DAs were not available, a copy was requested from the developers by email. If developers did not provide the information necessary for evaluating a DA, we excluded it. For each step (study selection and DA selection), we performed multiple pilots and teaching rounds until we reached at least 75% agreement before moving to the next phase.

Data extraction and synthesis

We used a data extraction grid developed by our team (available from the authors), and two reviewers independently extracted the characteristics of each DA that qualified as a DA according to IPDAS. The following characteristics were extracted from the DA: title, author, year of development or update, country, language, format, involvement of clients and healthcare professionals in its conception, decision point, options, target audience (client, caregiver, age, sex and gender), target users (healthcare professionals or care teams), accessibility for clients (free or paid), presence of a space for clients to indicate what they perceived as the advantages of each option, mention if a follow-up was requested for next steps, display of legal notice, use of design (graphic, table, drawing, picture, organigram, algorithm, none) and educational components (glossary, manual, scheme, explanation of abbreviations, tutorials, links, flow chart, none). In a further analysis, we extracted study author, publication year, mention of one more health professional and the nature of the involvement of the teams of healthcare professionals in the DA, that is, in its development (design or evaluation), use or both. We analysed the data using simple frequency counts and a narrative approach.

Assessment instrument

Two independent reviewers analysed whether the DAs met the six qualifying IPDAS criteria and excluded those that did not from further analyses. For the included DAs, we evaluated whether they met the IPDAS certification criteria for minimising risk of bias.¹⁷ The certification criteria include balanced presentation of options, a clear evidence synthesis process (citations, date of publications, update policy, information about the levels of uncertainty around event or outcome probabilities), the

