



## RESEARCH

# A Scoping Review of Evidence on the Use and Effectiveness of Decision Aids in Adult Social Care

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**Context:** Social care-related decisions can be complex but despite their widespread use in health care to help patients make similarly complex decisions, the use of decision aids in social care is not well examined.

**Objective:** To review the international research evidence on decision aids in adult social care and investigate the availability of such aids for planning later life care on adult social care-related websites in England.

**Methods:** Decision aid was defined broadly. Systematic searches for empirical research evidence published in English between 2000 and 2020. Searches were undertaken in January and February 2020. Websites of 11 UK social care-related voluntary and quasi-governmental organisations plus 53 English local councils searched for decision aids.

**Findings:** Five papers published between 2001 and 2019 reported the development of five different decision aids. Two decision aids were web-based; three were paper-based or of unspecified formats. Two were assessed against international criteria for decision aids. Three further papers reported evaluations of the effectiveness of two of these aids.

Most social care-related websites searched did not offer any relevant decision tools.

**Limitations:** Some papers described tools that were primarily research instruments. Relevant papers may have been missed due to technical challenges. Not all council websites were searched.

**Implications:** Future research to develop decision aids might benefit from drawing on earlier literature about people's attitudes to and readiness to engage with care planning and how this translates into willingness to use decision aids. Combining decision aids with strengths- and asset-based approaches in adult social care practice could be fruitful.

**Keywords:** care planning; decision aids; decision tools; later life care; scoping review; social care

## Background

In England, some people receive funding for all or part of their social care from their local area government (known as a local council) but many pay for their care from their own funds. These people are referred to as self-funders and are typically older people who have accumulated savings and assets over their working lives. The range of such assets can vary from relatively modest savings up to considerable wealth.

Making decisions about social care is a complex and emotional process for people of all ages, however it is paid for, but evidence suggests it is particularly difficult for older self-funders and their family carers who often face such decisions with little or no formal guidance or advice (Henwood and Hudson 2008; Putting People First Consortium et al. 2011; Baxter et al. 2017). A key challenge

is knowing where to start in thinking about care needs and arranging care, or who to talk to about it (Baxter et al. 2017). People who are eligible for funding from their local council are guided through the process by one or more professionals who assess care needs, suggest relevant care options and in many cases arrange for the delivery of that care and support from local providers. However, even with this professional support, the process can be confusing. Gathering information about different types of care and local care providers can help people understand the care system and build a picture of their options, but for members of the public who typically have little prior knowledge of social care, knowing where or how to find such information can be daunting (Baxter et al. 2017). Searches can also result in an overwhelming amount of information from which it is difficult to identify high-quality, relevant material. Financial issues are also known to be a major concern for self-funders (Baxter et al. 2017) but people can be reluctant to seek professional financial advice even though doing so can help them feel in control of their options for funding care (Baxter et al. 2018). Not understanding the potential benefits of financial advice

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and not knowing what to expect from a consultation are key barriers to seeking such advice (Heavey et al. 2019).

Professional, regulated financial advisers who specialise in later life care usually offer a short, general discussion about a self-funder's finances and care needs free of charge before either party commits to a longer-term, paid-for relationship. If self-funders or their carers were able to prepare better to have these conversations, they may be more inclined to engage and could also add value to such interactions by having more constructive conversations. One way in which individuals could prepare for such meetings whether financially or in terms of thinking through important criteria for care could be working through a decision aid, either independently or through a supported conversation.

The key aim of a decision aid is to improve the quality of a decision (see <http://ipdas.ohri.ca/what.html>). Decision aids are tools designed to support people's decisions by making them explicit, providing information on the options and any associated risks and benefits, and helping people clarify and so consider their personal values and preferences (BMJ 2013; Stacey et al. 2017). Decision aids can be used as 'self-help' tools worked through by an individual or in conjunction with a professional to facilitate shared decision making. They can be presented in various formats including web-based, video-based or on paper; there is evidence in relation to screening for prostate cancer that these different formats perform similarly in terms of decision quality (Baptista et al. 2018). Decision aids are used widely in health care to assist patients in making complex decisions about treatments and screening (Stacey et al. 2017; Wieringa et al. 2019). Evidence suggests they can increase people's knowledge and the accuracy of their perceptions of risk; decrease decisional conflict; and increase satisfaction with the decision, the decision-making process and/or preparation for making the decision (Stacey et al. 2017).

In 2003, the International Patient Decision Aid Standards (IPDAS) collaboration was founded to establish a shared evidence-based framework for enhancing the quality and effectiveness of patient decision aids. The resulting IPDAS criteria began as a 74-item checklist in 2006 and has since been adapted to create a minimum IPDAS criteria of 44 items (Joseph-Williams et al. 2014). Decision aids that meet the criteria are seen as reliable sources for assisting decision making. The minimum criteria are presented in three sections: six qualifying criteria that ensure the tool is in fact a decision aid; 10 certification criteria (including quality of the evidence synthesis process, disclosure of funding source, and a balanced presentation of options) and 28 quality criteria which improve the experience of using the decision aid, but would not adversely affect an individual's decision if not offered, for example, the provision of worksheets (Joseph-Williams et al. 2014).

Despite their widespread use in health care and the similarly complex decisions that people need to make in relation to social care, the use of decision aids in social care is not well examined. It seems reasonable that people needing social care might expect to find and benefit from resources to assist in their decision making, especially self-funders and their carers who do not routinely receive professional support. This paper therefore reviews the international

research evidence about decision aids in adult social care in order to identify relevance to and lessons for the English system. It also investigates the availability of such aids on adult social care-related websites in England.

## Methods

This rapid scoping review comprised a systematic review of research literature and search of English social care-related websites to identify evidence of the development and effectiveness of decision aids in adult social care. The stages of the review followed those described in Arksey and O'Malley (2005) and are described in detail below.

For the purposes of this review, the term 'decision aid' was defined broadly to ensure inclusion of as much relevant evidence as possible. It included any interactive tool that could be self-administered or completed with a professional, based in any format (e.g., web, video, telephone, or paper). In terms of content, decision aids of interest would aim to enable people to consider issues related to social care planning decisions and choices with regards to their current or future social care support needs. This includes (but is not limited to) the broad domains related to planning care needs, for example: personal care and household tasks, for example, when an older adult has activity of daily living (ADL) limitations; potential emotional, financial, or informational support and advice; advice on location and type of housing need or care residence and type of services or facilities offered at this residence.

## Review of research literature

### Search strategy

Search strategies were developed from terms for decision aids used in a Cochrane systematic review of decision aids for people making decisions about health treatment or screening (Stacey et al. 2017) and a systematic review of health-related decision aids (van Weert et al. 2016). These terms were combined with social care-related terms and tested initially in Social Policy and Practice to ensure they identified potentially relevant papers. The final search strategies were replicated with minor variations according to different terminology and search functions in each database. The search strategies are available on request from the corresponding author. Searches were conducted between 27th January and 4th February 2020.

The following databases were searched: ASSIA, Scopus, Social Services Abstracts, Social Policy and Practice and Social Care Online. All online databases were set to filter results by relevance.

Searches were restricted to English language publications since 2000. All study designs were included. **Table 1** gives the inclusion/exclusion criteria.

### Screening

Citations retrieved from Social Policy and Practice, Scopus and Social Care Online were managed within End-Note X10. For technical reasons, screening of references in other databases took place online and only included papers were downloaded.

Initial searches identified 26,382 references. After removal of duplicates and, due to further technical issues,

**Table 1:** Inclusion and exclusion criteria.

Criteria	Inclusion	Exclusion
Publication year	<ul style="list-style-type: none"> <li>• 2000 to 2020</li> </ul>	<ul style="list-style-type: none"> <li>• Published pre-2000</li> </ul>
Publication type	<ul style="list-style-type: none"> <li>• Peer reviewed journal papers</li> <li>• Grey literature, e.g., research reports from academic units</li> </ul>	<ul style="list-style-type: none"> <li>• Other grey literature e.g. theses and conference proceedings</li> </ul>
Type of article	<ul style="list-style-type: none"> <li>• Empirical research</li> <li>• Reviews of empirical research</li> </ul>	<ul style="list-style-type: none"> <li>• Policy papers or opinion pieces</li> <li>• Theoretical papers</li> </ul>
Location	<ul style="list-style-type: none"> <li>• Data from any country</li> </ul>	<ul style="list-style-type: none"> <li>• None</li> </ul>
Publication language	<ul style="list-style-type: none"> <li>• English</li> </ul>	<ul style="list-style-type: none"> <li>• Languages other than English</li> </ul>
Population group	<ul style="list-style-type: none"> <li>• People aged 18 or over</li> </ul>	<ul style="list-style-type: none"> <li>• Focus on children only</li> </ul>
Subject of evidence	<ul style="list-style-type: none"> <li>• Decision aids in adult social care/long-term care, including planning for and understanding finances, care needs, type, quality or location of care</li> </ul>	<ul style="list-style-type: none"> <li>• Decision aids with focus on:                             <ul style="list-style-type: none"> <li>- health care/services or medical conditions</li> <li>- housing/homelessness</li> <li>- welfare/benefit/employment schemes</li> <li>- 'big data'/system-level data</li> </ul> </li> <li>• Decision aids for predicting eligibility for care or reducing variation in professionals' decisions</li> </ul>

downloading of only the first 500 most relevant references from some databases to reference management software, 9,825 titles were screened for relevance by RM. One hundred fifty-nine were identified as related to decision aids/tools or decision making, and adult social care.

RM and KB assessed the titles and abstracts of these 159 papers for eligibility. Disagreements were resolved by consensus or adjudication by YB. Twenty-three papers were included at this stage. The full texts of these 23 papers were subsequently assessed for inclusion by RM and KB.

Three of these 23 papers met the inclusion criteria (Garvelink et al. 2016; Friedemann et al. 2004; Sorensen and Pinguart 2001). During full-text screening, it became apparent that the decision aid development work described by Garvelink et al. (2016) referred to a study protocol (Légaré et al. 2015) for a cluster randomised controlled trial (RCT) with the decision aid embedded within the trial. A search for papers about the RCT identified a fourth paper (not the RCT) that met the inclusion criteria (Garvelink et al. 2017).

Five papers that were excluded because they did not report empirical research (Alecxi and Blakeway 2012; Kane et al. 2007; Kohn 2004; Phillipson et al. 2019; Polniaszek and Klinger 2004) listed and described web-based resources aimed at helping people plan later life care. These included an interactive, self-administered decision aid called 'Long-Term Care Counselor' (LTCC) developed by the National Council on Ageing as part of the Centres for Medicare and Medicaid Services Long Term Care Initiative in the USA (Polniaszek and Klinger 2004; <https://longtermcare.acl.gov/>) and a decision aid developed by a US Minnesota State Board on Ageing (Kane et al. 2007) called the 'Long-Term Care Choices Navigator' (<https://longtermcarechoices.minnesotahelp.info/>.) The other three papers (Alecxi and Blakeway 2012; Kohn 2004; Phillipson et al. 2019) each summarised internet-based resources for planning later life care; gathering information about care facilities; and availability of care services.

An online search for a web-based decision tool described by Alecxi and Blakeway (2012) as 'currently in development' revealed one further study that met the review inclusion criteria (Hoffman et al. 2019; <https://longtermcare.dartmouth.edu/>).

Therefore, five studies (Friedemann et al. 2004; Garvelink et al. 2016; Garvelink et al. 2017; Hoffman et al. 2019; Sorensen and Pinguart 2001) were included in the review following initial searches.

**Forward citation tracking and handsearching for additional evidence**

Forward citation tracking of the five included papers via Web of Science (WoS) Cited Reference Search facility was undertaken to identify additional papers. The reference lists of these five papers were also hand-searched. Cited reference searches and hand-searching were conducted on 16th March 2020.

Twenty-one potentially relevant papers were identified from the forward citation search and none from the hand-searching. Titles and abstracts then full texts were screened using the eligibility criteria described in **Table 1**. Two papers were included (Pinguart and Sorensen 2002; Sorensen et al. 2012); both assessed the effectiveness of the PFCN tool developed in Sorensen et al. (2001) in terms of subjective well-being, depression, and anxiety.

None of the above methods identified the 'DOLCE' randomised controlled trial referred to by Garvelink et al. (2016), for which their decision guide about location of care was developed. A final online search identified a paper by Adekpedjou et al. (2020) on ResearchGate which described a trial investigating the effectiveness of an intervention to engage care-givers in health-related housing decisions for older adults. The intervention included the use of the decision guide developed by Garvelink et al. (2016).

Thus three additional papers were included that reported on the effectiveness of two of the decision aids described in the original five included papers.

**Figure 1** displays a flow chart of the review screening process.

**Quality appraisal**

As this was a rapid scoping review aimed at identifying the size and range of research evidence available, quality appraisal of studies was not undertaken.

**Data extraction**

RM extracted data from all included studies according to the following themes:

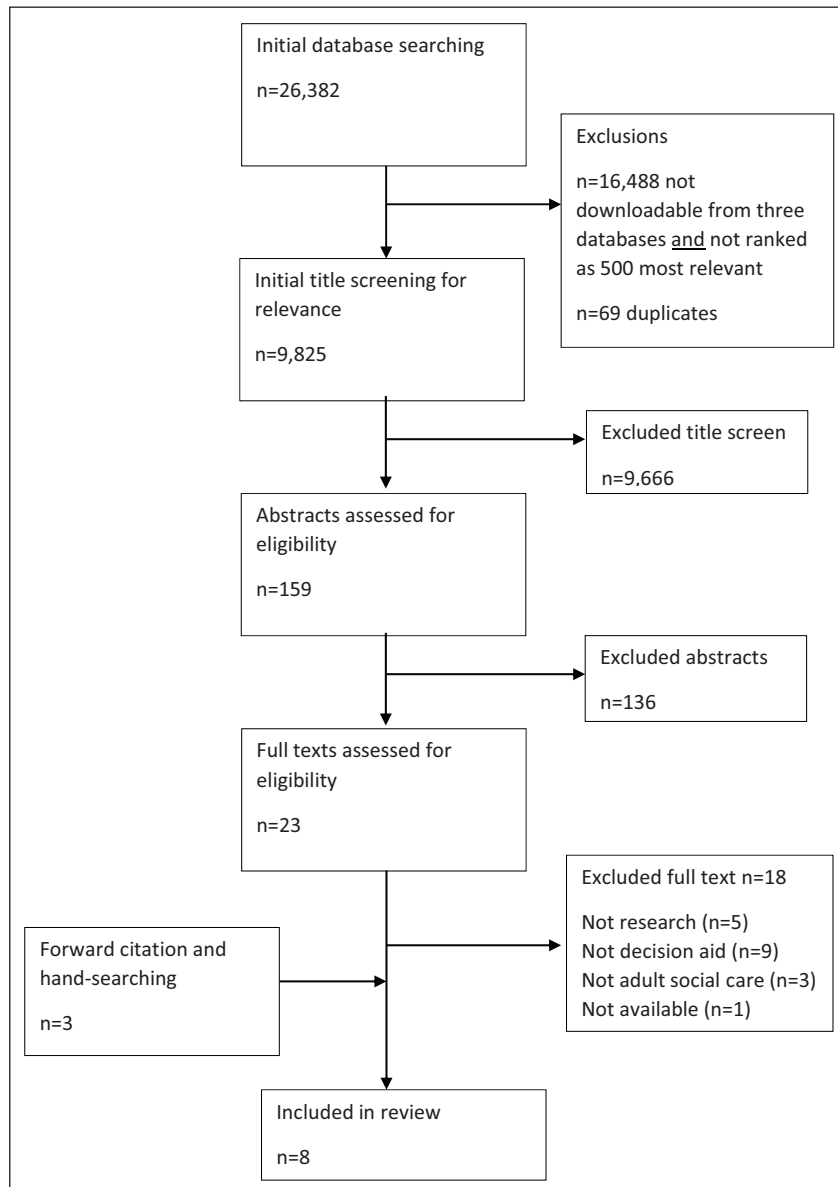
- the purpose of the decision aid;
- the target audience;
- the format of the decision aid;
- the topics covered;
- evidence of effectiveness and how this was measured; and
- the use of theory and/or the IPDAS guidelines in the development of the decision aid.