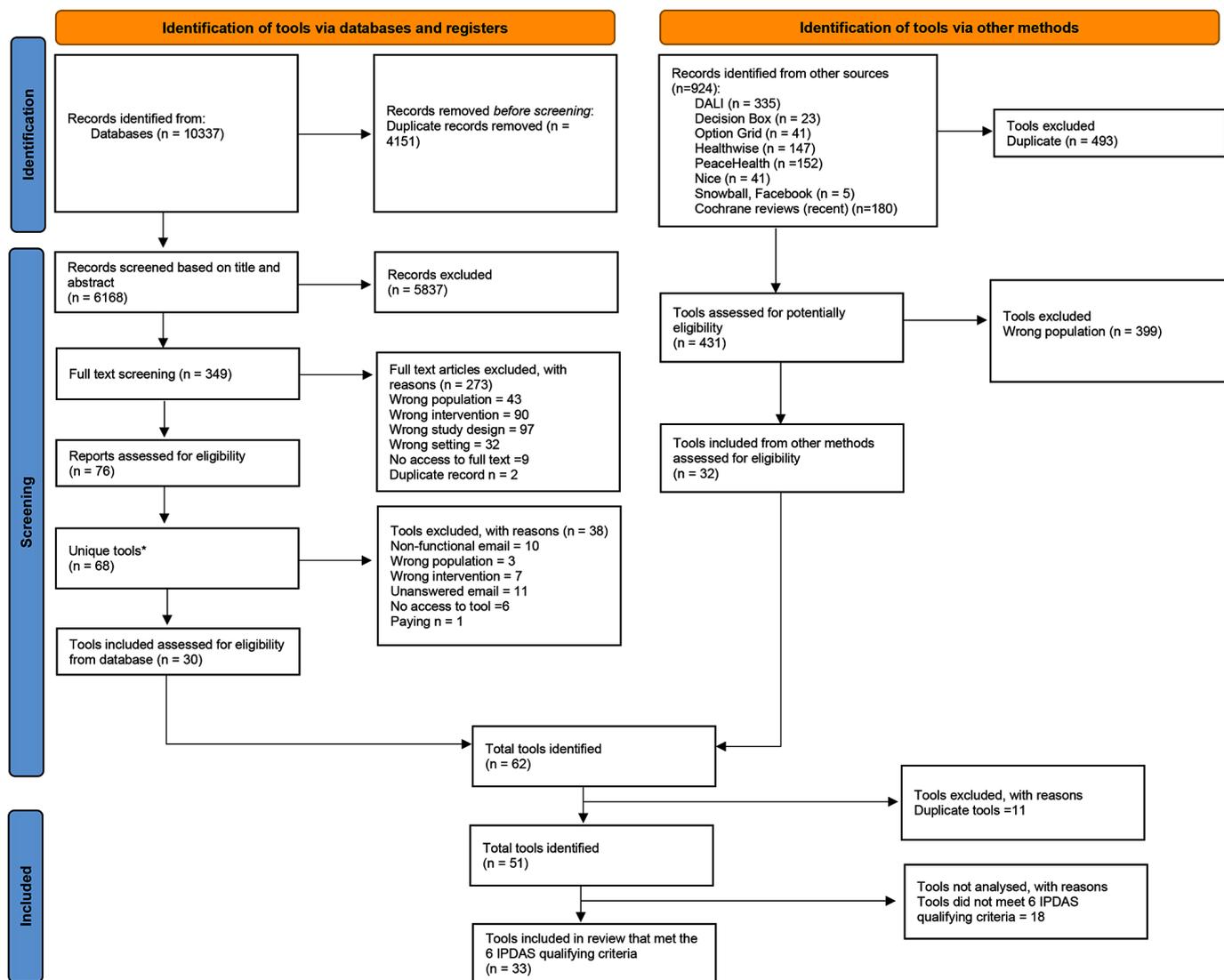


Figure 1 PRISMA flow diagram for systematic review. *Some tools were mentioned in more than one study, and some studies presented several tools in the same article. DA, decision aid; DALI, Decision Aids Library Inventory; IPDAS, International Patient Decision Aid Standards; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

funding source and four additional items related to DAs for screening or tests.¹⁷ We also analysed to what extent DAs excluded for not meeting qualifying criteria had nevertheless met certification criteria for minimising risk of bias. A DA with a higher score on IPDAS criteria suggested it met international standards but did not necessarily indicate high quality.

We reported our systematic review in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (online supplemental material 2).¹⁹

RESULTS

Figure 1 illustrates the PRISMA flow chart of this systematic review. Out of a total of 51 unique potentially eligible DAs, 33 met the six minimum qualifying IPDAS criteria and were included in the systematic review.

Characteristics of DAs

Table 1 and online supplemental table S1 depict the characteristics of the 33 DAs. The DAs included were developed between 2001 and 2020 in the USA (n=11; 33.3%), in Quebec, Canada (n=9; 27.3%), Canada (outside Quebec) (n=5; 15.2%), Australia (n=4; 12.1%), UK (n=2; 6.1%), Denmark (n=1; 3%) and Spain (n=1; 3%). Seventeen (51.5%) DAs are available in English, 5 (15.2%) in French, 7 (21.2%) in English and French and 4 (12.1%) in other languages (Spanish, Japanese, Taiwanese, Chinese, Greek and Italian). All DAs were accessible on the internet without requiring user registration. DAs were available in diverse formats: web (n=2; 6.1%), paper or PDF format (n=14; 42.4%), iPad application (n=1; 3%) and many other formats (n=16; 48.5%).

Regarding the decision points addressed by the DA, 8 were about choosing dialysis (eg, receiving it at home or elsewhere), 8 were about housing options (eg, stay at