**Review of English social care-related websites**

The second part of the review explored the extent to which decision aids were available and accessible to assist older people (including self-funders) and their carers to think about social care and paying for care in England.

The adult social care sections of the websites of one third of local councils in England (53/152), weighted by region and randomly selected, were searched for decision aids relevant to older adults and social care. In addition, the main search function tool of each website was used to search for variations of the following terms: 'decision aid/tool', 'planning long term care', 'planning social care/social support'. The first five pages of results were screened for evidence of or links to decision aids and other information about planning social care.

In addition, 11 third sector and quasi-governmental websites such as Age UK and the Money and Pensions Service (MAPS) were purposively selected and explored using the main homepage search function and the basic search terms described above.



**Figure 1:** Flowchart of screening process.

These searches were undertaken between 20th February and 10th March 2020.

## Findings

The following sections describe the included papers and give a narrative overview of the evidence, focussing on the key areas of interest detailed in the Methods. This is followed by an analysis of the decision aids on social care-related websites.

### *Description of studies*

**Tables 2 and 3** give a brief description of the original five papers included in the review and the data extracted from them, respectively, listed in order of publication date.

All five papers reported studies conducted in North America. Broadly, the decision aids were designed to support older adults and their family members (Garvelink et al. 2016; Hoffmann et al. 2019; Sorensen and Piquart 2001), and professionals (Friedemann et al. 2004) prepare and plan for their future social care needs (Friedemann et al. 2004; Hoffmann et al. 2019; Sorensen and Piquart 2001) or support decision making with regard to the future location of their care (Garvelink et al. 2016; Garvelink et al. 2017).

The two earliest papers (Friedemann et al. 2004; Sorensen and Piquart 2001) both developed what were primarily research measures with the potential for use in practice to aid decision making about care. The main purpose of Sorensen and Piquart's instrument, known as the PFCN (Preparation for Future Care Needs), was to increase knowledge about people's activities in preparation for long-term care in later life. Friedemann et al.'s measure, called the LTCP (Long-Term Care Planning) instrument, aimed to assess different types of preparation activities, including making concrete plans. The later papers (Garvelink et al. 2016; Garvelink et al. 2017; Hoffmann et al. 2019) each developed decision aids or guides specifically to support older people make decisions about long-term care. Hoffmann et al.'s aid was called Planning for Long-term Care and Garvelink et al.'s (2017) web-based aid was called SPINACH (SupPortIng seNIors And Caregivers to stay mobile at Home); Garvelink et al.'s (2016) decision aid was not named.

Sorensen and Piquart (2001) and Friedemann et al. (2004) generated items for their measures through focus groups and researcher consensus; they also conducted psychometric testing to measure the validity, reliability, and stability of the constructed scales. The two Garvelink and the Hoffmann studies used an iterative, multi-phase process comprising focus groups and qualitative interviews to develop their decision aids. Researchers agreed relevant items which were subsequently field tested with older adults for acceptability and usability.

### *Target audiences*

Sorensen and Piquart (2001) recommend their measure be used with older people as those aged less than 60 were unlikely to have sufficient current care needs to be interested in planning for future needs. Friedemann et al. (2004), however, suggest their tool be used by gerontolo-

gists and other professionals with people in their 'middle and later years' to help diagnose the strengths and gaps in their approaches to long-term care planning, or as part of educational interventions related to long-term care planning. The remaining three decision aids were targeted at older people or their caregivers and, in the case of Garvelink et al. (2016), administrators and other professionals working in home care teams.

### *Format of the decision aids*

The format of the Sorensen and Piquart (2001) and Friedemann et al. (2004) measures is not clear; both are likely to be paper questionnaires. The former is reproduced at the end of the Sorensen and Piquart article, and the authors suggest that if it is used in an interview format then response options should be shown in large print on response cards. The Garvelink et al. (2016) decision guide is produced in a 10-page coloured paper booklet in English and French, with examples of four pages reproduced in the paper.

Garvelink et al. (2017) and Hoffman et al. (2019) are both web-based interactive decision aids. Hoffman et al describe information as being presented at an 'overview' level with hyperlinks to additional detail and an option to print a summary of the decision process a user has followed. Garvelink et al. (2017) describe the SPINACH decision aid as three web pages: the first is the homepage where users can choose between English and French and which of the remaining pages to visit; the second page contains videos of a decision coach discussing how a decision should be made followed by 15 stakeholders talking about older people's housing options; and the third page contains links to local resources and other websites, and an option to add comments. The stakeholder videos were scripted, based on research interviews with 29 older people, carers, and professionals about important factors to consider in staying independent at home. Stakeholders included an older person, family caregivers, and professionals such as health and care workers and therapists.

### *Theories and guidelines used in developing the decision aids*

Friedemann et al. (2004) give a detailed description of the construction of the domains and individual items in their LTCP instrument. The theory behind the approach was developed by Friedemann (1995). It builds a model of interactions between the environment, the person and their health in nursing care. For the purposes of the 2004 study, the key concepts are control and acceptance. Control is defined as actions necessary to prevent or modify the potential ill effects of changes that may occur in the future. Acceptance is defined as a willingness to use available resources to adapt to new circumstances, rather than a passive acceptance of change. Friedemann et al. (2004) used these concepts to shape the domains in their tool, namely behaviour in relation to (1) finances; (2) wellness and function; and (3) the social and environmental situation; and attitudes to each, including willingness to adapt or ask for help. These are described further in the section 'Decision Aids' Domains' below.