Table 1 Characteristics of 33 included DAs

Characteristic of DA	n (%)	ID
Care setting		
Home care	31 (93.9)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 20, 22 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33
Community care	26 (78.8)	1,3, 4, 5, 6, 7, 8, 9, 11, 12, 13, 14, 15, 16,17, 18, 19,20, 21, 22, 23, 24, 25, 29, 32, 33
Clinical care	27 (81.8)	1, 3, 4, 5, 6, 7, 8, 9, 10, 11, 14, 15, 16, 17, 18, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33
DA addressed to older people	14 (42.4)	1, 2, 9, 10, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21
DA designed for caregiver friends or relatives	9 (27.3)	3, 4, 8, 10, 11, 16, 17, 18, 25
Legal notice	6 (18.2)	1, 2, 10, 11, 18, 25
Client involvement in DA design	19 (57.6)*	3, 6, 7, 9, 13, 14, 15, 16, 17, 18, 19, 20, 22, 24, 25, 26, 27, 28, 30
Personalisation		
A follow-up was requested for user with healthcare professional after consultation	32 (97)	All except 23
Space for users to indicate their own perceptions of pros and cons of options	19 (57.6)	1, 2, 3, 4, 5, 6, 7, 19, 21, 22, 24, 25, 26, 27, 28, 29, 31, 32, 33
Healthcare professionals mentioned in DA		
Nurses (eg, registered, community nurse, nurse practitioner)	10 (30.3)	1, 2, 4, 8, 10, 11, 19, 25, 26, 27
Doctors (eg, generalist or specialist)	18 (54.5)	1, 2, 3,4, 5, 6, 7, 8, 9, 11, 19, 24, 25, 26, 27, 31, 32, 33
Physiotherapists	1 (3)	24
Social workers	3 (9)	25, 26, 27
Healthcare professional or healthcare team	16 (48.5)	4, 10, 11, 12, 13, 14, 15, 18, 19, 20, 26, 27, 28, 31, 32, 33
Design		
Graphic	2 (6.1)	10, 19
Table	31 (93.9)	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33
Drawing	25 (75.8)	1, 2, 3, 6, 7, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 22, 24, 26, 27, 28, 29, 31, 33
Picture	10 (30.3)	3, 6, 11, 19, 22, 24, 28, 29, 30, 33,
Organisational chart	2 (6.1)	27, 28
Algorithm	0	
Educational component in DA		
Glossary	8 (2.2)	6, 13, 14, 17, 18, 27, 28
Manual	2 (6.1)	3, 10
Schema	0	
Abbreviation explanation	3 (9.1)	3, 6, 27
Tutorial	3 (9.1)	6, 19, 30
Presence of link	19 (57.6)	1, 2, 9, 12, 13, 14, 15, 16, 17, 18, 19, 20, 24, 26, 27, 28, 30, 32, 33

*Information on this decision aid is based on information from the publication studies and/or the decision aid.

DA, decision aid; ID, decision aid identification number.

home or move into long-term care), 3 were about older adults and driving (eg, keep driving or stop driving to use a community car service), 4 were about management of health conditions (eg, options for depression management in an Indigenous community, a group communication programme in community care for patients with a hearing problem), 7 were about improving quality of life

for older adults with memory problems and 3 were about feeding options for patients with dementia and malnutrition among older adults. Most decision-making points were about the health of an older adult (online supplemental table S1). None of the DAs found were about screening and tests.

The healthcare settings for which DAs were designed were home care (n=31; 93.9%), community care (n=26; 78.8%) and clinical care (n=27; 81.8%). Most could be used in all three. None mentioned the sex or gender of the user. All DAs focused on patients and their relatives. Nine were for use by caregivers, either of older adults with dementia or Alzheimer's (n=8) or of minor children (n=1). These DAs were for use by caregivers with patients unable to make decisions (eg, minor patient), or else related to caregiver health (eg, options to limit their stress). Six (18.2%) contained a legal mention. Five of these six DAs were aimed at caregivers, legal substitute decision makers or families of an older adult, and one was designed for parents of minor children.

All DAs were to be used with healthcare professionals and 10 specified nurses. The terms most used were 'doctors', 'healthcare teams' and 'health professionals'.

In 32 (97%) DAs, a follow-up with the healthcare professional was suggested after the consultation. As regards personalisation, 19 (57.6%) DAs offered users a blank space for indicating the advantages/disadvantages for each option.

In terms of visual features, most DAs included tables (n=31; 93.9%) or drawings (n=25; 75.8%) (table 1). There were very few other graphics (n=2; 6.1%) or charts (n=2; 6.1%), and no algorithms. As for educational components, 19 (57.6%) DAs included links to more information, 8 (2.2%) provided a glossary, 3 (9.1%) included a tutorial and 3 (9.1%) explained abbreviations or provided a manual. In 19 (57.6%) DAs, clients (patients or caregivers) were involved in designing the tool.