**Table 2:** Characteristics of papers describing development of decision aids (by publication date).

Author Year Country	Aims	Method and participant characteristics	Study findings
Sorensen and Pinquart 2001 USA	To develop a measure of older adults' preparation for future care needs	Three-phase design. <i>Phase 1:</i> Item generation via qualitative interviews with older people in USA and Eastern Germany. Qualitative analysis. <i>Phase 2:</i> Factor analysis of 242 questionnaires sent to 600 community dwelling adults. Sample: female 54%; age range 65–96 years (mean 75 years); ethnicity not reported. <i>Phase 3:</i> Scale validation using confirmatory factor analysis, reliability and stability coefficients from 590 (/1600) questionnaires from community dwelling adults. Sample: female 45%, age range 64–92 years (mean 74 years); ethnicity not reported.	<i>Phase 1:</i> Items generated from respondents developed into four domains. <i>Phase 2:</i> Findings not reported. <i>Phase 3:</i> Scale validation: <ul style="list-style-type: none"> <li>Reliability coefficients for the total scale 0.72 and 0.87.</li> <li>Stability over three months 0.32 to 0.72.</li> <li>Between 14.6% and 56.7% of the variance explained by items in a five-factor structure.</li> </ul>
Friedemann et al. 2004 USA	To develop and test an instrument to measure long-term-care planning behaviour	Two-phase design. <i>Phase 1:</i> Item generation from 60 researcher-formulated activity statements in focus groups with 18 older people. <i>Phase 2:</i> Exploratory principle axis factoring (PAF) Confirmatory factor analyses (CFA) of telephone questionnaires administered to 150 people aged 55–70 years; female 62%; 58% Hispanic; 11% African American or Black; 30% non-Hispanic White; 1% American Indian	<ul style="list-style-type: none"> <li>PAF found eigenvalues greater than 1 explaining 52% of the variance.</li> <li>CFA supported a five-factor structure with a comparative fit index of 0.987.</li> <li>Reliability ranged from 0.71 to 0.88.</li> </ul>
Garvelink et al. 2016 Canada	To develop a decision aid to support older people in making decisions about location of care	Iterative three-phase design. <i>Phase 1:</i> Qualitative interviews with six caregivers of older people recently facing decision about location of care; search for existing decision aids and summary of reviews. <i>Phase 2:</i> Usability testing of prototype guide. Sample: five caregivers; aged 57–68 years (median 68 years); all female. <i>Phase 3:</i> Final guide usability test. Sample: 4 older adults; mean age 82 years; all female. Ethnicity not reported. Usability assessment in Phases 2 and 3 included summary of open-ended comments.	Usability assessed by sample of four as: <ul style="list-style-type: none"> <li>Clear information on all pages (median 4/4 agreed; range per page 2/4 to 4/4)</li> <li>Correct length (4/4 participants agreed)</li> <li>Right length (4/4 agreed)</li> <li>Right amount of information (3/4 agreed)</li> <li>Acceptable balance of information (3/4 agreed);</li> <li>Helpful for decision-making (4/4 agreed)</li> </ul>
Garvelink et al. 2017 Canada	To develop and test the acceptability of an interactive website presenting information about options for staying independent at home	Iterative three-phase design. <i>Phase 1:</i> Qualitative interviews with four older people, three caregivers, 22 professionals. <i>Phase 2:</i> 30 videos of experts (e.g., family doctor, home care nurse, and social worker) presenting options and guidance for decision-making process. Integrated into interactive website. <i>Phase 3:</i> Evaluation of acceptability of website. Sample comprised: seven older females (mean age 75 years); seven caregivers; six professionals. Ethnicity not reported.	Evaluation of acceptability: <ul style="list-style-type: none"> <li>Clarity of the videos scored 3.6 out of 4</li> <li>Length of individual videos about right (17/21 participants)</li> <li>Amount of information in videos about right (17/21 participants)</li> <li>Length of videos taken as a whole (13/21 participants)</li> <li>Module was helpful (16/21); acceptable (18/21)</li> </ul>
Hoffman et al. 2019 USA	To develop and field-test a long-term care decision aid website for older adults	Iterative three-phase design. <i>Phase 1:</i> scoping review, search for existing evidence, initial design of decision aid by stakeholder panel. <i>Phase 2:</i> Design of 'storyboard'; iterative cycles of cognitive interviews with users. <i>Phase 3:</i> Field test of decision aid web site. Sample: 12 older adults (female 83%; aged 61–89 years (67% aged over 80 years); White/Caucasian 92%; somewhat comfortable with computers (42%). Acceptable utility defined as > 80% of participants answering at least 3/5 knowledge items correctly, and responding 'yes' to at least 3/4 decisional conflict scale items.	Field test: <ul style="list-style-type: none"> <li>11/12 participants scored &gt;60% correct on knowledge items (mean 83%) and reported moderate/low decisional conflict.</li> <li>8/12(67%) selected 'yes' on three or more decisional conflict scale items.</li> <li>10/12 (83%) rated the decision aid acceptable on 6/9 items</li> <li>All were able to use the website, spent an average of 26.3 minutes</li> </ul>

**Table 3:** Review data extracted from papers describing development of decision aids (by publication date).

Author Year Country	Name of decision aid (number of items)	Purpose	Target audience	Format and presentation of decision aid	Topics covered	Evidence of effectiveness	Use of theory or IPDAS criteria
Sorensen and Pinquart 2001 USA	Preparation for Future Care Needs (PFCN) instrument (29 items)	A measure to help older adults prepare for future care needs	Unclear. For use as a questionnaire or in an interview, with older people needing help or care to consider preparation for future care needs	Unclear. Probably paper-based tool. (The measure is printed in Appendix of article)	<ul style="list-style-type: none"> <li>• Becoming aware</li> <li>• Avoidance of preparation</li> <li>• Gathering information</li> <li>• Deciding on preferences</li> <li>• Concrete planning</li> <li>• Attitudes to planning (expectations of whether care will be needed in the future; expectation of never needing long-term care; perceived value of planning)</li> </ul>	None	No theory cited  Measure developed before IPDAS criteria published
Friedemann et al. 2004 USA	Long-term Care Planning (LTCP) instrument (23 items)	Instrument to examine how people approach planning for the time of life when formal or informal long-term care may be necessary	For use in research and by clinicians/care professionals involved in planning long term care tasks. As a diagnostic inventory for Gerontologists.	Unclear.	Long-term care planning behaviour in three areas: <ol style="list-style-type: none"> <li>Financial</li> <li>Wellness and functional ability</li> <li>Social and environment;</li> </ol> plus planning attitude (i.e. acceptance and non-acceptance of the need to change)	None	Cites the lead authors' 'Framework of Systemic Organisation' (Friedemann, 1995)  Instrument developed before IPDAS criteria published
Garvelink et al. 2016 Canada	Not stated (Unclear)	Decision guide to support caregivers, health professionals and older people in decision making about location of care	Older people, caregivers and clinicians/health professionals	10-page coloured booklet printed on A3 sized paper in English and French language	Location of care	None	No theory cited  Assessed against the IPDAS criteria
Garvelink et al. 2017 Canada	Supporting seniors And Caregivers to stay mobile at Home (SPINACH) (3 web-pages)	Decision guide to support caregivers, health professionals and older people in decision making about home care	Older people and caregivers	Internet-based interactive resource	Options for staying independent at home, including: <ul style="list-style-type: none"> <li>• the importance of thinking early</li> <li>• safety issues in and out of the home</li> <li>• social support</li> <li>• psychological and mental well-being</li> </ul>	None	No theory cited  Not assessed against the IPDAS criteria
Hoffman et al. 2019 USA	Planning for Long Term Care: choosing the best care and financial plan for your loved ones (Unclear)	Decision aid to educate and support older people and their family members in beginning a long-term care plan	Older people	Internet-based interactive resource	Four interactive, modular decision-making steps: <ul style="list-style-type: none"> <li>• Get the Facts</li> <li>• What Matters Most</li> <li>• Consider Your Resources</li> <li>• Make an Action Plan</li> </ul> Provides users with a My Decision Summary printout.	None	Use of decision and cognitive science theory cited and adaptation of the Ottawa Decision Support Framework  Assessed against the IPDAS criteria

Hoffman et al. (2019) described the use of decision and cognitive sciences, 'human computer interaction' and health services research in the development of their study and tool. They specifically described how the Ottawa Decision Support Framework (O'Connor et al. 1998) influenced their decision to address the varying needs of individuals over time and the varying roles that different individuals play in the decision-making process. They also recognised the different needs of people planning for care for the future compared to those facing crisis/imminent care, especially in relation to finances.