IPDAS criteria results

Table 2 describes the compliance with IPDAS criteria for each DA included. None of the DAs applied to screening or tests; therefore, the four certification criteria for this category were excluded. The two lowest rated DAs satisfied seven of the 12 remaining IPDAS criteria (six qualifying and six certification), that is, 58.3% of all items. Eleven (33.3%) DAs met 100% of all 12 IPDAS criteria. Eighteen tools were excluded from the 51 tools (figure 1) because they did not meet the six qualifying IPDAS criteria (for details of their evaluations see online supplemental material 3). The criterion of describing the negative features of the options was missing in all excluded tools, and four were generic DAs (with space to fill in for the decision point, the options and the evidence) that can be adapted to any type of decision.

Interprofessional team results

Outcomes evaluated included the presence of an interprofessional team (ie, more than one professional) in the development (ie, design and evaluation) or use of the DA (online supplemental table S2).^{20–35} In eight studies reporting on 11 DAs, an interprofessional team had designed the DAs, that is, various health professionals, researchers and/or clients (patients and caregivers) had been asked for their opinion on the DA topic and/

or involved in designing the tool. No studies indicated whether there was collaboration among health professionals in the home or community care setting. No DA mentioned interprofessional SDM. No DA provided for collaboration between different health professionals (eg, a space where different team members, including the patient and caregiver, could take notes relating to the client). One study reported qualitatively on the prospect of using the DA in a community nursing practice.²¹ Nurses appreciated the DA as additional information for them and for the caregiver. Community nurses saw DAs as an additional aid in their work during their home visits.

DISCUSSION

We found 33 DAs that could support SDM in the context of home and community care. The number of DAs in the home and community care sector is increasing rapidly, and DAs were produced by six countries, mostly in North America. DAs varied in terms of the decision point, and nearly half focused on the health of older adults. None of the DAs related to screening or tests. Several DAs were non-compliant with the IPDAS criterion on information about the levels of uncertainty around the event. Few DAs involved interprofessional teams and nurses in their development (design or evaluation). Our results lead us to make four main observations.

First, more than a third of the DAs were produced in the last 5 years and mostly in North America (USA and Canada) in the languages understood by the majority of their populations (English, French and Spanish). Home care has grown tremendously in the Americas (USA and Canada) due to increasing population age.^{36 37} Countries such as Australia, Japan and UK are also faced with an increase in the older population in recent years.³⁸ Ageing populations have specific health needs and require local and regular care, hence the rise of home care and the consequent need for decision support for people ageing at home. In Canada, a survey found that older adults receiving home and community care have experienced little SDM, with Quebec reporting the least experience of SDM in the whole country.³⁹ Yet, our results showed that in Canada, over the past few years, many DAs (n=12) have been developed to respond to the needs of older adults in home care. This suggests that perhaps the DAs are underused. The diversity of DA formats available (many are paper based) means they can be used by people without internet access, lack of familiarity with computers or telephone or living in remote areas. The diversity of formats could help reduce barriers to implementation to SDM.

Second, the DAs were designed for diverse decision points. This shows the broad range of services offered in home and community care, and the kinds of decisions that go with them. Whether the DA was for choosing a type of dialysis, the safest housing, or whether to resort to tube feeding, the users were receiving their care in their own homes or from community services. However, DAs

Table 2 Evaluation of DA according to 12 IPDAS criteria

DA		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33			
Qualifying criteria: criteria to be defined as decision aid	Describes the condition	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	States the decision	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Describes options	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Positive features	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Negative features	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Describes what it is like	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
Certification criteria: criteria to lower the risk making a biased decision*	Equal details	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Provides citations	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Publication date	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	Update policy																																				
	Levels of uncertainty																																				
	Funding source	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
	IPDAS score																																				
	Qualifying criteria, n out of 6	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	
	Certification criteria, n out of 6	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	

*Qualifying criteria were also inclusion criteria for these studies. See online supplemental material 3 for details of IPDAS evaluations of the 18 tools that did not meet the six qualifying criteria. DA, decision aid; ID, decision aid identification number; IPDAS, International Patient Decision Aid Standards.



did not represent all home care, such as home births, postpartum care at home or care given by social workers. More than a third were intended for older adults. Further studies on the home and community care sector could subclassify populations receiving home care. Another way to tackle the heterogeneity of decision points in this sector would be to use generic DAs. We identified four generic DAs that could be adapted to any type of health-related or social decision (online supplemental material 3). Generic DAs such as the Ottawa Personal Decision Guide have served as models for the development of several DAs in the context of home and community care.⁴⁰ The Ottawa Personal Decision Guide has also been adapted to support decision-making by Indigenous women,⁴¹ and may be effective in meeting the decision-making needs of other vulnerable populations.

Third, although many DAs did not respect the IPDAS criterion on information about the levels of uncertainty around the event or outcome probabilities, this criterion depends on the existence of evidence on the options which may not have been available at the time of development.

Finally, few DAs were developed with the involvement of interprofessional teams, and how they could be used by interprofessional teams was not clear. Yet, in most cases, home care and community care involve an interprofessional team. Furthermore, although nurses are among the largest providers of home care services,⁴² they were rarely referred to. The literature has shown it is possible to implement interprofessional SDM in home care and that it benefits patients and the health system alike.³ However, our results show there are few DAs that support interprofessional SDM. A DA for home and community care could be an interactive 'living document' that reflects an interprofessional approach by allowing sequential (as opposed to synchronous) interprofessional collaboration. An interprofessional collaborative DA could contain sections where the various team members, including the patient and caregiver, could take notes. Before a consultation, clients could consult the DA and identify questions they want to ask the care team. During consultation, the nurse or geriatrician could use the DA with the older adult and the family, answer their questions, give them personalised advice and leave notes in the DA for the client, caregivers and other professionals (eg, social workers, dietitians) to consult later. After each encounter, information (such as about the client's values and preferences) could be added to the DA and transferred to the next healthcare professional the client sees. Thus, the DA would promote the exchange of essential patient-centred information and knowledge between healthcare professionals. Such an approach would not increase professional workloads but could help transcend the limited purview of each profession, improve interprofessional relations and orient everyone involved towards the common goal of supporting and engaging patients in decision-making.³ As an example, there is a DA for life-sustaining interventions (eg, cardiopulmonary resuscitation) using a wiki

platform allowing several collaborators to edit, update and complete the DA online.⁴³ This collaborative DA can be individually tailored to a patient's risk factors and used a technology favouring interprofessional teamwork.

Our review has some limitations. We did not pay for access to two commercial DAs that we identified, as we only included those that were free and publicly available. Compared with the 26 tools to which we did not have access (either the authors' email was non-functional or no response from the authors), the two commercial DAs captured but not analysed represent a low risk of bias for our study. Also, the definition of home and community care varies by country and health system, and therefore our keyword search may have missed some relevant tools. We opted for these generic terms rather than including certain decision conditions typical of home and community care, as in some medical systems in other countries these conditions may not be cared for home and community care settings. Furthermore, many producers of the DAs did not publish data about their development process or the impact of their DA, and some may have involved interprofessional teams or clients without reporting on it. Few studies reported whether their DA met the IPDAS criteria on their websites or platforms, information that could be used to improve the standardisation of patient decision tools.

Our findings have important implications for future research and clinical practice. First, they highlight the need for a standardised method to produce and publish DAs for home and community care that enable us to measure and compare the impacts and effectiveness of these tools in practice. Second, while our study found many DAs for older people and caregivers in home care, in order to be implemented these may need to be more personalised and 'dynamic' to match the reality of each user. There was little robust evidence on effectiveness and involvement of professional teams in the use of DAs for home care. Further research should test their usefulness in clinical practice and especially in interprofessional teams, as well as design implementation strategies. Third, our results confirm other studies showing that it is necessary to encourage the practice of SDM in African and other low-income countries, where few SDM tools are available,^{44 45} in order to reduce global inequities in patient-centred care.