Three studies did not explicitly discuss the use of theory in the development of their decision aids (Garvelink et al. 2017; Garvelink et al. 2016; Sorensen and Pinquart 2001) although Sorensen and Pinquart briefly mentioned being influenced by decision making, problem solving and everyday planning models, but did not report details.

Two studies assessed the quality of the decision aid against the IPDAS criteria (Hoffmann et al. 2019; Garvelink et al. 2016). Garvelink et al. (2016) found that their tool met only eight of the 12 IPDAS criteria and consequently labelled it a decision guide rather than aid. Garvelink et al. (2017) presented no evidence of using the IPDAS or any other criteria. The remaining two studies (Friedemann et al, 2004; Sorensen and Pinquart, 2001) developed decision aids prior to publication of the IPDAS criteria.

#### **The decision aids' domains**

All of the decision aids aimed to support people with planning for long-term care in later life, with Garvelink et al. (2016) focusing specifically on location of care and Garvelink et al. (2017) on home care.

The domains covered by the two Garvelink papers are not clear. Garvelink et al. (2016) described the end product as comprising 'six steps to involve elderly people, caregivers and healthcare professionals in the decision-making process about location of care' (p11) but gave no detail about what these steps entailed. Garvelink et al. (2017) stated that their research had 'uncovered numerous decisional needs, including the need to start thinking about this decision early on, safety issues inside and outside the home, and the importance of social supports and psychological or mental well-being' (p12). No more detail is provided and it is not clear whether these are all or only some of the domains covered in the final decision aid.

The three remaining papers described the domains of their decision aids in detail. Column six (Topics covered) of **Table 3** presents these domains, illustrating how these are shared across decision aids. All three decision aids contain a section aimed at helping people gather information and consider what is important to them before taking practical steps to formulate a plan. The similarity between the Sorensen and Pinquart PFCN instrument and Hoffmann et al.'s Planning for Long Term Care website is striking, each encouraging people to gather information, consider their personal preferences and formulate a plan.

The PFCN (Sorensen and Pinquart 2001) and LTCP (Friedemann et al. 2004), both developed primarily as research instruments but available for use as decision aids, each include a section on people's attitudes towards

care. These sections are aimed at understanding whether or not people are prepared to think about the possibility of needing care in the future and, should the need arise, whether they are likely to engage in planning or take any other relevant actions.

#### **Evaluation of decision aids**

None of the original five papers that met the review inclusion criteria evaluated the effectiveness of the decision aid they developed. However, the three additional studies identified through citation searching offer some insights into effectiveness. **Table 4** describes the studies and findings.

Sorensen and Pinquart (2002a) measured the association between the PFCN instrument (developed in Sorensen and Pinquart 2001) and subjective well-being in a cross-sectional study in Germany. They found that for older adults, although being aware of the necessity to plan for future care needs was associated with increased worry, anxiety, and higher levels of depressive symptoms, gathering information and making concrete plans for care were associated with less worry and anxiety and higher satisfaction. Sorensen et al. (2012) similarly evaluated the relationship between mental well-being and preparation for care using the PFCN instrument in the USA. They also found that people who had made concrete care plans at baseline were less likely to develop depression two years later compared to people who had avoided planning.

Adekpedjou et al. (2020) evaluated the effect of training home care teams in shared decision making on the proportion of caregivers taking an active role in decision making in a randomised controlled trial. The shared decision-making intervention included the Garvelink (2016) guide to support caregivers, health professionals, and older people in decision making about location of care. The evaluation found that the proportion of caregivers reporting an active role in decision making increased by 18% in the intervention compared to the control group.

#### **Decision aids offered on social care-related websites in England**

The search of 11 third-sector and quasi-governmental UK websites and 53 English local council websites revealed one interactive housing and care tool called Housing Options for Older People (HOOP), various cost calculators to help people understand eligibility for and the costs of care, and an interactive tool to help plan support and well-being. **Table 5** shows the distribution across websites. We found no formal evidence about the development or evaluation of these tools.

HOOP is an interactive self-help tool that encourages users to consider their current home and how they live in it. It assists people in accessing information on a range of housing, care and well-being-related matters. Users of the tool are prompted to highlight issues of concern to them now or in the future, or of no concern. The sections cover: size and space; cost; condition; comfort and design; security and safety; location; managing to live independently; and quality of life. Results are summarised with a description of and links to further information, for example concerns about the costs of care lead to a description



**Table 4:** Characteristics of papers assessing effectiveness of included decision aids.

Authors Year Country	Aim of paper	Methods	Participant characteristics	Study findings
Pinquart and Sorensen 2002a Germany (evaluated PFCN, Sorensen et al. 2001)	To investigate associations between different aspects of coping with risk of needing help or care in future and worry, depression and satisfaction with preparation for future care needs (FCN)	Cross-sectional study to test 4 hypotheses on the impact on subjective well-being (worry, depression, satisfaction) of preparedness and planning for future care needs. Measures included elements of the PFCN questionnaire; Center for Epidemiological Studies Depression Scale, short form; satisfaction with preparation for FCN, ADLs and IADLs; perceived usefulness of planning.  Questionnaires sent to 1,200 community-dwelling older adults (65 or older) in large cities and rural areas of Germany.	607 questionnaires returned (response rate 45%). Mean age 74 years (range 65–93 years); female 48%; married 63%, widowed 27%; divorced 5%, never married 5%; ethnicity not reported.	<ul style="list-style-type: none"> <li>• Becoming aware of FCN associated with higher levels of worrying and depression.</li> <li>• Gathering information and concrete planning predicted lower levels of worrying and depression and higher levels of satisfaction with preparations.</li> <li>• Avoiders had lowest levels of worries and depression, whereas planners were most satisfied with their preparation activities.</li> <li>• Thinking about future risks without making concrete plans was associated with the lowest levels of psychological wellbeing.</li> </ul>
Sorensen et al. 2012 USA (evaluated PFCN, Sorensen et al. 2001)	To investigate relationship between planning for future care and subsequent mental health	Longitudinal study with 2-year follow-up that examined the relationship between preparations for future care using the PFCN questionnaire and depression and anxiety (measured by the Structured Clinical Interview for DSM-IV, the Hamilton Depression Rating Scale and the Clinical Anxiety Scale).  Assessments took place at primary care clinics.	385 patients aged 65 and over attending primary care health facilities. Mean age 79 years; female 61%; white 96%; married 58%; widowed 27%. 190 (57%) complete data on PFCN measure and diagnostic interview at baseline and follow-up at 2 years.	<ul style="list-style-type: none"> <li>• Major depression present for 3% and minor depression 4%.</li> <li>• More baseline Concrete Planning significantly related to lower likelihood of being diagnosed with major or minor depression at two-year follow-up.</li> <li>• Avoidance independently associated with greater depression symptoms after two years, but not with anxiety symptoms or diagnosis of depression.</li> </ul>
Adepedjou et al. 2019 Canada (evaluated unnamed booklet, Garvelink et al. 2016)	To evaluate the impact of training inter-professional home care teams in shared decision making (SDM) in health-related housing decisions.	Two-arm pragmatic cluster randomized trial with home care teams working in health centres randomized to receive training in inter-professional SDM, including use of a decision guide (Garvelink et al, 2016) (intervention) or not (control).  Primary outcome: proportion of caregivers of cognitively impaired older people reporting an active role in decision making (measured by modified Control Preference Scale). Secondary outcome: preferred health-related housing option and actual health-related housing decision (remain at home or move to a care facility).	Consecutive enrolment of a random group of 16 health centres. 309 caregivers recruited, 296 included in analysis. Median age of caregivers 61 years (IQR: 54–70); female 75%; married or living with a partner 77%; retired 50%; ethnicity not reported.	<ul style="list-style-type: none"> <li>• Primary outcome: Intervention increased the proportion of caregivers who reported an active role in the decision making by 12% (95% CI: -2% to 27%; p = .10). Sensitivity analysis to remove between cluster variance suggested intervention increased the proportion of caregivers reporting an active or collaborative role during decision making from 12% to 18% (95% CI: 7%–29%; p &lt; .01).</li> <li>• Secondary outcome: Intervention showed no effect on caregivers' preferred health-related housing option, decision made, decisional conflict, decision regret or burden of care as perceived by caregivers.</li> </ul>

**Table 5:** Resources offered on third sector/quasi-governmental and local council websites.

Resources identified	Number of websites identified as offering this type of resource	
	Third sector/quasi-governmental	Local council
Housing Options for Older People (HOOP) interactive tool.	3	5
Cost calculator	2	1
Interactive self-help tool to help plan support and well-being	0	1
No decision aids (information only e.g., signposting elsewhere, fact sheets)	7	46

of and link to specialist financial advisers registered with the Society of Later Life Advisers (SOLLA). Results can be saved or printed for future reference. The tool is provided by the Elderly Accommodation Council (EAC) and sponsored by Legal and General.

Online cost calculators aimed to help people understand costs of care and/or their eligibility for local council help with funding care. For example, some calculators estimated costs of care based on criteria such as region, home or residential care, type of need (e.g., frailty or dementia) or expected length of time needing care (e.g., <https://ukcareguide.co.uk/care-home-costs/>). Others calculated costs of care and also whether someone might be a self-funder or eligible for help meeting care costs (e.g., <https://www.which.co.uk/older-life-care/financing-care/cost-of-care-and-eligibility-checker/>).

One of the local council websites reviewed provided an interactive tool for planning and creating a health and well-being plan. This was aimed at all adults over 18 years of age and was not tailored to older adults planning future care and support needs.

## Discussion

This rapid scoping review sought international research evidence on the development, use and effectiveness of decision aids in adult social care and investigated the availability of such aids for planning later life care on adult social care-related websites in England.

The review identified a paucity of evidence about the development or effectiveness of such decision aids. Five papers described the development of five different decision aids (three in the USA and two in Canada) and three papers assessed the effectiveness of two of those decision aids. The investigation of English adult social care-related websites found very few examples of resources that could be categorised as decision aids.

Those decision aids that were identified in either research papers or on websites were interactive in that they encouraged the decision maker to follow key steps and answer a number of questions. Target audiences were older people and/or their family caregivers. There was some overlap in the content of the decision aids, including gathering information, considering personal preferences and encouraging planning. There was very limited evidence on the effectiveness of any of the decision aids identified. The evidence that does exist suggests some increase in numbers of care-givers reporting an active role

in decision making following use of one of the decision aids (Garvelink et al. 2016) but mixed messages about the effect on anxiety of awareness of, and making plans for, future care needs (Sorensen and Pinquart 2002a; Sorensen 2012).

Although the IPDAS criteria define and judge the quality of decision aids against at least 44 items (Joseph-Williams et al. 2014), we took a more flexible approach given our remit to scope the research evidence base. For the purposes of this review, we defined a decision aid in broad terms in line with the IPDAS collaboration's general statement that a decision aid should improve the quality of a decision (see <http://ipdas.ohri.ca/what.html>). We therefore included research instruments that could also be used in practice as decision tools, a decision aid that failed to meet the IPDAS criteria, and decision aids that were developed prior to or were not tested against these criteria. The HOOP decision tool and cost calculators identified through the searches of English websites would also have been excluded if we had taken a more stringent approach. This review also identified several papers containing lists of resources aimed at helping people make choices about later life care, but excluded these from the review due to lack of research evidence about their development or evaluation. However, the existence of these resources suggests that there is an appetite for such aids to decision making but it is concerning that, for the majority, their quality is unproven.

## Implications for research

By using a wide-ranging definition of a decision aid, this review has identified two broad empirical areas relating to decision tools in adult social care. The first, older, literature relates to measures of people's attitudes to and readiness to engage with care planning and the possibility of needing care in the future (Sorensen and Pinquart 2001; Friedemann et al. 2004). The second, and more recent, area comprises the development of decision aids aimed at assisting people in making decisions that are current (Garvelink et al. 2016, 2017; Hoffmann et al. 2019). However, we found no evidence of any links between the earlier and later literature. Specifically, there is no evidence that a positive attitude to thinking about care and a willingness to engage in doing so, as measured by the PFCN and LTCP instruments, translates into willingness to use a decision tool. This does not mean that there is no link, but that it has not been investigated. There are also quite stark differences in the ways in which the earlier measures and the later

decision tools were developed, the former typically underpinned by psychometric properties and the latter driven by guidelines such as those from IPDAS. These disparities suggest a lack of connection between the academic interest in people's attitudes to and engagement with planning for social care, and the development of practical tools for use in real-world settings. Given evidence that people are reluctant to plan for social care or paying for care (Dixon et al. 2019; Heavey et al. 2019), future research to develop decision aids might benefit from drawing on both fields.

For the three archetypal decision tools reported in included papers (Garvelink et al. 2016, 2017; Hoffmann et al. 2019), we found only one related evaluation, but this shed little light on the effectiveness of the decision tool itself as the evaluation was of a wider shared decision-making intervention of which the tool was just one part. Similarly, we found no evidence of robust development or evaluation of the (albeit limited range of) tools available on adult social care websites in the UK. This lack of evidence of formal development and evaluation is in stark contrast to health care and illustrates how far research and development of decision aids for use in social care has to travel; the IPDAS collaboration to enhance the quality and effectiveness of patient decision aids was established in 2003 but seemingly has yet to be adopted at scale by social care researchers. We suggest decision aids developed for use in adult social care follow the IPDAS guidelines and are evaluated in robust trials. The purpose of decision aids is to improve the quality of decisions and it is this decision quality along with people's preparedness for making decisions which needs to be evaluated. There are validated measures designed to evaluate the impact of decision aids in health care (see for example Bennett et al. 2010; Légaré et al. 2010; O'Connor 1995). These measures ask, amongst other things, whether people feel better prepared to make a decision after using the aid, if it has helped people to organise their thoughts or prepared them for their next discussion with their doctor. The challenge is to test and validate these or similar measures for social care.

One area for social care research to consider in developing decision aids is how to measure and elucidate the risks and benefits associated with different options. Decision aids in health are often used to assist choices about treatment or screening options. The risks and benefits of different options are typically quantifiable, for example, the proportion of people experiencing a side effect from taking a drug. There are also experts in health conditions who can help a patient work through the options and make an informed choice. In social care, research needs to consider whether the risks and benefits are quantifiable in the same way. For example, can a decision aid quantify the risks and benefits associated with home care compared to a care home, or paying for care from income and savings compared to purchase of a financial product? In addition, while social care professionals may be able to offer information about systems and available support, what would be the most productive role for them in a shared decision-making scenario? These unknowns mean that the experience of working through a decision aid in social care may well be very different to health care. The lack of research

evidence about decision aids relating to social care in the UK suggests this is an area that social care researchers need to address.