CONCLUSION

Our study found that in fact there were far more DAs for home and community care than we expected, because we searched beyond purely quantitative sources. This indicates a need to look beyond the peer-review literature to find tools relevant to this context. More quantitative research should be done to evaluate existing DAs, whether produced in research or by developers to the mutual benefit of both. There is a clearly need for tools that can help clients in this sector, especially older people facing various types of health decision. However, not all

DAs meet international standards for DAs, not enough of them have been designed or evaluated by the interprofessional teams that care for people receiving home and community care and none were documented as being designed for use by all members of the interprofessional team. Integrating an interprofessional approach into the design of DAs for home care could improve decision-making for people receiving these services, interprofessional relations as well as team-patient communication for the benefit of patients and their families.

Author affiliations

- ¹Department of Social and Preventive Medicine, Faculty of Medicine, Université Laval, Quebec, Quebec, Canada
²VITAM—Centre de recherche en santé durable, Centre intégré universitaire de santé et services sociaux de la Capitale-Nationale, Quebec, Quebec, Canada
³Canada Research Chair in Shared Decision Making and Knowledge Translation, Patient-partner, Quebec, Quebec, Canada
⁴Quebec Centre for Excellence on Aging, Quebec, Quebec, Canada
⁵Department of Family Medicine and Emergency Medicine, Faculty of Medicine, Université Laval, Quebec, Quebec, Canada
⁶Centre intégré de santé et de services sociaux de Chaudière-Appalaches, Lévis, Quebec, Canada
⁷Department of Anesthesiology and Intensive Care, Faculty of Medicine, Université Laval, Quebec, Quebec, Canada
⁸School of Nursing, University of Ottawa, Ottawa, Ontario, Canada
⁹Clinical Epidemiology Program, Ottawa Hospital Research Institute, Patient Decision Aids Research Group, Ottawa, Ontario, Canada

Twitter Anik M C Giguere @AnikGiguere, Patrick M Archambault @patarchambault and France Légaré @SDM_ULAVL

Acknowledgements The authors express their gratitude to Nathalie Rheault, our team's library information specialist, for her contribution to designing the search strategy and to retrieving data. We are grateful to Hervé Tchala Vignon Zomahoun, Ali Ben Charif, Amédée Gogovor, Rosana Carvalho Silva, Mayara Costa Mansur Tavares, Philippe Russenger-Tran, Ella Diendere, Sébastien Drouin and Coralie Assy for supporting the selection process. We thank Maya Fakhfakh and Lucas Gomes in data collection for their contributions. We thank Louisa Blair for her editorial assistance.

Contributors Primary supervision : FL. Study concept and design: TL, KVP, EA, AMCG, PMA, DS and FL. Data collection: TL and KVP. Data analysis: TL, KVP, EA, AMCG, PMA, DS and FL. Manuscript writing: TL, KVP, EA, AMCG, PMA, DS and FL. First version of the manuscript : TL. Decision to submit the manuscript for publication: TL, KVP, EA, AMCG, PMA, DS and FL. All authors reviewed the study findings, and read and approved the final version before submission.

Funding Financial support for this study was provided entirely by a Foundation Grant (FDN-159937) from the Canadian Institutes of Health Research (CIHR).

Disclaimer The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing and publishing the report. FL holds a Tier 1 Canada Research Chair in Shared Decision Making and Knowledge.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines,

terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Tania Lognon <http://orcid.org/0000-0001-9045-2817>
 Karine V Plourde <http://orcid.org/0000-0001-8628-3950>
 Anik M C Giguere <http://orcid.org/0000-0001-9928-7395>
 Patrick M Archambault <http://orcid.org/0000-0002-5090-6439>
 Dawn Stacey <http://orcid.org/0000-0002-2681-741X>
 France Légaré <http://orcid.org/0000-0002-2296-6696>