Furthermore, it is important for researchers to bear in mind the target audience. The decision tools described in this review were all aimed at older people or people approaching older age. They were produced as websites, on paper or both. There is some evidence (Baptista et al. 2018) to suggest that the form of media makes little difference to the use or outcomes of decision aids in health care, but this has not been tested in an older population making decisions about social care. Moreover, Tomko et al. (2015) concluded, in their comparison of a web versus paper-based decision aid for prostate cancer screening of 40–75-year-olds, that when it is not possible to provide people with a decision aid in their preferred media, paper will be used more commonly than web-based materials. Thus, the target population needs to be at the heart of development. However, in developing decision aids going forward, there is a balance to be considered between creating a decision aid that is accessible to an individual older person, who might prefer paper, and making it available to as many individuals as possible, which might necessitate online versions.

#### ***Implications for adult social care practice***

None of the research papers included in the review reported on studies undertaken or decision aids used in England. Indeed, all the decision aids were developed and, other than the Pinguart and Sorensen (2002a) study, evaluated in North America. This suggests that North American countries have gone some way to recognising the importance of people planning for social care needs in later life and are proactively providing resources to facilitate this. In doing so, they are assisting and empowering people to make considered decisions around future care needs. People in England do not appear to be receiving the same assistance, despite also having an ageing population and the need to consider care, and the costs of care, in later life. Furthermore, while the decision aids identified in this review facilitate users to think about care and its costs in a structured way, none explicitly focus on preparing people to have better quality or more constructive conversations with professionals. This is a key omission if an aim of such decision tools is to enhance the quality of decision making.

It could be argued that the state-funded social care system in England reduces the relevance of decision tools developed in other countries. However, the tools identified focus on future care needs, including but not limited to planning for the costs of care. Even where paying for care is considered, in comparing the social care system in England with the United States (see Robertson, Gregory and Jabbal 2014) there are in fact many similarities; importantly, in both countries people are expected to pay for social care from their own resources until they are depleted to the point where the person becomes eligible for the safety net of local council funding or Medicaid, respectively. Thus tools to facilitate the decision-making processes about care and paying for care developed in the USA may be relevant in England. In addition, an evaluation of the Preparation for Future Care Needs tool that was developed in the United

States took place in Germany (Pinquart and Sorensen 2002a), suggesting that the concept of decision tools to assist with planning for social care is pertinent more widely.

The absence of decision aids in social care is strikingly different to health care. The range of decision aids available suggests it is generally accepted that patients face complex choices about treatments or screening and that they can benefit from the use of decision aids, often as part of a shared decision-making process. Of the papers included in this review, only Adekpedjou et al. (2020) evaluates shared decision making. Moreover, the complexity of decisions in social care does not appear to be recognised. Older people and their families make choices about long-term care without the same level of formal decision-making support that is available for patients with a wide range of conditions. Self-funders in particular lack formal support. Nevertheless, there are practices in social care that contain elements of a shared decision-making process. These practices, known as strengths- or asset-based approaches, aim to build on an individual's strengths and capabilities and those of their networks in order to achieve their goals. This is a complex area with many models. One model is the 'three conversations' approach (<http://partners4change.co.uk/the-three-conversations/>) which comprises three distinct discussions between social care professionals and people needing support, focusing on people's strengths and community assets, and their long-term outcomes, with conversations built around 'what a good life looks like' (ibid.). To our knowledge, this and similar approaches do not currently encompass the use of decision aids. However, as a key purpose of decision aids is to help people clarify their personal values and preferences (BMJ 2013; Stacey et al. 2017), in other words what encompasses personal goals and a 'good life', marrying the two approaches may be fruitful.

### Limitations

This rapid scoping review aimed for a wide coverage of papers. As such, some papers were included that stretch the definition of a decision aid. Conversely, a small number of relevant papers were identified through forward citation and internet searching but were not picked up through the formal searches; some relevant papers may therefore have been missed.

Due to technical issues, only 500 citations each could be downloaded from three of the databases searched. Before downloading, the search results were sorted by relevance and checked to ensure they contained potentially pertinent papers, but it is possible that some papers that would have been included were not downloaded.

The review of local council adult social care and third-sector websites was not comprehensive; due to time constraints, searches were limited to one third of council websites and 11 third-sector sites. Some online decision aids may therefore not have been identified.

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### Competing Interests

The authors have no competing interests to declare.

### References

- Adekpedjou, R, Stacey, D, Brière, N, Freitas, A, Garvelink, MM, Dogba, MJ, Durand, PJ, Desroches, S, Croteau, J, Rivest, LP and Légaré, F.** 2020. Engaging caregivers in health-related housing decisions for older adults with cognitive impairment: A cluster randomized trial. *The Gerontologist*, 60(5): 947–957. DOI: <https://doi.org/10.1093/geront/gnz045>
- Alecxih, L and Blakeway, C.** (2012). Deciding on care options in the digital age. *Generations*, 36(1): 77–82. <https://www.jstor.org/stable/44875740> [Accessed 15 September 2020].
- Arksey, H and O'Malley, L.** (2005). *Scoping studies: Towards a methodological framework*. *International Journal of Social Research Methodology*, 19–32. DOI: <https://doi.org/10.1080/1364557032000119616>
- Baptista, S, Teles Sampaio, E, Heleno, B, Azevedo, LF and Martins, C.** (2018). Web-based versus usual care and other formats of decision aids to support prostate cancer screening decisions: Systematic review and meta-analysis. *J Med Internet Res*, 20(6): e228. DOI: <https://doi.org/10.2196/jmir.9070>
- Baxter, K, Heavey, E and Birks, Y.** (2017). Older self-funders and their information needs. London: NIHR School for Social Care Research. [https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings\\_RF062.pdf](https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF062.pdf) [Accessed 09 August 2020].
- Baxter, K, Heavey, E and Birks, Y.** (2018). Independent financial advice about funding social care in later life. London: School for Social Care Research. [https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings\\_RF109.pdf](https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF109.pdf) [Accessed 09 August 2020].
- Bennett, C, Graham, ID, Kristjansson, E, Kearing, SA, Clay, KF and O'Connor, AM.** (2010). Validation of a preparation for decision making scale. *Patient Educ Couns*, 78(1): 130–133. <https://doi.org/10.1016/j.pec.2009.05.012>
- BMJ.** (2013). An introduction to patient decision aids. *British Medical Journal*, 347. DOI: <https://doi.org/10.1136/bmj.f4147>
- Dixon, J, Trathen, A, Wittenberg, R, Mays, N, Wistow, G and Knapp, M.** (2019). Funding and planning for social care in later life: A deliberative focus group study. *Health and Social Care in the Community*, 27(5). DOI: <https://doi.org/10.1111/hsc.12768>
- Friedemann, ML.** (1995). *The framework of systemic organization: A conceptual approach to families and nursing*. Thousand Oaks, CA: Sage, ISBN: 9780803949140.
- Friedemann, ML, Newman, FL, Seff, LR and Dunlop, BD.** (2004). Planning for long-term care: Concept,