REFERENCES

- Government of Canada. *Home and community health care*. . . Government of Canada, 2016: 2016. 04–13.
- Fraser KD, Strang V. Decision-Making and nurse case management: a philosophical perspective. *ANS Adv Nurs Sci* 2004;27:32–43.
- Légaré F, Stacey D, Pouliot S, et al. Interprofessionalism and shared decision-making in primary care: a stepwise approach towards a new model. *J Interprof Care* 2011;25:18–25.
- D'Amour D, Ferrada-Videla M, San Martín Rodríguez L, et al. The conceptual basis for interprofessional collaboration: core concepts and theoretical frameworks. *J Interprof Care* 2005;19 Suppl 1:116–31.
- Légaré F, Stacey D, Brière N, et al. An interprofessional approach to shared decision making: an exploratory case study with family caregivers of one IP home care team. *BMC Geriatr* 2014;14:83.
- Garvelink MM, Emond J, Menear M, et al. Development of a decision guide to support the elderly in decision making about location of care: an iterative, user-centered design. *Res Involv Engagem* 2016;2:26.
- Légaré F, Stacey D, Brière N, et al. Healthcare providers' intentions to engage in an interprofessional approach to shared decision-making in home care programs: a mixed methods study. *J Interprof Care* 2013;27:214–22.
- O'Connor AM, Wennberg JE, Legare F, et al. Toward the 'tipping point': decision aids and informed patient choice. *Health Aff* 2007;26:716–25.
- Stacey D, Légaré F, Lewis K, et al. Decision AIDS for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:CD001431.
- Stacey D, Legare F, Col NF. Decision AIDS for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2014;1:CD001431.
- Yu CH, Ke C, Jovicic A, et al. Beyond pros and cons - developing a patient decision aid to cultivate dialog to build relationships: insights from a qualitative study and decision aid development. *BMC Med Inform Decis Mak* 2019;19:186.
- Joseph-Williams N, Elwyn G, Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014;94:291–309.
- Stacey D, Pomey M-P, O'Connor AM, et al. Adoption and sustainability of decision support for patients facing health decisions: an implementation case study in nursing. *Implement Sci* 2006;1:17.
- Scholl I, LaRussa A, Hahlweg P, et al. Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review. *Implement Sci* 2018;13:40.
- van Weert JCM, van Munster BC, Sanders R, et al. Decision AIDS to help older people make health decisions: a systematic review and meta-analysis. *BMC Med Inform Decis Mak* 2016;16:45.
- Hoefel L, Lewis KB, O'Connor A, et al. 20Th anniversary update of the Ottawa decision support framework: Part 2 subanalysis of a systematic review of patient decision AIDS. *Med Decis Making* 2020;40:522–39.
- Joseph-Williams N, Newcombe R, Politi M, et al. Toward minimum standards for certifying patient decision AIDS: a modified Delphi consensus process. *Med Decis Making* 2014;34:699–710.