- definition, and measurement. *Gerontologist*, 44(4): 520–530. DOI: <https://doi.org/10.1093/geront/44.4.520>
- Garvelink, MM, Emond, J, Menear, M, Brière, N, Freitas, A, Boland, L, Becerra Perez, MM, Blair, L, Stacey, D and Légaré, F.** (2016). Development of a decision guide to support the elderly in decision making about location of care: An iterative, user-centered design. *Research Involvement and Engagement*, 2(26). DOI: <https://doi.org/10.1186/s40900-016-0040-0>
- Garvelink, MM, Jones, CA, Archambault, PM, Roy, N, Blair, L and Légaré, F.** (2017). Deciding how to stay independent at home in later years: Development and acceptability testing of an informative web-based module. *JMIR Hum Factors*, 4(4): e32. DOI: <https://doi.org/10.2196/humanfactors.8387>
- Heavey, E, Baxter, K and Birks, Y.** (2019). Financial advice for funding later life care: A scoping review of evidence from England. *Journal of Long-Term Care*, 51–65. DOI: <https://doi.org/10.31389/jltc.8>
- Henwood, M and Hudson, B.** (2008). Lost to the system? The impact of Fair Access to Care. A report commissioned by the Commission for Social Care Inspection for the production of The state of social care in England 2006–07. London: Commission for Social Care Inspection. <http://www.melaniehenwood.com/perch/resources/cscifacslosttothesystem.pdf> [Accessed 09 August 2020].
- Hoffman, AS, Bateman, DR, Ganoe, C, Punjasthitkul, S, Das, AK, Hoffman, DB, Housten, AJ, Peirce, HA, Dreyer, L, Tang, C, Bennett, A and Bartels, SJ.** (2019). Development and field testing of a long-term care decision aid website for older adults: Engaging patients and caregivers in user-centered design. *The Gerontologist*, gnz141. DOI: <https://doi.org/10.1093/geront/gnz141>
- International Patient Decision Aids Standards (IPDAS) Collaboration.** [Accessed 09 April 2020] <http://ipdas.ohri.ca/>.
- Joseph-Williams, N, Newcombe, R, Politi, M, Durand, MA, Sivell, S, Stacey, D, O'Connor, A, Volk, RJ, Edwards, A, Bennett, C, Pignone, M, Thomson, R and Elwyn, G.** (2014). Toward minimum standards for certifying patient decision aids: A modified delphi consensus process. *Medical Decision Making*, 34(6): 699–710. DOI: <https://doi.org/10.1177/0272989x13501721>
- Kane, RL, Krista, B and Mary, C.** (2007). Helping people make better long-term-care decisions. *Gerontologist*, 47(2): 244–24. DOI: <https://doi.org/10.1093/geront/47.2.244>
- Kohn, KC.** (2004). Making housing and care decisions for an older adult: Resources on the internet. *Journal of Consumer Health on the Internet*, 8(4): 55–65. DOI: [https://doi.org/10.1300/J381v08n04\\_05](https://doi.org/10.1300/J381v08n04_05)
- Légaré, F, Brière, N, Stacey, D, Bourassa, H, Desroches, S, Dumont, S, Fraser, K, Freitas, A, Rivest, LP and Roy, L.** (2015). Improving Decision making On Location of Care with the frail Elderly and their caregivers (the DOLCE study): Study protocol for a cluster randomized controlled trial. *Trials*, 16: 50. <https://doi.org/10.1186/s13063-015-0567-7>
- Légaré, F, Kearing, S, Clay, K, Gagnon, S, D'Amours, D, Rousseau, M and O'Connor, A.** (2010). 'Are you SURE?' *Canadian Family Physician*, 56(8): e308. Available from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2920798/> [Accessed 07 January 2021].
- O'Connor, AM.** (1995). User Manual - Decision self-efficacy scale. Ottawa: Ottawa Hospital Research institute, ©1995, modified 2002. Available from [https://decisionaid.ohri.ca/docs/develop/User\\_Manuals/UM\\_Decision\\_SelfEfficacy.pdf](https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decision_SelfEfficacy.pdf) [Accessed 07 January 2021]. DOI: <https://doi.org/10.1037/t23888-000>
- Phillipson, L, Low, LF and Dreyfus, S.** (2019). Consumer-directed care for older Australians: Are resources identified on the Web adequate to support decisions about home-based care packages? *Australian Journal of Social Issues*, 54(2): 135–156. DOI: <https://doi.org/10.1002/ajs4.66>
- Pinquart, M and Sorensen, S.** (2002). Psychological outcomes of preparation for future care needs. *Journal of Applied Gerontology*, 21(4): 452–470. DOI: <https://doi.org/10.1177/073346402237632>
- Polniaszek, S and Klinger, C.** (2004). Long-term care counselor: An electronic decision support tool. *Care Management Journals*, 5(3): 139–144. DOI: <https://doi.org/10.1891/cmaj.2004.5.3.139>
- Putting People First Consortium, Institute of Public Care Oxford Brookes University and Melanie Henwood Associates.** (2011). People who pay for care: quantitative and qualitative analysis of self-funders in the social care market. London: Putting People First Consortium. [https://ipc.brookes.ac.uk/publications/People\\_who\\_pay\\_for\\_care\\_-\\_report\\_12\\_1\\_11\\_final.pdf](https://ipc.brookes.ac.uk/publications/People_who_pay_for_care_-_report_12_1_11_final.pdf) [Accessed 09 August 2020].
- Robertson, R, Gregory, S and Jabbal, J.** (2014). The social care and health systems of nine countries. London: The King's Fund. <https://www.kingsfund.org.uk/sites/default/files/media/commission-background-paper-social-care-health-system-other-countries.pdf> [Accessed 06 January 2021].
- Sorensen, S, Mak, W, Chapman, B, Duberstein, PR and Lyness, JM.** (2012). The relationship of preparation for future care to depression and anxiety in older primary care patients at 2-Year follow-up. *American Journal of Geriatric Psychiatry*, 20(10): 887–894. DOI: <https://doi.org/10.1097/jgp.0b013e31822ccd8c>
- Sorensen, S and Pinquart, M.** (2001). Developing a measure of older adults' preparation for future care needs. *International Journal of Aging and Human Development*, 53(2): 137–165. DOI: <https://doi.org/10.2190/1R0D-30TC-F4K1-F0DW>
- Stacey, D, Légaré, F, Lewis, K, Barry, MJ, Bennett, CL, Eden, KB, Holmes-Rovner, M, Llewellyn-Thomas, H, Lyddiatt, A, Thomson, R and Trevena, L.** (2017). Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*, 4: CD001431. [Accessed 14.1.20]. DOI: <https://doi.org/10.1002/14651858.CD001431.pub5>

- Tomko, C, Davis, KM, Luta, G, Krist, AH, Woolf, SH and Taylor, KL.** (2015). A comparison of web-based versus print-based decision AIDS for prostate cancer screening: Participants' evaluation and utilization. *Journal of General Internal Medicine*, 30(1): 33–42. DOI: <https://doi.org/10.1007/s11606-014-2994-7>
- van Weert, JCM, van Munster, BC, Sanders, R, Spijker, R, Hooft, L and Jansen, J.** (2016). Decision aids to help older people make health decisions: A systematic review and meta-analysis. *BMC Medical Informatics and Decision Making*, 16(45). DOI: <https://doi.org/10.1186/s12911-016-0281-8>
- Wieringa, TH, Rodriguez-Gutierrez, R, Spencer-Bonilla, G, de Wit, M, Ponce, OJ, Sanchez-Herrera, MF, Espinoza, NR, Zisman-Ilani, Y, Kunneman, M, Schoonmade, LJ, Montori, VM and Snoek, FJ.** (2019). Decision aids that facilitate elements of shared decision making in chronic illnesses: A systematic review. *Systematic Reviews*, 8(1): 121. DOI: <https://doi.org/10.1186/s13643-019-1034-4>

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