- 18 Durand M-A, Carpenter L, Dolan H, *et al.* Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PLoS One* 2014;9:e94670.
- 19 Page MJ, McKenzie JE, Bossuyt PM, *et al.* The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71.
- 20 Stirling C, Leggett S, Lloyd B, *et al.* Decision AIDS for respite service choices by carers of people with dementia: development and pilot RCT. *BMC Med Inform Decis Mak* 2012;12:21.
- 21 Stirling C, Lloyd B, Scott J, *et al.* A qualitative study of professional and client perspectives on information flows and decision aid use. *BMC Med Inform Decis Mak* 2012;12:26.
- 22 Green MJ, Van Scoy LJ, Foy AJ, *et al.* A randomized controlled trial of strategies to improve family members' preparedness for surrogate decision-making. *Am J Hosp Palliat Care* 2018;35:866–74.
- 23 Dales RE, O'Connor A, Hebert P, *et al.* Intubation and mechanical ventilation for COPD: development of an instrument to elicit patient preferences. *Chest* 1999;116:792–800.
- 24 Kuraoka Y, Nakayama K. Factors influencing decision regret regarding placement of a PEG among substitute decision-makers of older persons in Japan: a prospective study. *BMC Geriatr* 2017;17:134.
- 25 Snyder EA, Caprio AJ, Wessell K, *et al.* Impact of a decision aid on surrogate decision-makers' perceptions of feeding options for patients with dementia. *J Am Med Dir Assoc* 2013;14:114–8.
- 26 Hanson LC. Tube feeding versus assisted oral feeding for persons with dementia: using evidence to support decision-making. *Ann Longterm Care* 2013;21:36–9.
- 27 Bilodeau G, Witteman H, Légaré F, *et al.* Reducing complexity of patient decision AIDS for community-based older adults with dementia and their caregivers: multiple case study of decision boxes. *BMJ Open* 2019;9:e027727.
- 28 Avey JP, Dirks LG, Dillard DA, *et al.* Depression management interests among Alaska native and American Indian adults in primary care. *J Affect Disord* 2018;239:214–9.
- 29 Dirks LG, Avey JP, Hiratsuka VY, *et al.* Disseminating the results of a depression management study in an urban Alaska native health care system. *Am Indian Alsk Native Ment Health Res* 2018;25:62–79.
- 30 Laplante-Lévesque A, Hickson L, Worrall L. Factors influencing rehabilitation decisions of adults with acquired hearing impairment. *Int J Audiol* 2010;49:497–507.
- 31 Patel S, Ngunjiri A, Hee SW, *et al.* Primum non nocere: shared informed decision making in low back pain—a pilot cluster randomised trial. *BMC Musculoskelet Disord* 2014;15:282.
- 32 Fortnum D, Grennan K, Smolonogov T. End-stage kidney disease patient evaluation of the Australian 'My Kidneys, My Choice' decision aid. *Clin Kidney J* 2015;8:469–75.
- 33 Morton RL, Howard K, Webster AC, *et al.* Patient information about options for treatment (Pinot): a prospective national study of information given to incident CKD stage 5 patients. *Nephrol Dial Transplant* 2011;26:1266–74.
- 34 Aguilera Flórez AI, Linares Fano B, Alonso Rojo AC. Análisis del impacto de Los valores personales en La elección del Tratamiento Sustitutivo renal. *Enfermería Nefrológica* 2017;20:209–14.
- 35 Schatell D. A Paradigm Shift in Options, Education, and an Online Decision Aid: 'My Life, My Dialysis Choice'. *Nephrol Nurs J* 2015;42:149.
- 36 Howes C. Home care. *New Labor Forum* 2015;24:98–105.
- 37 Spetz J, Stone RI, Chapman SA, *et al.* Home and community-based workforce for patients with serious illness requires support to meet growing needs. *Health Aff* 2019;38:902–9.
- 38 Population Reference Bureau. *2020 world population data sheet*, 2020. ISBN: 978-0-917136-14-6. <https://www.prb.org/collections/data-sheets/>
- 39 Haesebaert J, Adekpedjou R, Croteau J, *et al.* Shared decision-making experienced by Canadians facing health care decisions: a web-based survey. *CMAJ Open* 2019;7:E210–6.
- 40 Stacey D, Ludwig C, Archambault P, *et al.* Feasibility of rapidly developing and widely disseminating patient decision AIDS to respond to urgent decisional needs due to the COVID-19 pandemic. *Med Decis Making* 2021;41:233–9.
- 41 Jull J, Giles A, *et al.* Minwaashin Lodge, The Aboriginal Women's Support Centre. Cultural adaptation of a shared decision making tool with aboriginal women: a qualitative study. *BMC Med Inform Decis Mak* 2015;15:1.
- 42 Ganann R, Weeres A, Lam A, *et al.* Optimization of home care nurses in Canada: a scoping review. *Health Soc Care Community* 2019;27:e604–21.
- 43 Plaisance A, Witteman HO, LeBlanc A, *et al.* Development of a decision aid for cardiopulmonary resuscitation and invasive mechanical ventilation in the intensive care unit employing user-centered design and a wiki platform for rapid prototyping. *PLoS One* 2018;13:e0191844.
- 44 Diouf NT, Ben Charif A, Adisso L, *et al.* Shared decision making in West Africa: the forgotten area. *Z Evid Fortbild Qual Gesundhwes* 2017;123-124:7–11.
- 45 Härter M, Moumjid N, Cornuz J, *et al.* Shared decision making in 2017: international accomplishments in policy, research and implementation. *Z Evid Fortbild Qual Gesundhwes* 2017;123-124:1–5.